

Fractured Lives: Partnering Younger People with Stroke

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Abstract

Stroke is often sudden and unexpected, but what follows is often a long-term trajectory, marked by uncertainties. The ‘suddenness’ and ‘unexpectedness’ of stroke may be felt particularly by working age individuals and people around them, given that stroke is commonly considered a disease of old age and/or caused by a sedentary lifestyle. Almost all individuals who had a stroke at a ‘younger’ age return home, as they tend to make a better recovery trajectory compared to ‘older’ individuals, but also due to the lack of other appropriate options. Once home, they are usually supported by family members, with their spouse often providing the bulk of support.

In my thesis, I explore experiences of spouses of people who have had a stroke whilst in their working age (29-54). Drawing on qualitative data collected through policy document analysis, ethnographic interviews and participant observation in Victoria, Australia, I challenge the notion of ‘carers’ as constructed in current healthcare and policy discourses. While policy and healthcare practice assume that the spouses of people who had a stroke will suddenly become ‘carers’, and that they exist only within the ‘care relationship’ – a self-contained unit – my participants’ accounts illuminate that the everyday lives of ‘carers’ are much more complex. The onset of stroke fractures participants’ assumed coherence in life, and their various social relationships. Their participation in everyday practices of ‘informal caregiving’ was one of many interwoven, yet sometimes conflicting, identity performances. By delineating how their fractured lives, in a network of various relationships, were constantly reformed and restructured, I aim to generate a basis on which service providers, healthcare practitioners, policy makers and members of the wider society can engage in a constructive and critical discussion towards creating a ‘caring society’.

Certificate of Authorship / Originality

I certify that the work in this thesis contains no material that has been accepted for another degree or diploma in any university or other institution. I also certify that the thesis has been written by me. Any help that I have received in my research work and the preparation of the thesis itself has been acknowledged. In addition, I certify that, to the best of my knowledge, this thesis contains no material previously published or written by another person, except where due reference is made in the text of the thesis.

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Chapter 1

Informal Care as a ‘Public Issue’

Each morning in this country more than 2.6 million people wake up and their first thought is for the needs of someone else. These people are Australia’s carers... What they do not only makes a profound difference to the lives of those they care for, but makes an important contribution to the economic and social life of the nation. (Forward from relevant ministers in the *National Carer Strategy*, Commonwealth of Australia, 2011, p. 5)

‘Informal care’ is a relatively new term. Throughout history, family members, friends and other community members, mostly women, have tended to the sick, young and elderly, yet such terms as ‘informal carer’, ‘carer’ and ‘caregiver’ did not feature in policy, academic, and public discourses until the 1970s (Bytheway & Johnson, 2008; Heaton, 1999). In Australia, the records of the federal parliament show that the words ‘caregiver’ or ‘carer’ were not used before the 1980s.¹ The idea that individuals who provide care to family members or friends form a distinct social group worthy of public attention is, therefore, a relatively new phenomenon. Since that time, the concept of informal care has quickly captured the public imagination, as implications of demographic changes – particularly those related to societal ageing – have emerged as focal points in the Australian public policy arena.

¹ Prior to 1981, when my search showed the first record of the terms in Hansard (the transcripts of parliamentary debates), it was used once in 1976. I will elaborate about this incidence in Chapter 3.

As in many advanced economies, the combination of declining fertility rates and increasing life expectancy in Australia has resulted in a shift from a traditional ‘population pyramid’ structure comprising large numbers of younger people and fewer elderly, to more of a ‘population column’ (Australian Institute of health and Welfare, 2010). This is characterised by a rising proportion of elderly people, together with an increasing median population age (see Figure 1.1). In 2013, 14 percent of the population were aged 65 and over and 1.9 percent were aged 85 and over. According to a projection by the Australian Institute of Health and Welfare (2014a, p. 256) – based on *Australian Demographic Statistics*, the quarterly estimates of the Australian population published by Australian Bureau of Statistics (ABS) – by 2053, 21 percent of the population will be aged 65 and over and 4.2 percent aged 85 and over.

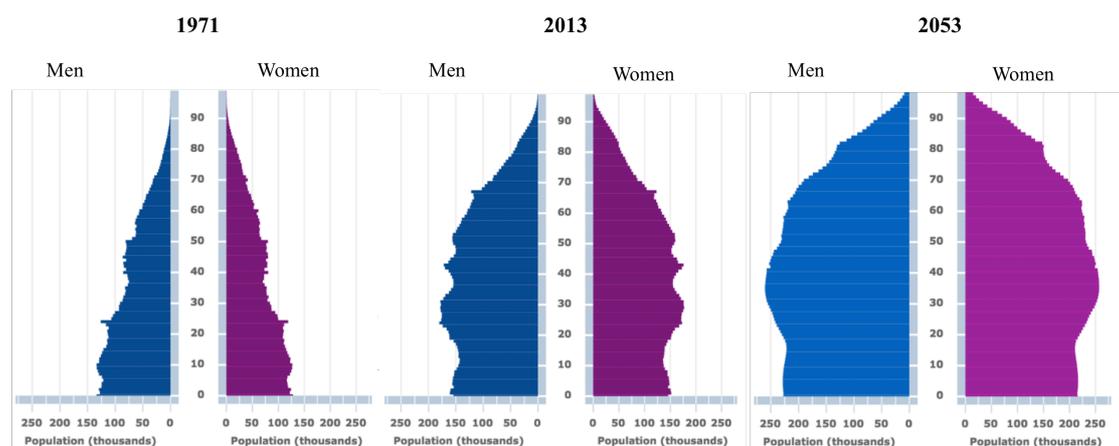


Figure 1.1: Changing age structure in Australia (Taken from an interactive graph on the ABS website: Australian Bureau of Statistics, 2014)

This change in population age structure has been somewhat slower in Australia than in other developed countries such as Italy, Canada and Japan, due to sustained immigration in the latter part of the twentieth century in combination with the later timing and longer duration of the post-World War II ‘baby boom’ (Jenkins et al., 2003). Nonetheless, this shift in age distribution, known as population ageing, in

Australia (as elsewhere) has significant consequences. From an economic perspective, population ageing is associated with slowing economic growth and increasing governmental expenditure (Australian Government, 2010). As an increasing proportion of the population reach retirement age, labour supply and economic output decline; this coincides with a growth in governmental spending on the Age Pension (Productivity Commission, 2013). Older people also have a higher prevalence of chronic illnesses and associated disabilities, and are more likely to require services in the health and aged care systems (Access Economics, 2010). This has led to a widespread assumption² that population ageing is a ‘burden’, as Australia’s shrinking proportion of tax-paying ‘healthy’ workers will soon be unable to support these increasing numbers of elderly people (Browning & Heine, 2012).

By the same token, working age people with disabilities and chronic illnesses are seen in the public health discourse, and in economic debates, as not only causing an economic burden, but also contributing to a further imbalance in the ratio of ‘dependent’ to ‘productive’ populations. This is exemplified by the greater weight given to disabilities and death amongst those in working age groups than non-working age groups in calculating the disability-adjusted life year (DALY), a measure widely used³ to examine the specific disease burden on populations as well as to reflect overall population health status (Riegelman & Kirkwood, 2014). This demonstrates

² According to Betts (2014), this assumption is unjustified. She demonstrates that, despite Australia’s increasing population ageing, the labour force participation rate and ratio of ‘dependents’ to those in workforce are at a record high. Gee (2002) has undertaken a similar analysis, with the same conclusion, in the Canadian context.

³ This has been used most prominently by the World Bank, which commissioned the development of the measure, and the World Health Organization, which adopted the DALY in 1996. The measure has been criticised for its reductionist tendency, in which socio-economic, environmental, and gender contexts are ignored in the assessment of the impacts of diseases and disabilities (Allotey et al., 2003).

that, through the burden of disease framework, disabilities in working age people are seen as a threat to the health system and society generally.

Care provision for people with a disability, long-term health condition, or age-related frailty – all of which Manderson and Smith-Morris (2010) call “chronic conditions” – can be differentiated into two types. The differentiation between ‘formal’ and ‘informal’ depends on how care provision is arranged, who provides care, and to which social group the care provider belongs, in relation to the recipient of care (Kahana et al., 1994). Formal care is provided by people employed by public, non-governmental/not-for-profit, and private/for-profit service agencies. It is delivered by trained and paid professionals and paraprofessionals, and by unskilled but paid assistants in the health and community sectors. In contrast, informal carers do not receive financial payment from the recipient of care, although they may have access to minimal public welfare payments (Chapter 3). They are also not required to undertake formal training nor to obtain a formal qualification in order to become an informal carer. In most cases, informal care is provided by family and friends at home. However, this dichotomy between formal and informal care is contestable. This is because care provision is labour that involves various non-financial costs, including physical and emotional costs, as well as direct and indirect (i.e. opportunity) financial costs (Cass, 2007; Daly & Lewis, 2000; Fine, 2007b). The fluid nature and situatedness of care provision also means that it can often cross the boundary between formal and informal (Allen & Ciambone, 2003). It is perhaps more fruitful to conceptualise informal care as relationally based. As Rosemary Warmington (2011, p. 6), the CEO of Carers SA, states: “People become [informal] carers usually through an existing relationship with family and friends.”

In 2012, 2.7 million individuals in Australia were identified as informal carers, who provided unpaid assistance to their family members or friends (Australian Bureau of Statistics, 2014). Following current and projected population ageing trends, especially as the ‘baby boomer’ generation ages (Jenkins et al., 2003), the demand for these informal carers is increasing, with the bulk of frail aged and disability support provided by family members and friends.

Health economics of care

These informal carers (hereafter carers) make invaluable contributions to the health and aged care systems. Informal care provided within the community, the majority of which is carried out by women, would equate to a vast monetary value out of the public budget, were public or for-profit programs to replace them. Carers in Australia were estimated to provide 1.32 billion hours of unpaid care in 2010, a proportion of which was spent in lieu of paid employment, causing a productivity loss of A\$6.5 billion to the formal economy (Access Economics, 2010). While this productivity loss captures economic reductions on personal and business levels, it is in fact miniscule compared to considerable savings carers make for the wider Australian economy. If all hours of informal care were replaced with formal care services, it would have cost the nation A\$40.9 billion in 2010 (Access Economics, 2010).

In economic terms, the costs of caring can be conceptualised in two main ways. Direct costs relate to the extra expenses incurred by carers as a result of taking on the caring role, including the financial cost of home modifications or transport, as well as health costs for carers spent on managing the strains and stresses associated with caring. In contrast, indirect costs include the opportunity costs of reduced employment, leisure and other activities to provide care, the time spent on care activities, and the impact of caring on the wellbeing of the carers (Hill et al., 2011).

These direct and indirect costs of caring are significant: one Melbourne-based study estimated that the opportunity costs alone borne by the carers of individuals who had a stroke could be valued at A\$171.4 million (in 1997 dollars: Dewey et al., 2002). Hill and colleagues (2011) suggest that, while the direct costs of caring are difficult to estimate due to the lack of research and methodological complications, they are likely to be significant, as the evidence of increased financial stress for carers are compelling. For example, the *Families Caring for a Person with a Disability* survey conducted in 2006 by the Australian Institute of Family Studies (AIFS) and the Department of Families, Housing, Community Services and Indigenous Affairs (FaHCSIA) found that around 30 per cent of families receiving a carer income support payment (Carer Payment or Carer Allowance) had experienced financial hardship to the extent that they had difficulty paying electricity, gas or telephone bills on time; this was double the rate of the general population (Edwards et al., 2008).

Evidence of indirect opportunity costs around reduced employment is more readily available and shows that limited participation in paid employment due to care responsibilities has significant consequences. A report commissioned by Carers Australia (Nepal et al., 2008) found that, in 2006, over half of female primary carers aged 30 to 64 years were not in the paid labour force, compared to less than a third of other women in the same age group. The report also found that of those women who do work, carers spend fewer hours in paid employment than do other women (ibid.). In 2007, a consortium of high profile Australian businesses and non-profit organisations reported that a quarter of employees with care responsibilities reduced their hours of work and/or were likely to leave the workforce, and that a third was not able to maintain a position at a level commensurate with their skills and qualifications (Taskforce on Care Costs, 2007). The financial implications of caring extend into the

future. Lost or reduced employment opportunities could also mean long-term financial insecurity, including precarious future career pathways and limited savings and superannuation payouts.

In recognition of the reduced financial status of the carers, income support explicitly for carers was introduced in Australia in 1983. Its initial scope was limited; it was for husbands of women who were aged or ‘invalid’ pensioners with a severe disability (Daniels, 2011). As I discuss in Chapter 3, the scope of social security payments for carers and the broader carer support service system has broadened since this time. This has gained momentum especially in the last decade, leading to the introduction of carer-specific policy frameworks (rather than as a section of disability and aged care policies) at both federal and state levels. How to provide care to frail aged and younger people with disabilities – a question, which, throughout the history, had been seen as personal troubles – has now become constructed as a public issue.

Conceptualisation of care

But who exactly are the ‘carers’? The answer depends on how ‘care’ and related concepts are defined, conceptualised and studied. In one of the more obvious examples, the large increase in the number of ‘primary carers’ between 2003 and 2009 in Australia (from 19 percent to 29 percent of all carers) was primarily due to changes in how primary carers were identified and by whom (Australian Bureau of Statistics, 2010b). In the 2003 *Survey of Disability, Ageing and Carers* (SDAC), a ‘responsible adult’ of the household nominated the primary carer; in the 2009 SDAC, it was the care recipient who identified their primary carer. This gave rise to different realities of informal care, which emerged from different practices of ‘knowing’ about caregiving. This particular change was of a political nature. In the lead up to the 2009 SDAC, community-based consultations were met with “a strong response from survey

users asking that the care recipients identify their primary carer, based on the view they were likely to be in a better position to know who this person was in comparison to other people in their household” (Australian Bureau of Statistics, 2008, as cited in Dean, 2008, p. 6). This change in the definition, categorisation and conceptualisation of a term reveals a different picture of a phenomenon, and brings with it certain consequences, as Law (2009) highlights – knowledge practices not only describe realities, but they also enact them. Different political, social, economic and moral practices, all of which are temporally and historically situated, generate different realities. For this reason, the different ways in which caregiving has been conceptualised need some scrutiny.

As stated above, since the 1970s, informal care has gradually been receiving increasing public attention. Twigg and Atkin (1994, pp. 2-6) attribute this increased prominence within public consciousness to at least two socio-political factors. First, in the context of women's increased workforce participation, the feminist movement problematised the taken-for-granted notion of domestic labour, including unpaid child, disability and aged care provision, as the primary function of women. This later inspired the carers' movement, as I discuss in Chapter 3. Second, a shift in the political economic agenda in the contexts of the demographic changes and the rise of neoliberalism led to recognition of carers as valuable resources. These are explained in detail below.

Feminist scholars in the 1970s, such as Diana Leonard Baker, Sheila Allen, Juliet Mitchell, Ann Oakley and Sandra Burman, were pioneers in demonstrating how the socially constructed concept of care acted to render the care work undertaken by women invisible (Graham, 1983). Historically, it has been – in trends continuing to the present day – assumed that a family member, typically a woman, would provide

assistance and support to other family members as a common and unproblematic part of family life; caring for a sick or elderly family member was therefore understood as an extension of this normative and pervasive aspect of family life (Twigg et al., 1994). In fact, care provision was considered such a ‘natural’ activity that carers themselves did not consider that they belonged to a distinctive social category (Bytheway & Johnson, 2008). Feminist scholarship and the feminist movement exposed this unchallenged notion of care as a ‘labour of love’ that ought to be provided by women through marriage and kinship obligations (Baker & Allen, 1976; Graham, 1991, 1983; Land, 1978; Leira, 1994). These scholars also pointed to the unequal burden of caring assumed by women in the context of increased participation by women in the paid labour market (Finch & Groves, 1980; Graham, 1991). What was previously invisible to the public has now been brought to light, due to feminist scholarship and activism.

Despite this, assumptions around caregiving as an essentially feminine activity persevere, as I discuss in Chapter 3 in the policy context. Although many men are involved in providing care, gender differences persist in the primacy of care. According to the 2012 iteration of the abovementioned SDAC (Australian Bureau of Statistics, 2013), while 44 percent of all carers in Australia were men, only 30 percent of all *primary* carers were men; women were therefore most often nominated by the care recipients as providing the bulk of informal assistance. Furthermore, women are also more likely than men to perform relatively intensive and complex care tasks, often involving intimate personal care (Navaie-Waliser et al., 2002; Neal et al., 1997). The gender difference is more pronounced for carers in the 25-55 years age groups, which comprise people typically considered in their ‘working age’. Women make up 79 percent, 82 percent and 74 percent of primary carers in the age groups of 25-34, 35-44 and 45-55 years, respectively (based on figures from Australian Bureau of

Statistics, 2014). Increased female workforce participation, delayed childbearing, and a growing elderly population, together with the normative expectation that women ‘do care work’, have created the so-called ‘sandwich’ or ‘pivot’⁴ generation of women, who have to juggle competing demands of child rearing, paid work, care for their ageing parents, and/or other sick/disabled family members (Grundy & Henretta, 2006; Mooney et al., 2002; Spillman & Pezzin, 2000). In this thread of discourse, informal care has been constructed as a burden primarily shouldered by women.

Political economy of care

As I have discussed above, the ‘discovery’ of carers was initially about the recognition of ‘work’ they engage in, and the oft-burdensome nature of it. However, another thread of informal care discourse soon arrived on the back of a completely different ideological influence. The last three decades have seen significant changes in the model of governance and, consequently, the role of the state in the provision of welfare services in Western liberal democracies such as Australia. One of the manifestations of these changes has been an ongoing shift in the locus of the healthcare services provision — the responsibility for healthcare provision has shifted from state-run healthcare institutions to individuals, especially to informal carers in the community (Fine, 1995). While the initiation of this trend is attributed to human rights concerns about the dehumanising aspects of institutionalisation, it also coincided with the rise of a market-oriented neoliberal philosophy that has become a dominant paradigm in public and policy discourses (Henderson, 2005; Horton, 2007; McGregor, 2001). In this section, I outline how this shift has influenced the notion of care, as it is currently understood.

⁴ Of two terms, ‘pivot’ has more metaphorical merits than ‘sandwich’, since the latter does not quite convey the dynamic nature and multiplicity of tasks incorporated in the carer role, as I show in this thesis.

The shift towards neoliberal philosophy provided the rationale for what Heaton (1999, p. 761) refers to as the shift “from care *in* the community to care *by* the community.” The policies of deinstitutionalisation, which occurred especially in the context of mental health care but also in aged and disability care, were initially developed in the 1960s and 1970s in Western countries, in order to shift the locus of care from large-scale institutions to state-run community residential homes. The aim of this shift was to decrease the likelihood of abuse and neglect that were common in large “total institutions” (Goffman, 1961), to facilitate patients’ recovery and adaptive behaviours in more ‘natural’ community settings, and to secure their right to live at or close to home so as to encourage their participation in culturally normative activities (Fine, 1995; French, 2009; Landesman & Butterfield, 1987; MacKinnon & Coleborne, 2003; Young et al., 1998).

However, the emphasis of these policies has shifted since the 1970s, when neoliberal ideology had started to emerge, towards relocating in-patients to their own homes (Heaton, 1999). Rather than framing ‘community’ as the location of care provision, community has come to be redefined as both the location and the provider of care. In this revised model, there is now an expectation that ‘community and home care’ are provided primarily by informal carers, rather than the state, as was the case in earlier deinstitutionalisation policies. This shift was therefore motivated by a mixture of pragmatic and human rights agendas. The deinstitutionalisation of care and the expansion of state-run community care programs also created a source of employment for women seeking paid work outside the home. Ironically, deinstitutionalisation also met with an increased demand for formal services,⁵ leaving

⁵ It is ironic, because the reason why the demand for services increased may have been to do with more women working in the health and social services sector – a traditionally feminine field – rather than providing unpaid care at home.

the system under a constant strain; thus state-run care in community programs has come to be portrayed as a target for structural economic reforms (Fine, 2004). Neoliberalism, or economic rationalism, was seen as a solution.

Neoliberalism assumes that a free market economy, achieved through privatisation and deregulation, is the key to economic and social progress (Murray, 2013; Western et al., 2007). The assumption here is that competition in a free market economy stimulates entrepreneurialism, which will result in innovative and efficient service provision, with greater outputs at lower costs (McGregor, 2001). Individuals are constructed as rational, decision-making consumers, whose choice-making fuels competition and guides innovation in the market economy. The economy in this framework is portrayed as a self-regulating, naturally evolving system, which efficiently supplies resources – commodities – for material, education, health and welfare needs by responding to market demand, with the trimming out of those ‘excess’ goods and services not in demand. Under neoliberalism, redistribution of resources through taxation is criticised as unjust, and is seen as creating welfare dependency (Palley, 2004). According to this ideology, state-run institutions are inefficient and seen as a hindrance to the self-regulating free market economy, which, so far as proponents of neoliberalism are concerned, is far superior to governments in managing limited resources (Beeson & Firth, 1998).

Applying this approach to healthcare means shifting responsibilities for the delivery of care from government institutions towards the private sector, thus “setting health care up as a private good for sale rather than a public good paid for with tax dollars” (McGregor, 2001, p. 83). Healthcare, in this frame, is no longer seen as a right or entitlement. Instead, healthcare service users are framed as self-interested consumers, who make rational decisions based on available information. ‘Health

consumerism' is seen as an accountable system that encourages consumer participation in defining needs, decision-making and evaluating outcomes through market forces (Horton, 2007).

The rise of neoliberalism and the application of its principles in healthcare has been gradual in Australia, a country that historically has employed a mixed economy of welfare service provision consisting of state, not-for-profit, and for-profit sectors (Harris & McDonald, 2000). However, health has not been immune to broad public policy reforms implemented since the 1980s. The gain in momentum in neoliberal healthcare reforms implemented by both Labor and Coalition governments⁶ over the last two decades has resulted in greater emphasis being placed on non-state sectors for the delivery of healthcare (Beeson & Firth, 1998; Henderson, 2005; Horton, 2007). At the same time, despite the rhetoric of individual decision-making in healthcare, the cost of for-profit healthcare has remained largely out of reach for many, especially those with ongoing care needs, including as a result of chronic illness and disability. Sandwiched between disability and human rights obligations on the one hand, and the ideologically and economically motivated retreat of the welfare state on the other, successive governments have had to find pragmatic solutions that could accommodate both frameworks. In this context, informal care has come to be seen as a cost-effective measure for maintaining the health and disability care systems; carers are now conceptualised as a cheap human 'resource' that enables community care of people with disabilities.

⁶ Australian democracy is based on a two-party system, in which the two dominant parties – the centre-right Liberal Party (the Liberal-National coalition) and the centre-left Labor Party – alternate in power. However, the influence of neoliberalism on both parties in the last several decades has resulted in a loss of their traditional distinctiveness (Lavelle, 2008). For a nuanced analysis of this 'party convergence thesis', see Goot (2004).

The influence of neoliberal ideology goes well beyond the market economy; its moral implications extend into non-economic areas of life. By framing individuals as free, autonomous and agentive entrepreneurs who are always capable of making rational choices that favour themselves (Cheshire & Lawrence, 2005), neoliberalism sets clear parameters for the involvement of the state. The government's role in this framework is to ensure individuals can make the 'right' decisions as autonomous, self-reliant, and self-governing citizens in relation to their bodies, minds, wealth and behaviours, as well as the conduct of their families (Angus, 2012; Fitzsimons, 2002; Henderson, 2005; Hill, 2006; Larner, 2000; Petersen & Lupton, 1996). Individuals are, therefore, held morally accountable for the decisions that they make; those who make 'wrong' choices are represented as less-than-proper citizens, irresponsible and incapable of self-governance (Fineman, 1995; Galvin, 2002). In this paradigm, illness and recovery from it fall into the moral domain. 'Being sick' contradicts the notion of the 'good' citizen, that is, an active and productive participant of the neoliberal enterprise society. A sick person is seen as blameworthy for not preventing him/herself becoming ill in the face of known risks, or for not working hard enough to recover (Galvin, 2002). Those who are not capable of self-governance require external control and, in the absence of state intervention, families are required to take responsibility for and to manage their sick family members (Henderson, 2005).

This development has been compounded by a fear that a decline in traditional family arrangements – led by shifts in gender roles and increasing 'non-traditional' household structures such as single parent families – would mean that people would abandon their family members in need (Fine, 2005; Weicht, 2009; Williams, 2004). In response, successive governments in Australia since the 1980s have created a moral imperative for families to adopt a caregiving role by inculcating 'traditional' family

values in them by introducing work and family policies, such as the Family Tax Initiative, that favour ‘traditional’ families (Hill, 2006; Hutchison, 2009). The family – narrowly conceptualised as the nuclear family – has come to be framed as a self-governing unit responsible for looking after its own wellbeing, much the same as the neoliberal individual. This ideological value can be observed, for instance, in a lecture entitled *The Beliefs and Values Which Guide the Federal Government* that John Howard (1996) delivered in the first year of his decade-long prime ministership:

[The government champions] opportunities...for individuals to work hard and to achieve for themselves and their families... Values such as individual freedom, choice, diversity, opportunity, and the importance of strong families and communities as bulwarks against the intrusive power of the State (paras 44, 75).

Within this values-based framework, state interventions are criticised as undermining personal and family responsibilities (Bell, 1993), and these are only provided on a contractual basis: support becomes available when and only if certain obligations and criteria are met (Henderson, 2005). Here, informal caregiving is constructed as the moral responsibility of the family unit.

Tensions

These different discursive threads – constructions of informal caregiving as burden, economic resource, and moral responsibility – converged to bring ‘informal carers’ from the private sphere to the public arena. Informal carers have now become an important policy target group, as is reflected through the increasing attention paid to them in policies (Chapter 3). This development has not been without tensions. Constructions of informal care as moral imperative and cheap economic resource

meant that self-management of chronic illness and disability within the family has become emphasised, undervaluing – and even further exacerbating – the construction of informal caregiving as burdensome (Essue et al., 2010). The burden discourse also has not been uncontested. The disability movement, with its focus on the disabling aspects of the society rather than individual impairments – the social model of disability (Oliver & Sapey, 1983; Shakespeare & Watson, 2002) – and advocacy for the emancipation and independence of ‘disabled’ people, has historically had an awkward relationship with the feminist and carers’ movements. The emphasis on caregiver burden involved in the management of impairments that characterises much health-related research has been seen as incompatible with the objectives of the disability movement (Beckett, 2007; Hughes, 2005; Kroger, 2009). The emergence of the carers’ movement has also created a (false) sense of competition over funding and resources between the carers’ movement and disability movement (Lloyd, 2006). This was because governments have been reluctant to allocate large-scale extra financial commitments to make room for the informal care sector.

Stroke informal care

Informal stroke caregiving provides a useful case study in exploring the impact of an illness on family carers: the sudden onset of stroke, its long-term recovery trajectory (Burton, 2000), and the ‘invisible’ nature of some of resultant disabilities, all illuminate the pronounced emotional, practical, social and economic impacts on caregiving experiences (Röding et al., 2003; Stone, 2005). Providing informal care to family members who have had stroke can have an adverse impact on the physical, psychological and financial wellbeing of carers, their marital relationships, quality of life and participation in social and economic activities (Blonder et al., 2007; Dorsey & Vaca, 1998; Han & Haley, 1999; Low et al., 1999; White et al., 2006). In the last

stroke-specific population-based study conducted in Melbourne in 1997, Dewey and colleagues (2002) found that six to twelve months after stroke, persons who had no ongoing care needs prior to their first-ever-stroke event required on average 12 hours per week for wide-ranging community-based, domestic, and personal tasks. Many carers, in the workforce at the time they began providing informal care, stayed in employment, either with the same or reduced hours, and often provided care during personal time that would have otherwise been used as leisure or family time, by using existing leave entitlements, or through rearranging their work schedules (Dewey et al., 2002). In this way, carers juggled competing commitments: unpaid work as a carer, paid employment as the (often primary or only) source of income for the household, other general household duties, and often other care responsibilities such as care of children or parents.

Stroke carers are likely to have poorer physical health than before taking on the caregiving role (Williams, 1993), and their psychological wellbeing is often affected negatively immediately following a stroke (Forsberg-Wärleby et al., 2001), a trend that often sustains over time (Wright et al., 1999). They also have a lower level of general life satisfaction in the years following stroke (Achten et al., 2012; Forsberg-Warleby et al., 2004). Their marital/spousal relationships often suffer (Visser-Meily et al., 2009), possibly due to difficulty adjusting to an altered relationship that is defined – at least in the short to medium term – by care provision rather than based on mutual partnership (Coombs, 2007), affecting their relationship dynamics; this often extends to other, non-spousal relationships. The various consequences of stroke, such as depression, emotional fluctuation, behavioural and personality changes, problems with communication (e.g. speech), fatigue, lack of motivation and a reduction in sexual functioning can lead to tension,

misunderstandings, or feelings of neglect (Anderson et al., 1995; Bäckström & Sundin, 2010; Kitzmüller et al., 2012; Smith et al., 2004; Visser-Meily et al., 2008). Carers' emotional wellbeing seems to be directly related to the perceived burden of care (Wyller et al., 2003), whereby the perceived burden is associated with both carer's and stroke survivor's objective health status, survivor's age and the number of caregiving tasks performed (van Exel et al., 2005). It also appears that the 'invisible' effects of stroke, such as cognitive, communicative, behavioural and emotional changes in the person, rather than functional status, cause the greatest distress in carers (Dorsey & Vaca, 1998; van den Heuvel et al., 2001). The effects of care provision too extend beyond the actual carer; their children also tend to display behavioural, psychological and emotional problems (van de Port et al., 2007; Visser-Meily et al., 2005).

Caring is not all burden; some research also notes positive outcomes associated with the caregiving role, such as a sense of pride by caregivers in their role, fulfilment, satisfaction and feeling closer to the stroke survivor and other family members (Greenwood et al., 2008; Mackenzie & Greenwood, 2012). I will elaborate on this in Chapter 8.

Gaps in research

The early literature typically coming from psychological perspectives has primarily focused on the strain and burden of caregiving, with data generated through the utilisation of predominantly quantitative approaches. As these studies often explore caregiving experiences from the perspectives of healthcare professionals, many do not convey the more subtle and nuanced effects of informal care, such as how carers negotiate changes in role, self-identity, sexuality, or social relationships within the family and in the wider community (Greenwood et al., 2009a). Also, the findings of

these studies are often not presented in fully contextualised accounts. Wider and interrelating social, structural and systemic factors need to be taken into consideration, in order to capture how people experience illness and caregiving within the context of their personal and social circumstances (Charmaz, 2010). The shift in the healthcare system, as discussed above, with deinstitutionalisation and the prevalence of ‘care by the community’ (Heaton, 1999), have placed greater care responsibility on informal carers. Against this backdrop of the withdrawing welfare state, financial pressures constrain the healthcare system, and as a result, stroke rehabilitation is driven largely by the needs of the providers rather than the needs of the patients (Teasell, 2011). Consequently, inadequate and/or inappropriate health and disability care services provided by formal healthcare services can cause what Hart (2001) calls ‘system induced setbacks’ in stroke recovery. So too, carers can be lost and ‘fall through the cracks’ in the increasingly complex and rapidly changing healthcare system, in which tasks such as obtaining information, managing bills and payment requests, and navigating the system, generally are incredibly confusing (Sales, 2003).

An increasing number of qualitative studies provide glimpses of a more dynamic and complex picture of stroke caregiving processes (Gaugler, 2010). For example, even though caregiving is overwhelmingly represented as a burden and hindrance to social functioning, buried underneath these accounts of suffering are brief, interspersed moments of affection and reward (Opie, 1992). In some qualitative studies, carers report their momentarily strong appreciation for the partner, and of life in general, and a sense of togetherness in complicated, contradictory yet intertwining accounts of burden and reward (Bäckström & Sundin, 2009; Buschenfeld et al., 2009; Green & King, 2009; Greenwood et al., 2009b).

Specific demographic differences may also contribute to unique caregiving experiences. This is particularly notable where stroke occurs in an atypical population group; there is a gap in understanding how stroke affects the carers of persons who had stroke while in their working age. This oversight is at odds with a growing recognition that young stroke survivors have distinctive needs and specific priorities that are significantly different to these of an older population (Culler et al., 2011; Hartke et al., 2011; Rödning et al., 2003). It would be fruitful to explore how stroke caregiving and age interact in the neoliberal political economic climate, in which the notion of citizenship is often closely associated with the productive body – economically producing and socially engaged subjects (Bacchi, 2009).

A relatively small number of studies that specifically describe challenges faced by carers of persons who had a stroke while in their working age (Banks & Pearson, 2004; Bäckström & Sundin, 2007, 2009, 2010; Bäckström et al., 2010; Buschenfeld et al., 2009; Drummond et al., 2007) tend not to make any systematic and conceptual remarks regarding how age and experiences of caregiving interact. Consequentially, it is difficult to grasp how their results differ from those reported elsewhere for carers of older individuals. However, Buschenfeld and colleagues (2009) suggest that carers of younger individuals face a larger range of perceived losses than older carers, which might reflect the greater changes that caring brings to the lives of people in younger age groups. The relationship between age and perception of the consequences of caregiving remains understudied, yet, it is not difficult to imagine that stroke events in people of working age may have significant impacts on carers, as well as on the healthcare system and wider communities.

Contrary to the popular belief that it is a disease that affects only ‘old people’, stroke affects a significant number of younger people. It is estimated that, in 2008,

approximately 37,000 individuals (15 per cent) of persons who had a stroke were under the age of 55 (based on figures from Australian Bureau of Statistics, 2010a). Furthermore, approximately 34 percent of persons who had stroke at the age of 55 or under reported in the 2009 SDAC that they had a disability as a result of stroke (Australian Institute of Health and Welfare, 2013). While the age group break-down is not available, the findings from the same survey also indicates that a high proportion (87 per cent) of individuals living at home, with a disability resulting from stroke, were receiving some type of assistance (Australian Institute of Health and Welfare, 2013). Since young individuals generally live longer post-stroke than older individuals, the long-term impact of stroke in this population is significant to both the person who had a stroke and their carers, on whose support they rely (Jordan, 2007).

Men as carers

How gender may interact with experiences of stroke caregiving is another domain that is often overlooked. As discussed above, much of the research in the last several decades, especially from feminist scholars, has been concerned with the additional and unequal burden and responsibilities that women are expected to shoulder when their close ones fall ill. Given that a large proportion of carers are women, and that the notion of caregiving in everyday discourse is still associated with the traditional female role, it is not surprising to find that far less attention has been paid to the experiences of men in caregiving research. However, as I mentioned above, a substantial number of men currently provide informal care and their contributions should not be neglected. Particularly in quantitative studies that present sex-disaggregated statistics, male carers are often used as a base group to highlight the contributions that female carers make, as evidenced in statements highlighting that men comprise *only* 30 per cent of the primary carers, or that men only provide care

when there is an absence of a female carer. In this way, the contributions that they make are effectively dismissed in a gender comparative presentation (Thompson, 2002). While this is justified in so far as the collective contributions made by female carers far outweigh those of male carers, these comparative studies trivialise the contributions of individual male carers, as Fisher (1994, p. 677) suggests:

There are circumstances where men accept the obligation to care, undertake intimate personal care, and derive identity and reward from their caring work, driven by similar motives and experiencing similar struggles as women ... One important way to promote non-sexist community care will be to explore the conditions where men's caring is undertaken and how it can be understood and developed.

In order to avoid stereotyping men's experiences of caregiving, the challenges and needs of male carers, both individually and as a cohort, are worth investigating. For example, although many men do not take up a primary carer role, this does not mean that their contributions and challenges are insignificant. Essex et al (2002) found that fathers of adult children with developmental disabilities, who are often not categorised as primary carer, are as actively engaged as the mothers in care activities to enhance the social and emotional wellbeing of their child, and they also provide valuable emotional support to their female spouses, who are defined as primary carer. Whilst it is important to recognise that some elements of caregiving by men and women are similar, identifying what makes male and female caregiving unique is equally valuable in gaining a fuller picture of caregiving. The limited research available in this area indicates there may be gender differences in how caregiving impacts on the health and wellbeing of carers. For example, women appear to experience greater psychological distress and lower quality of life, while men tend to

struggle dealing with cognitive and emotional changes in their partners (Alexander & Wilz, 2010; Larson et al., 2008; Pinguart & Sörensen, 2006). Further understanding of how male and female carers experience caregiving will play an important role in developing and promoting gender sensitive community care and support policy and practice (Kramer, 2002).

Aims and objectives

The aim of the study reported in this thesis was to investigate how spouses understand and experience the caregiving they provide to persons aged between 25 and 55 who had had a stroke. Specifically, I sought to describe and analyse:

- How socio-demographic factors, age and gender in particular, influence caregiving experiences;
- Carers' ability to access formal and informal support;
- How stroke and related disabilities, especially 'invisible' ones, and consequential care requirements, are understood by carers;
- How carers negotiate multiple roles and responsibilities in caregiving relationships;
- Carers' perspectives about how their social worlds have been affected by their caregiving role, and how these may be affected into the future;
- How affective aspects of caregiving mediate, and are shaped by, care relationships; and
- How assumptions made about carers in policy and practice influence carers' experiences.

On the language of informal care

Research and clinical literature and policy documents employ a variety of words to describe individuals in stroke care relationships, such as ‘care provider’, ‘supporter’, ‘caregiver’, ‘cared-for’, ‘patient’, ‘dependent’, ‘survivor’, ‘victim’, ‘client’ and ‘care recipient’. I have used these terms interchangeably in this review of the literature to reflect the language used by authors, as a collective, when referring to certain individuals in the specific circumstances that are the focus of their study. However, it is also important to be aware of the potential effects of using any specific term to categorise individuals. This is because language plays a significant role in producing subjective experiences by simultaneously facilitating and constraining what we think, talk and do about given phenomena (Treichler, 1999). As McDonald (2006), in the context of social work, argues:

The words we use to describe those who use our services are, at one level, metaphors that indicate how we conceive them. At another level, such labels operate discursively, constructing both the relationship and attendant identities of people participating in the relationships, inducing very practical and material outcomes (p. 115).

Different labels for individuals involved in social and healthcare reflect differing assumptions about the nature of social relations in which they are located (McLaughlin, 2009). In the present study, I sought to problematise some of the taken-for-granted assumptions around informal care provision for individuals who had a stroke. A note on terminology around informal stroke care relationships, therefore, would be appropriate.

Terms such as ‘dependent’, ‘cared-for’, ‘victim’, ‘patient’ and ‘care recipient’ imply passivity and lack of agency in the care relationship (Henderson & Forbat,

2002). These terms may also have negative connotations, implying that these individuals are not productive, require resources, and are therefore burdensome to the functioning and prosperity of a society (Blaxter, 2010), in which “participation in productive work is rewarded and therefore central to an individual’s self-esteem” (Bond 1992, p. 12). On the other hand, the term ‘survivor’ portrays the individual as active, triumphant and empowered. However, it is deeply embedded with the neoliberal notion that individuals are responsible for ‘conquering’ hardship or illness and that those who did not ‘win the battle’ – because they were either incapable or unwilling to – were weak or unsuccessful. Furthermore, as Kaiser (2008) argues, the term ‘survivor’ masks the sense of uncertainty and ongoing challenges faced by individuals who live with an illness that affects them long after its onset. Although Kaiser’s argument is made in regards to cancer ‘survivors’, it is also relevant in the context of individuals who had a stroke. This is because, as I discuss in later chapters, the presence of stroke is often felt long after its onset, including various stroke sequelae and a lingering sense of uncertainty surrounding stroke reoccurrence.

The terms ‘carer’ and ‘caregiver’ provide a very static and one-dimensional image of individuals engaging in what are quite ubiquitous behaviours – throughout life, to a varying degree, everyone gives or receives care. After all, ‘independence’, when defined as complete self-reliance, is a myth, because everyone in society is dependent on support from one another and existing social arrangements and structures, so providing us with access to resources and a meaningful life (Galvin, 2005). In this sense, we are all *interdependent* (Galvin, 2005), and the binary logic of dividing people into those who provide care, on one hand, and those who receive care, on the other, diverts our attention away from the complexity apparent in care relationships (Molyneaux et al., 2011). Furthermore, ‘voluntary carers’ as a word to

describe a family member providing care is not accurate, because caring within family is usually not voluntary. Family care is often motivated by a variety of reasons, as I discuss in Chapter 8, including familial obligations and a lack of alternative options. The word ‘voluntary carer’ implies that the caregiving role is something that an individual can possess or assume, and dispossess, at will, as if it were a mantle.

For the absence of better terminology, in this dissertation I use the terms ‘individuals who had a stroke’ and ‘carers’ reluctantly. In the presentation of data, efforts are made to use pseudonyms and the role of the person within the spousal relationship (e.g. husband, partner), rather than the generic labels of ‘carer’ and ‘person who had a stroke’. I also use the term ‘stroke-affected partner’ to refer to partners of the participants, although I acknowledge the limitation of the usage of the term. Indeed, it contradicts one of my main theses that the impact of stroke extends beyond the persons who have had it. It often *directly* affects their spouse therefore, one could argue, as s/he too is a ‘stroke-affected’ person. However, the use of the term ‘stroke-affected’ allows me to clearly indicate which one of partners (i.e. a participant or his/her partner) I am referring to in my text. This has some merit, as I want to address both of them as ‘partner/spouse’, therefore locating them in their spousal relationship. Similarly, whilst the adjective ‘informal’ may be taken to imply that informal care is casual and lacking in quality, structure and process (Australian Institute of Health and Welfare, 2004), again, I reluctantly used the term to differentiate informal care from the care provided by ‘formal’ governmental, not-for-profit and for-profit agencies and institutions.

Thesis outline

In Chapter 2, *Studying Care and the Impact of Stroke*, I outline the research design and methodology. First, I describe the social constructionist research paradigm and

interpretivist theoretical perspectives which shape the questions asked in this thesis. Following this, I outline my research approach, of ethnography with inspirations from constructionist grounded theory (Charmaz, 2007), that justifies the research methods I used to explore those questions. This includes the interpretive lens through which data are analysed. My positioning within the research and discussions around rigor in social constructionist qualitative research are also outlined.

Chapter 3, *Who cares about carers? Carer and disability policy and support services*, traces the development of the notion of informal care in health and welfare policies in Australia. Since the 1980s, when ‘informal care’ first entered the political discourse, it has increasingly attracted attention in political debates, leading to the enactments of *Carer Recognition Act 2010* (Commonwealth of Australia, 2010) in the federal parliament, and *Carers Recognition Act 2012* (Parliament of Victoria, 2012) in the Victorian parliament. In this chapter, I provide descriptions of these policy frameworks to contextualise the participants’ accounts that I introduce and elaborate in succeeding chapters.

In Chapter 4, *Stroke as unexpected illness*, I turn to the events around the onset of first stroke and at the acute and sub-acute hospitals. I explore how uncertainty in the course of the medical emergency and consequent treatment and in-patient rehabilitation exposed fragility in a seemingly unified and internally coherent self in partners. They were thrown into fault lines – between informed and uncertain, reflexive and detached, hopeful and grieving, and active agent and passive recipient. Their identity became fragmented – or rather, fragmentation of their identity became evident – and this conflicted with historically and discursively constructed normative ideals of the self: unified, coherent, individualised, rational, volitional, and agentic (Rose, 1998).

The time around discharge home, for many participants, was marked by anxiety. In Chapter 5, *Your whole world's turned into chaos*, I explore how the turbulent time of discharge home of the person who had a stroke, impacted upon the spouses' lifeworld. The sudden and unexpected nature of stroke left them little or no time to prepare themselves for changes necessitated in their life, or for time to deal with uncertainties surrounding their partner's recovery. Furthermore, with publicly funded outpatient and community rehabilitation programs largely acting as a 'hand-over' period, they were often left on their own to manage care duties, as there was an assumption that once the person who had a stroke was out of the hospital, they were 'functional enough' to smoothly reintegrate into the community. The impact of stroke on participants was often not acknowledged, as many of the sequelae of stroke were 'invisible' to those who did not spend a significant period of time with the person so affected. Time was also a factor, as their support and social networks assumed that time would fix everything. In this sense, they became 'invisible' – seen but unnoticed. This could largely be attributed to the economics of the funding system, with much political and public imaginations being diverted to prevention and acute treatment of stroke. Some participants actively resisted this structural 'silencing' and attempted to advocate for themselves. However, there were limitations to such an individualised solution to what were structural and systemic issues.

The home space has become an important site of health care delivery. Healthcare policy and practice assume that home-based care is cost efficient for the public health care system, and that it is clinically beneficial to the patients' functional and social-emotional wellbeing. Home, in this framework, is seen to 'naturally' provide continuity and stability. In Chapter 6, *Orchestrating home*, I challenge this notion. Participants' accounts illustrate that home is not a self-contained, fixed entity

that exists naturally or inevitably. Instead, making of home, and therefore the therapeutic qualities of home, requires constant orchestrating efforts that require mobilisation of various materials, meanings and practices, situated both internal and external to the physical and symbolic bounds of the home space.

Healthcare and carer policy and practice inevitably construct certain normativities – morally appropriate ideals about self-care, and social, employment, and healthcare participation. In Chapter 7, *Creating a new normal*, I delineate how these normativities, as discursive constructions, are practiced and not practiced in the everyday lives of the participants. Participants discussed various ways through which they attempted to enact a sense of normalcy – their ideas about what was ‘normal’ based on their lives prior to their partner’s stroke as well as how they perceived was a ‘common’ way of living. Normativities as constructed in policy and practice were sometimes congruent with practices of enacting normalcy. However, at other times, they caused frictions.

In Chapter 8, *The loss of mutuality*, I discuss how the nature of the spousal relationship was altered in the lives of both after stroke. Various stroke sequelae necessitated rearrangements of roles and responsibilities within spousal relationships, and this had cascading effects on the way in which participants performed their identity not only as a spouse, but also other identities located in other relationships – including of parenting, filial, and professional natures.

I open Chapter 9, *Ordering a caring society*, with a quote from *Disability Politics and Theory* by A.J. Withers (2012). While the passage concerns ableism and (false) assumptions of dependence, I borrow it to draw our attention to the interdependent nature of relationships – not only within, but also amongst them. Carer policy and health and disability care practices largely construct care relationships as

static. They treat care relationships as self-contained units, and cheap resources that enable continued operation of health, disability and aged care systems within the current political economic framework. The increasing carer recognition in policy and political arena has so far focused on how to prolong these care relationships within economically rational measures. I challenge this notion of ‘carers’ as constructed in current healthcare and policy discourses by drawing on a synthesis of findings from this study.

Chapter 2

Studying Care and the Impact of Stroke

It was March, 1999. My father was in his early 50s. He was styling his hair one morning as he was preparing to head out to work, when he became unsteady on his feet. He told my mother, who had come into the bathroom after hearing a loud, sudden noise, that he could not feel his leg. He then collapsed. He was immediately taken to the hospital, and underwent surgery. He had had a haemorrhagic stroke, and very nearly died. My mother and sister were at the hospital, waiting in anguish and hoping for a successful conclusion to the operation. He was in the hospital for the following three months. Stroke left him with various severe sequelae, including hemiplegia, spatial neglect, cognitive problems, and urinary incontinence. None of this I knew, because I was in Melbourne, some 8,000 km away from this event unfolding in Japan.

I had been living in Melbourne and studying at high school for a year prior to the event. It took another 12 months before I came to know about it. Out of parental concern/compassion, my mother decided to respect my father's wish not to notify me – amazingly, he told her in his fading consciousness. They did not want me to come back to Japan, just as I was settling into a new country and at school. I took notice of his frequent absence from home when I made my monthly phone calls home – my mum would tell me that he was on a business trip, or that staying back at work late – but I thought nothing of it, as he had always been busy with work. When my

mother told me of his stroke over the phone 12 months after the event, I cried uncontrollably.

Over the following years, through my intermittent phone calls and trips back to Japan, I have come to know of mum's struggles. For a long time, I did not want to hear about this. I was still coming to terms with the drastic changes in dad, and did not have the mental capacity, maturity or energy to absorb all her 'whinging'. Besides, I was busy with my own life. On my trips back home, I would spend much time catching up friends. On one of the trips, she told me that she felt I was neglecting her (and dad) by not spending much time with them and, perhaps, listening to her stories.

I first thought of doing this PhD project several years ago, because I wanted to know what life was like for my mother. I had been feeling guilty, because I have been so distanced from her everyday life, preoccupied by her caring duties. A couple years ago, with my PhD research well underway, I return to Japan for a visit to my parents. During this visit, I saw my mother handle my father roughly, while throwing what I thought were harsh words at him. I could not bear seeing such a sight – it was my father, after all. And so I told her, in a critical tone, to ease off. After a long pause, she turned around and responded, crying: "You say you are doing research, but you understand nothing about this."

This remark was something that I have since had to grapple with. *Do I really understand?* In writing this chapter, in which I describe the methodological approach I adopted, and the methods I used to collect data, I have come to a conclusion. No, I do not think I do really, certainly not experientially. Nor should I pretend that I do. What I can do, however, is to

listen to people's stories, and to take them seriously. I can also share these stories so that, hopefully, others will also take them seriously. I hope my thesis will resonate with my mother, my research participants, other people in their lives after stroke, and whoever else reads it.

* * * *

Writing is an act of intervention. Stories told and accounts written about them are situated in time, space, culture and society. These representations⁷ are political performances, for they do not merely offer descriptions, but 'perform' – make and remake – certain realities (Law & Singleton, 2000). While the aim of my study was to investigate how spouses of younger persons who have had a stroke experience their lives, my intention is not to offer a grand narrative about what their lives *are* like 'out there'.⁸ What I tried to achieve through this thesis is both modest and ambitious. It is modest in that my claims are partial and situated; accounts I offer are not constructed based on how typical they were of the study 'population' – or even amongst participants – as I discuss below. It is ambitious, because I have sought to challenge and interfere with assumptions that were made to appear 'natural' and 'self-evident' by existing modes of performing informal care. In writing this thesis, and colluding with particular versions of 'informal care' contributed by participants, I wished to inspire further discussions that, hopefully, articulate alternative modes of performing 'stroke care'. In order to achieve this aim, I drew upon an ethnographic approach. In

⁷ As the discussions in this chapter should make it clear, I do not use the word 'representation' to mean a reflection of 'reality out there'. I use it to refer to the authorship of re-presentation and re-telling. However, I also feel uncomfortable using the hyphenated version of the word, because it assumes that the sources, the 'original' stories, are static, singular, powerless, and innocent, which are then reconfigured to suit the author's agenda. However, these stories too perform realities to certain political effects. Some examples of this can be seen in the incidences during participant observation that I discuss below.

⁸ Too often, studies present their theoretical claims as if they were ever in the present tense, sailing effortlessly across time and space.

this chapter, I outline the research paradigm used in the study, followed by descriptions of the research strategy and methods used for data collection and analysis. Measures taken to ensure the quality of my study, as well as ethical considerations, are also discussed.

Research paradigm

Different knowledge practices generate different realities. How research questions are formulated, data are collected, interpreted and presented, and conclusions are drawn, all depend on the researcher's beliefs about the world and how it should be studied and understood. It is therefore imperative that I set out my assumptions here.

The research paradigm employed in my study adopts a constructionist epistemology. Constructionism⁹ rejects the notion that meaningful reality only exists as objective truth, independent of human mind, waiting to be discovered (Burr, 2003). Rather, a constructionist approach regards all knowledge and meaningful realities as being constructed in and out of interactions amongst individuals within their social contexts (Burr, 2003; Charmaz, 2009). That is, phenomena do not inherently have meanings. Instead, people construct meanings and make sense of their world through social interactions in particular situations.

Declaring that all meaningful reality is socially constructed, however, does not imply that the phenomena themselves are not real. I agree with Crotty (1998) who, somewhat counter-intuitively, states that constructionism is compatible with both realism and relativism. Realism, often associated with objectivism and positivism

⁹ Constructionism and constructivism are often used interchangeably, although they are slightly different. Constructivism tends to focus on cognitive processes individuals undergo in mentally constructing the world as experienced, while the concern of constructionism is on social rather than individual cognitive processes in meaning making (Young & Collin, 2004). However this distinction is often of a technical nature, and the boundary is blurry in the literature. I outline my understanding of constructionism in this chapter.

(e.g. Denzin & Lincoln, 2005), is an ontological notion that the world and external events materially exist. However, realism as an ontological position does not necessarily belong exclusively to objectivism. According to Crotty (1998: 10-11), constructionism as an epistemology has a realist ontological dimension because it acknowledges that what is outside the human mind is real; the thing that we call a 'tree' exists regardless of anyone being aware of its existence. However, concepts and ideas – knowledge – about the tree have to be constructed in and out of interactions between people and the world around them (Crotty, 1998). That is, all meaningful reality, or truth, is a product of social interactions.

Constructionism is also relativist because it treats knowledge as historically and culturally situated, rather than as an absolute and eternal truth (Charmaz, 2009). It is probable that each individual involved in the same event perceives, understands, interprets, experiences and makes sense of the event in different ways; it is also possible that the same individual understands and makes sense of a phenomenon in different ways in different circumstances and situations. Indeed, a multiplicity of realities is possible. However, that socially constructed, multiple realities exist does not equate to the notion of 'anything goes', often evident in more extreme forms of subjectivism (Holden & Lynch, 2004). In such views, there is no way of distinguishing one way of knowing from another, as everything is constructed internally and every claim to knowledge has equal standing with every other claim. However, realities are not confined just in the mind; realism reminds us that meaningful realities are constructed in social, historical, and material contexts (Crotty, 1998). In this study, I examine the subjective experiences of carers, paying particular attention to how the discursive construction of informal care influences their social life-world. However, this is not to say that caregiving practices and other material

circumstances in themselves are not worthy of attention; whether interpreted as burden, reward, both or otherwise, caregiving experiences involve materially real practices. Caregiving as a meaningful reality is reified in the complex web of relations between individuals, institutions, material circumstances and practices.

My research was informed by a feminist research approach, in that I emphasised the feelings, experiential knowledge, intuition, empathy, reciprocity, and relationships of participants (Stacey, 1988). However, I do not position myself as a feminist for a simple reason: irrespective of my gender, I “do not actively struggle against the exploitation of women in *everyday life*” (Harding, 1989, p. 12 [emphasis added]). Indeed, I benefit in various domains of my life from just being a man, yet I often accept the status quo. Furthermore, given my father’s health condition, I very much doubt I was allowed to – let alone encouraged to – pursue my career and academic aspirations in a foreign country, had I been a woman in Japan – a highly patriarchal society.

Sensitising concepts

Although an inductive research approach guided the present study, my disciplinary perspectives shaped the research question, which phenomena I paid attention to, how, where and when data were collected, and what sense I made of them (Charmaz, 2007) – things which Blumer (1969) termed 'sensitising concepts'. A sensitising concept “gives the user a general sense of reference and guidance in approaching empirical instances... sensitizing concepts merely suggest directions along which to look” (Blumer, 1969, p. 148). General principles of interpretivism underlay my methodology and loosely formed a frame through which I viewed the world. The concept of biographical disruption, first coined by Bury (1982) and further refined by

Williams (2000), initially guided my data collection strategy as a sensitising concept. Below, I describe these.

Embodying constructionist epistemology, interpretivism as a broad theoretical umbrella is concerned with how individuals construct meaning and make sense of the world. That is, an interpretivist approach “looks for culturally derived and historically situated interpretations of the social life-world” (Crotty, 1998, p. 67). Following the interpretivist tradition, Michael Bury (1982) observes how middle-aged rheumatoid arthritis patients make sense of their illness in the context of their lives. He suggests that the onset of arthritis, an illness commonly viewed as a consequence of becoming old, presents itself as a ‘major kind of disruptive experience’, or a form of ‘biographical disruption’. Chronic illness as biographical disruption includes three aspects: the disruption of taken-for-granted assumptions and behaviours; disruptions in explanatory systems previously used by the individual, requiring a fundamental re-evaluate his/her biography and self-concept; and the attempt, successful or otherwise, at the mobilisation of resources – physical, social, financial, medical and cultural – in the face of an altered situation (Bury, 1982).

Bury (1991) also makes distinctions in the variety of responses to biographically disrupting events. *Coping* can be seen as a cognitive process whereby individuals attempt to minimise the effects of biographical disruption on their self-identity and a sense of ‘coherence’ and ‘potency’, whereas *strategy* refers to the actions individuals take in order to mobilise resources and maximise favourable outcomes (Bury, 1991). He further suggests that *style* could be thought of as the way people respond to and present important features of their biographically disruptive events and circumstances. While closely related to the process of coping and strategy, his conceptualisation of style directs attention to how people draw upon ‘cultural

repertoires' embedded in discourses about the body and self (Bury, 1991). Thus, coping refers to psychological, strategy concerns practical, and style represents cultural elements of an individual's response to biographical disruption.

The concept of biographical disruption has attracted a number of criticisms and consequent revisions. For example, the concept has been criticised for assuming that there is a 'normal life trajectory' (Williams, 2000). 'Normal' is a relative concept and is situated in time, space and cultural and social contexts (Manderson, 2011). A clear example of this can be seen in Carricaburu and Pierret's study (1995) of men who contracted HIV through homosexual relations, for whom HIV-positive status strengthened their sense of collective identity due to the culturally held assumptions around homosexuality and HIV. Another aspect of Bury's conceptualisation that has been questioned is his treatment of individuals as having rational, calculating agency, and his neglect of emotions and embodied experiences (Reeve et al., 2010). The embodied experience of losing a breast, for example, may deeply and emotionally scar a woman's sense of femininity, despite her cognitive ability to defy the societal obsession with breasts as a symbol of sexuality (Manderson, 2011).

The concept of biographical disruption was a useful starting point in my data collection as it directed my attention to the profoundly disruptive nature of stroke on partners. Traces of this concept should be evident in my analysis presented in the substantive chapters (Chapters 4-8). However, as my data collection and analysis progressed, it also became obvious that both the disruption and people's responses to them were not singular – as the original concept suggests – but multifaceted and occurred in different domains of their lives. In other words, the concept did not quite capture the complex and nuanced nature of disruption and consequences presented in empirical materials. I shall revisit this in Chapter 9.

Research strategy

People draw on discourses to construct their own reality and, in doing so, “draw on a shared language, rules, and traditions, not only for expressing it but, moreover, for experiencing it” (Charmaz, 2009: 142-143). In order to investigate this enactment of reality, which may be defined in multiple ways, I sought to examine the standpoints of the participants, their historical locations and social circumstances. To do this, I drew on ethnographic methods to explore the everyday life experiences of participants, with the goal of problematising their realities (following Charmaz, 2007). This enabled me to tease out participants’ presuppositions, as well as my own, delineating embedded taken-for-granted ‘common sense’ knowledge, and situating the construction of meanings and actions in social, political, historical, and material circumstances.

To achieve 'thick description' (Geertz, 1973) – densely textured and contextualised accounts of social actions and their meanings – that typically characterises ethnography, I sought to capture the elements outlined by Punch and Punch (2005: 160-161). First, through participant observation, I became familiar with and documented people’s taken-for-granted assumptions and rules in the field (Charmaz & Olesen, 1997). This was important in grasping meanings involved in formal and informal stroke care practices. Second, I collected people’s perspectives on events, actions and contexts through casual conversations in the field and formal in-depth interviews. I provide detailed discussions about in-depth interviews and participant observation below. Third, my data collection was prolonged and repetitive, in order to encapsulate multiplicity of meanings and layers of cultural interpretation. Gaining access to and collecting data that were rich enough to allow me to reconstruct ‘thick descriptions’ took time and commitment. Along the way, I encountered various

events and individuals that also had transformative effects, as I discuss in detail later in the chapter. Fourth, and on a related note, data collection in ethnography often involves techniques other than what are typically considered ‘fieldwork’ (participant observation and in-depth interviews) to obtain rich and contextualised data. In my study, I drew on documentation related to carer, healthcare and welfare policies, parliamentary debates, and other publicly available material to problematise dominant, often taken-for-granted, social and cultural meanings surrounding informal care. Fifth, as with many ethnographic studies, my study was iterative in its nature, rather than pre-formulated. This was where elements of the grounded theory method were useful, and offered inspirations in my unfolding data collection and analysis.

‘Grounded theory’ is a somewhat confusing concept; it is both an overall strategy for doing research and a particular set of data collection and analysis techniques and procedures to implement that strategy (Punch & Punch, 2005). Therefore, it is perhaps more useful to conceptualise the ‘grounded theory’ as a “systematic, inductive, and comparative approach for conducting inquiry for the purpose of constructing theory” (Bryant & Charmaz, 2007, p. 1). In a grounded theory study, the researcher collects data to develop concepts, which in turn elicit further data collection, and the emerging theoretical framework is continually refined in this iterative process (Charmaz, 2007). While it was originally developed by Barney Glaser and Anselm Strauss during their landmark ethnographic study *Awareness of Dying* (Glaser & Strauss, 1965), grounded theory as an inductive research design is treated distinctively and specifically in many methodological textbooks (e.g. Creswell, 1998; Punch & Punch, 2005). This is because an ethnographic study may or may not incorporate a grounded theory approach; for example, the *Extended Case Method* of ethnography (Burawoy, 1998) advocates the use of an existing theory as a

starting point, as well as the analytical tool, in order to identify flaws in the theory that can be improved upon.

Nonetheless, ethnography and grounded theory have been shown to be highly compatible and complementary; the grounded theory method can help the researcher develop a more complete picture of the research setting by removing a rigid and artificial separation of data collection and analysis often seen in other forms of ethnographic research (Charmaz, 2007; Timmermans & Tavory, 2007). The open-ended, yet systematic nature of the grounded theory could help an ethnographer overcome several problems often faced in other forms of ethnography employing a deductive approach. These include: (1) uncritically and prematurely adopting research participants' views; (2) being overwhelmed by the abundance of data in the setting because s/he is attempting to capture everything about the setting prior to data analysis; (3) superficial, random data collection in cases where the pre-formulated theoretical framework was found to be not empirically 'grounded'; (4) the risk of reductionism stemming from the over-reliance on the stock disciplinary knowledge (*etic* views) and overlooking dimensions that are in fact significant to the participants (*emic* views) (Charmaz, 2007, p. 23). Conversely, ethnography can help a researcher go deep into the experiences of the participants rather than looking on as a naïve outsider, as has been claimed of some grounded theory studies without an ethnographic orientation (Charmaz, 2007).

As Morse (2009) suggests, there are many varieties of grounded theory. The differences of these variations stem from divergences in epistemological assumptions and objectives of each approach. Glaser's 'classic' grounded theory (1998; Glaser & Strauss, 1967), for example, bases itself on an objectivist epistemology and assumes a singular, 'real' reality; hence it aims to 'discover' data and pursues abstract

conceptualisations and context-free generalisation (Charmaz, 2009). I mainly draw upon constructionist grounded theory suggested by Charmaz (2007), which aligns itself with constructionism, the epistemological stance I take.

The constructionist grounded theory assumes multiple realities, and data, as with any other ‘social facts’ or realities, are socially constructed through interactions. That is, “data do not provide a window on reality. Rather, the ‘discovered’ reality arises from the interactive process and its temporal, cultural, and structural contexts” (Charmaz, 2000, p. 524). The goal is to construct theory, here defined as an interpretive framework that invokes “imaginative understanding” of the studied historically – and socially – situated phenomenon rather than a universal statement of linear reasoning that aim for causality and predictability (Charmaz, 2007, p. 231). Since this type of theory accepts that reality is multiple and relative, generalisation is taken as partial, conditional, and situated in time, space, positions, actions and interactions (Charmaz, 2009). Grounded theory studies in other traditions are usually written around a core variable that integrates all the categories and sub-categories. These are presented using a neat, linear logic, often accompanied by flow-chart looking conceptual framework. This is not the kind of theory I am presenting here. A constructivist grounded ‘theory’ is often not readily identifiable as a theory because it lacks an overarching, core variable integrating all the themes (Jones & Noble, 2007). Rather, it “remains embedded in the narrative, in its many stories” (Charmaz, 2000, p. 527). The end product is interpretive theory that has credibility, originality, resonance, and usefulness (Charmaz, 2009).

The study area

My study of care and caregiving took place in the state of Victoria, located in the southeast of Australia. While it is the smallest state on the Australian mainland, it is

the second most populous state in the country: most (4.3 million) of its 5.8 million population is concentrated in the Greater Melbourne¹⁰ metropolitan area (as estimated at 31 March 2014: Australian Bureau of Statistics, 2014).

As stroke is not routinely considered notifiable and so is not reported to the state Department of Health,¹¹ there is no centralised incidence and prevalence data available. This made it difficult to know the number of persons who have had a stroke, and therefore to get a sense of how many people are stroke-related carers in Victoria. The most recent population-based study estimating the incident rate for stroke was conducted in inner northern Melbourne suburbs in 1996-97 (Thrift et al., 2000). Although almost two decades old, it is still widely used (e.g. Australian Institute of Health and Welfare, 2013) due to the absence of more recent incident rate data. According to this study, 56 individuals (31 men and 25 women) per 100,000 people aged between 25 and 55 had a stroke in the previous 12 months, and 54 of those had their first-ever-in-lifetime stroke. Assuming that these incident rates have remained stable and that the rates are similar in other sections of Victoria, an estimated 1,314 Victorians aged between 25 and 55 (730 men and 584 women) had a first-ever stroke

¹⁰ Technically, 'Greater Melbourne' as defined in the Australian Statistical Geography Standard (ASGS) (Australian Bureau of Statistics 2011b) covers areas much larger than the area typically referred to as metropolitan Melbourne by local residents. This is because the Australian Bureau of Statistics, the publisher of the ASGS, does not define the distinction between metropolitan and non-metropolitan areas. The ASGS superseded the Australian Standard Geographical Classification (ASGC) in 2011. However, in Figure 2.1, I illustrate Melbourne as defined by the ASGC, which was, as at 10 December 2014, still being used by the Victorian Department of Health in its definition of region divisions (Victorian Department of Health, 2011). Greater Melbourne as defined in the ASGS is also closer to the colloquially known Melbourne.

¹¹ Certain infectious diseases are legally required to be reported to the Department of Health in Australia to prevent or control the spread of infection. Some chronic diseases are registered also; for example, the Victorian Cancer Registry (VCR) is legally required to maintain a population-based cancer registry.

in the 12 months preceding 30 June 2013 (based on figures from Australian Bureau of Statistics, 2014).

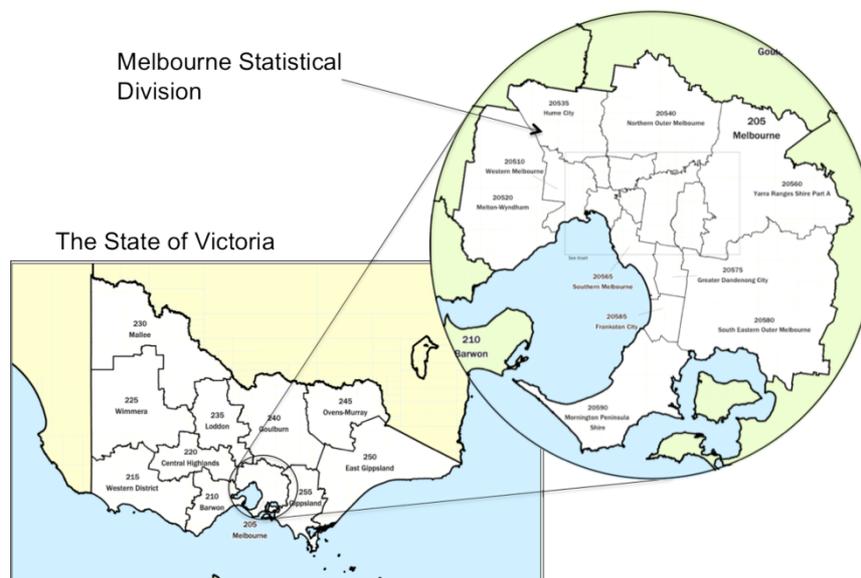


Figure 2.1: The state of Victoria and the Greater Melbourne as defined in Australian Standard Geographical Classification (Source: Australian Bureau of Statistics, 2011a).

Furthermore, based on self-reports from the 2007-08 National Health Survey (Australian Bureau of Statistics, 2010a), an estimated 0.2% of people aged 25-34, 0.4% of people aged 35-44 and 0.6% of Australians aged 45-54 had stroke sometime in their lives (i.e. the prevalence rate). This corresponds to 9,520 Victorians affected (based on figures from Australian Bureau of Statistics, 2014). It was difficult to know how many of them had a spouse who could be identified as carer. Nonetheless, it should provide a rough estimate of the sample population for the study.

Collecting data

As mentioned above, I used three interrelated methods in order to achieve the research aim – (1) document analysis (2) participant observation, and (3) in-depth interviews. Ethics clearance to conduct this research was received from the Monash

University Human Research Ethics Committee (MUHREC). Formally, this meant that participation in the research was voluntary self-nomination. A written explanatory statement, detailing the project outline and potential ethical implications, was provided to potential participants prior to obtaining their informed consent to be interviewed. My training and work experience in the field of mental health meant that I felt I was equipped for cases where participants developed a mental health crisis. I had completed two mental health intervention courses: Mental Health First Aid (Kitchener & Jorm, 2002); and Applied Suicide Intervention Skills Training (ASIST) (Ramsay et al., 1999), and have previously held volunteer and paid positions at mental health related organisations (Richmond Fellowship Victoria, now known as Mind; Anxiety Disorder Association of Victoria; and depressionNet).

Every effort was made to ensure questions that I asked in in-depth interviews were not likely to cause distress. However, it was sometimes difficult to know what could trigger emotional distress in interviews. For example, a discussion around family support with one of the participants triggered an emotional response because the discussion reminded her of a relative who had recently passed away from a non-stroke related cause. Sensitive information was not solicited during participant observation. Data collection strategies with individuals, as discussed above, were as non-intrusive as possible. Data were de-identified and participants were given pseudonyms, to ensure that participants cannot be identified.

Yet, as I discuss below in relation to participant observation and interviews – though not in relation to policy document analysis – as I became involved with people – the more I worked in the ‘field’ of stroke and the support of those affected by it – routinely issues emerged that were ethical as well as epistemological. In the section

below, I discuss how the various data collections techniques were used, and draw attention to issues that had ethical implications in this context.

(1) Identifying circulating discourses: policy document analysis.

As policy documents are both cultural products and productive, they reflect the specific social and historical contexts within which they are constructed, while simultaneously producing certain realities (Bacchi, 2009). Building on the different conceptualisations of informal care that have emerged in the last several decades (as outlined in Chapter 1), my policy document analysis complemented the more traditional ethnographic data collection techniques, described below, and pointed my attention to the cultural assumptions that shaped policies, and thus to the realities that were therefore reproduced. In doing so, I was able to see how such policies could affect their target population at the local level, and this also enabled me to link micro- and macro-factors.

Typically, policy analysis focuses on how and what kind of solution is provided under certain policy positions. However, by uncritically accepting the problem assumed in policies in the first place, this approach bypasses interrogation of the social and historical conditions under which certain phenomena are problematised or left unproblematised (Bacchi, 2009). Without examining the problematisation process itself, the analysis of policy may overlook how issues are represented in ways that “mystify power relations and often create individuals responsible for their own ‘failures’, drawing attention away from the structures that create unequal outcomes” (Bacchi, 2000, p. 46). In describing problems, policies ‘perform’ particular notions of and assumptions about the phenomena – the truth – to which they are addressing. These assumptions frame the proposed solutions appear self-evident and common-sensical. As Deleuze (2004, p. 198) eloquently states: “A solution always has the

truth it deserves according to the problem to which it is a response, and the problem always has the solution it deserves in proportion to its own truth or falsity – in other words, in proportion to its sense.”

My examination of how informal care for chronic illness was conceptualised in the discourses of Australian policy and not-for-profit arenas was inspired by Bacchi's (2009) *What's the Problem Represented to be* (WPR) approach. The WPR approach assumes that *policy problems* are socially constructed, rather than existing ‘out there’ in the society, waiting to be ‘discovered’ and ‘solved’ (Bacchi & Eveline, 2010). This proposition does not dismiss the conditions that are defined as *problematic* as mere ‘subjective’ constructions and thus not ‘real’. To the contrary, the focus of the WPR approach is to identify how policies create different impressions of those conditions, which have real and meaningful effects on how people are treated and how they live their lives (Bacchi & Eveline, 2010). The goal of this approach is to delineate how ‘problems’ are represented; what kind of taken-for-granted assumptions are drawn upon in the recommended solutions, making them appear as self-evident; what other problematisations might be identified but are neglected, ignored, or played down; and what power relations are evident in these representations (Bacchi, 2009).

The WPR approach suggests employing six interrelated questions in guiding the document analysis process. These questions are (Bacchi, 2009):

- What’s the ‘problem’ represented to be in the specific document?
- What presuppositions or assumptions underlie this representation of the ‘problem’?
- How has this representation of the ‘problem’ come about?
- What is left unproblematic in this problem representation?
- What effects are produced by this representation of the ‘problem’? and

- How/where has this representation of the ‘problem’ been produced, disseminated and defended?

These questions were used in my analysis in a flexible, rather than rigid, manner. This approach allowed me to consider carefully how informal caregiving was problematised in policy documents, and what kinds of solution were offered to address the ‘problem’.

Documents for policy document analysis were collected through searching for relevant key words such as informal care, family care and disability in the Federal and Victorian Hansard and websites of relevant Federal and Victorian government departments, public inquiries, and not-for-profit organisations (e.g. Federal Department of Health and Ageing, Victorian Departments of Health and Human Services, Centrelink, Productivity Commission, Carers Australia, the National Stroke Foundation). Documents included parliamentary debates, reports commissioned by government agencies, submissions from not-for-profit organisations and individuals to public inquiries, and information and ‘factsheet’ materials published for carers. Data collected through participant observation and in-depth interviews (discussed below) provided further empirical flesh that illuminated the points of convergence and points of contradiction in discursive and experiential constructions of care provision.

(2) Working in the field: participant observation

Over eighteen months in 2012 and 2013, I conducted extensive participant observation through attending support group meetings, volunteering as a part-time office assistant in the headquarters of StrokeVic (pseudonym), a state-wide stroke peer support organisation, and attending various stroke-related events. During this phase of my study, I was able to observe, in the contexts of spouses and people who have had stroke, the patterns of physical and psychosocial caregiving tasks, the

type(s) of support networks that people could and did (or did not) access, and interactions between spouses with each other or with other members of the community. Casual conversations were held throughout to elicit meanings that emerge through such interactions. Field notes were taken where it was appropriate. In all instances, people who I encountered were aware of my status as researcher: nevertheless, in cases where I documented interactions that involved individuals other than research participants (i.e. people with whom I conducted in-depth interview), data will be presented as contextual, anonymised data unless explicit informed consent was obtained from the individuals involved.

Participant observation is a data-collection technique whereby a researcher builds relationships with participants, gaining local knowledge through active involvement in routinised activities within the research setting (Schensul et al., 1999). In taking this approach, I was able to pay careful attention to the ongoing, fluid interactions and processes, in order to understand the subtle, implicit underlying assumptions that may not surface during interviews due to their taken-for-granted nature (Emerson et al., 1995). In doing so, I moved from a position of passivity to being actively engaged in participants' reality construction, which meant that I sometimes found myself treading the "political fault lines" (Emerson et al., 1995, p. 3), where frictions occur between differing priorities and points of view, and experiences at first hand enabling and constraining conditions under which people conduct their lives.

I initially approached StrokeVic during the early stages of the project to seek contextual information about stroke care in Victoria. Following an introductory email, I met with Margaret (pseudonym), a woman aged in her 70s, in a small office in the Melbourne city centre. After our meeting, she mentioned that the organisation was in

need of volunteers to work in the office. I offered her my services, as I have had experience working in the community sector both professionally and as a volunteer. This offer was gratefully accepted, and our friendship began.¹² As a volunteer office assistant, my work at StrokeVic involved providing various kinds of administrative support, such as responding to phone inquiries, project management support, and setting up a database and entering data, on a weekly basis at the office. Margaret acted as a gatekeeper; she introduced me to three participants for in-depth interviews, one of who then introduced me to another interview participant. Margaret also invited me to forums, symposiums and exhibitions that were organised by StrokeVic.

Margaret also introduced me to many stroke support group coordinators for the purposes of recruitment, and to help me network with people in the sector. One of these coordinators was Janice. She enthusiastically invited me to her group, which I attended throughout the fieldwork. She also suggested me to visit another support group for people living with aphasia. Technically, the aphasia group was a choir group for people living with aphasia following stroke and, therefore, calling the group a ‘support group’ may devalue the primary objective of the group, which was singing, and their artistic endeavour. In fact, one of my main observations at the group activities, which included numerous public performances,¹³ was that people often undervalued the group’s artistic expressions. This was often reflected in the relatively small amount of payment that they received (usually in the form of ‘donation’) for their performances at various events. Many people wanted the group to perform for

¹² The role of friendship in ethnographic research is explored in Tillmann-Healy (2003) and Beech et al (2009). I specifically use the word ‘friendship’ here, despite the large age gap (which could have been that of a mother – child, or even a grandparent – grandchild, relationship), since Margaret used the word in the Christmas cards she has given to me. The same could be said about Janice, although, being in her early 60s, she was younger than Margaret.

¹³ One of the public performances was at a large conference dinner in front of more than a thousand delegates.

them (and the group had a busy schedule), yet sometimes they did so in a subtly exploitive attitude that ‘singing in front of people is beneficial to them’. However, in the sections and chapters that follow, I refer to this group as a support group for two reasons. First, this helps me to de-identify the group and people involved in events that I describe in later chapters. Second, the group did indeed provide social and emotional support to members – people who have had a stroke and those who accompanied them to the group, most often their spouse. In fact, in the absence of stroke-specific carer support groups, the group offered a unique setting for carers to have discussions amongst themselves while the persons who have had a stroke were rehearsing. I developed a close relationship with members of the aphasia group. I once mentioned to some of the group members that I play tabla, Indian drums. They asked me to bring them to the next meeting to play, and this became my weekly routine until I concluded my fieldwork with the group in late 2013. I provided accompaniment to their singing, and performed with them at several concerts.

People like Margaret, Janice, and other support group coordinators acted as key informants and gatekeepers. They agreed to facilitate my entry into the field, and also provided me with commentaries about the formal stroke and other disability care services. They were often willing to help me when I had a question, although my questions were targeted around policy and practice in the formal services, rather than informal caregiving per se. Nonetheless, some of the comments they made informed some aspects of my probing strategy in in-depth interviews with participants. These key informants were aware that I was writing a thesis and, when I wanted to write about a specific incident involving them, I obtained their permission to describe it in a way that de-identified them and their group.

I attended all thirteen active stroke support groups in Melbourne and one regional stroke support group during my fieldwork. There were other Melbourne support groups that were listed on StrokeVic and the National Stroke Foundation websites when I commenced my fieldwork; however, upon contacting them, it turned out that they were not currently active.¹⁴ Also, due to the time and resource constraints involved in conducting this PhD research project, I was only able to attend the one regional stroke support group on one occasion. As I will discuss in later chapters, stroke support groups were attended by both persons who have had a stroke and their carer, almost always their spouse. All of them were held on a weekday, except for two groups targeted at younger people; these met on the weekend. There was one stroke carer group listed on the StrokeVic website; however it had merged with a stroke support group by the time I started my project.¹⁵

I initially contacted the group coordinators to seek their permission to attend the group. I was usually given a couple of minutes to introduce myself; I spoke about my personal connection to stroke and informal stroke care, and provided a brief overview of the study. Of the 13 groups in Melbourne, I attended three on a regular basis throughout the duration of my fieldwork. My attendance at other groups also typically spanned several months, except for one group that I attended only once. My decisions to conclude my visits to these groups were made in light of theoretical sampling that guided my research, although it was also partly based on pragmatic reasons. Many groups were attended only by members who were older than those aged 25-55 who were the population to be included in the study. In these cases, I

¹⁴ Some new groups in Melbourne started after I concluded my fieldwork.

¹⁵ I am not sure when the stroke carer support group was established. However, I have obtained an information booklet published in 1999 by the group, so I assume the group was active around that time. People told me that the carer group merged with the stroke support group, which was mostly attended by their spouses anyway, 'a few years ago'.

concluded my visits once I had attended the groups for a few months and observed that there were no new, younger members in attendance. Other group meetings coincided with the meetings of the groups that I attended regularly or occurred at the same time as my paid work commitments. After I attended those groups intermittently, I decided to focus on the groups that I could attend on a more regular basis – and which involved greater numbers of younger people.

In my study, I encountered intra-sectoral politics between and within different organisations and services, and everyday personality clashes. Those occasions reminded me that research encounters – like any social relations – involved complex social dynamics, which affected and were affected by everyone in the field. Various decisions were made by people in the field, myself included – from such trivial things as whether to drink a cup of tea offered by someone or to take cupcakes with me to interviews, to more complex ones including what to say and how to say them in a conversation. All of these decisions had the potential to directly or indirectly affect the outcome of my research. For this reason, where appropriate, I insert into my discussions my actions during and reactions to research encounters.

Research encounters in the field can sometimes be uncomfortable experiences, exposing the researcher to emotional (and physical, although not applicable in my study) vulnerability (Behar, 1996). Lerum (2001) argues that researchers often don 'academic armour' in order to protect themselves from such vulnerability. Academic armour includes the use of obscure 'academese', professional attire and personal appearance, and ideological assumptions and attitudes that, while acknowledging the experiential knowledge of 'lay people', also suggest that researchers are the experts at 'intellectualising' these 'lay' experiences (Lerum, 2001: 470-71). These strategies are used to command legitimacy and respect as 'expert', and to claim an intellectual

territory. At the same time, they facilitate emotional detachment that allows researchers to feel safe in research encounters. Such armour may be useful, and indeed may be a necessity, in some contexts, as I discuss below. However, dropping the armour was immensely beneficial in my study, and it formed a large part of the performative and dynamic aspect of my fieldwork (Manderson et al., 2006). I tried to ensure at StrokeVic that my written communication was short and concise, after I heard Margaret complaining that “university graduates’ writing is too wordy.” It probably reflected the organisation’s positioning itself with values of grassroots and mutual support, away from clinically and public health oriented perspectives. Eager to earn trust and establish rapport, I wanted to avoid projecting myself in as a ‘detached, expert observer’. At the same time, however, I did not want to be seen as completely ‘naïve’. Given how salient the notion of kinship obligation was in the topic of informal caregiving, presenting myself in such a way would have risked myself being seen as ‘playing dumb’ or, worse, being uncaring. Furthermore, my open discussion about my own parents with stroke support group members enabled me to develop a certain level of rapport. People often asked me about how my parents were going, and every time I told them of a trip back to Japan, they responded with a ‘oh, good on you!’ Also, openly discussing my parents during in-depth interviews, where appropriate, sometimes helped me to probe further into certain areas of enquiry.

My age (I was in my late twenties to early thirties when I was undertaking field research) and gender (male), I believe, also played a role in forging particular relationships in the field. For example, based on my age and Japanese origin, Janice assumed I was computer savvy. She often asked me about problems on her computer and, after I solved them, she would give me some food to take home, such as home pressed olive oil. Also, for a period of time after I told her that I liked multigrain

bread, Margaret baked a loaf of bread every week for me to take home. I took this as a ‘thank you’ gift for my voluntary work, but also as reflecting my building relationships with these people.

Some of the open conversations I had in the field brought moments of personal transformation (Lerum, 2001). During the initial stages of my fieldwork, I did not disclose too much about my parents. In a stroke support group meeting, I introduced myself to a couple who had been away on overseas holidays and therefore had missed my formal, two-minute introduction to the group. I explained to them my research and objectives in a rather dry, formal manner, when another member, who I call Mark, interrupted me: “Mutsumi, when you introduce yourself to people, you have to tell them about your parents. People relate to you that way. It’s important that you talk about them.” The couple I was talking to nodded in agreement. I responded to the comment by thanking Mark for his suggestion, before adding my feeling of unease in doing so: “I feel guilty actively advertising about my parents, because that would mean I’m using them to earn people’s trust.” Mark assured me that my parents wouldn’t mind because what I’m doing is for a good reason. After this incident, I decided to openly discuss my parents where appropriate. I did not share everything; rather, my disclosure was orchestrated in a particular way. I did not tell some aspects of my experience with, and observation of, my parents that might portray them (and myself) in an overly negative light. This involved downplaying some of my mother’s behaviours towards my father, which I thought was harsh at times, and some of my father’s stroke sequelae such as cognitive difficulties; sometimes I avoided talking about my frustration over these all together. I did not want to depict my father as a ‘burden’ and my mother as ‘paternalistic’. This was done partly to manage what people thought of my parents and me (cf. Goffman, 1959). The biggest motivation for

this, however, was to avoid implying that I thought of people I met on the field in a similar way – that I was making some sort of moral judgement on their conduct.

While all groups were welcoming, not all of them embraced the idea of having a researcher as a fixture of the group. One of the groups invited me to a meeting as a one-off occasion. At another group, the group coordinator communicated to me after I had attended the group for a few months that there were some members at the group who felt uncomfortable with my regular attendance. They felt that the group was held for people living with stroke, and that it was therefore inappropriate for me to join them on an ongoing basis.¹⁶ After I thanked the group members at the next meeting, I concluded my fieldwork with this group. These events – particularly the latter incident – highlighted my outsider status, and I felt rejected. I was upset over the following few days: *I thought I was establishing rapport – What have I done wrong? Was I too intrusive in adopting the vulnerable, personal approach in my interactions? Did I, perhaps, assume the moral high ground by virtue of conducting research that was meant to ‘benefit’ them?*

After this incident, I reviewed my note-taking practice. I stopped taking field notes while I attended a stroke support group, and sat at the back of the room, quietly, in an attempt to avoid being intrusive. This somewhat emotionally detached approach, however, was not appreciated. At a stroke support group, one of the members, Frank, asked me why I was not taking notes or doing visible ‘work’. I explained to him that I did not want to be intrusive by scribbling down my field notes in front of people. I

¹⁶ It was something that I did not pick up during my attendance at the meeting. On the contrary, I actually felt that I was beginning to establish rapport with many members. I also observed that StrokeVic and some of the key members of this group did not enjoy a particularly intimate working relationship. I later concluded that it was not possible to find a neat causal factor leading to the incident. This reinforces my point above that, research settings are often ‘messy’ with its share of politics and personality clashes just like any other social settings.

then showed him my notebook, saying that I was going to write notes later. Frank laughed, and said: “You will need a bigger book than that!” People with health problems often want their stories to be heard (Warren et al., 2006), and, in fact, some interview participants were appreciative that their stories were going to be told through this research project, as I will discuss in Chapter 5. For many participants, carrying a notebook and visibly taking field notes on it – a conduct I initially considered was part of academic armour – was actually considered a gesture that I was taking their stories seriously.

(3) Taking stories seriously: in-depth interviews.

I conducted interviews with 17 spouses who self-identified as a carer¹⁷ over a period of 12 months. Table 2.1 shows the summary of participant characteristics (the recruitment materials used are included in Appendix 1); all participants are referred to here via pseudonyms. Most participants were recruited from stroke support groups, and lived in metropolitan Melbourne. However, five participants lived in rural regions, from an hour and a half to four hours from the city centre. Two of these participants were recruited through StrokeVic, and the rest were recruited through a rural stroke support group. Of the metropolitan participants, seven were recruited from stroke support groups, three were recruited through a flyer distributed through my personal network, and a participant was recruited through StrokeVic. This participant I met through StrokeVic then introduced me to another participant who resided in a metropolitan area. Two participants, Adam and Belinda were spouses, but both of them had had stroke. They met years after their stroke, and did not see their caring for each other as an ‘additional’ responsibility in their spousal relationship. Consequently,

¹⁷ I did not use the word ‘primary carer’ in my recruitment, because it was not the kind of word people used in the field. People used the word ‘carer’ to mean the primary carer.

they rejected the notion of making a clear distinction between a carer and care-recipient. This will be further elaborated in Chapter 8. Yvette self-identified as a carer to her ex-husband Chris. These ‘anomalous’ participants were recruited based on the theoretical sampling strategy that I discuss below.

Of the 17 participants, 13 were women. This overrepresentation of women in the sample reflected the gender composition of stroke support groups, through which most of the participants were recruited. While I saw some older men attending the support groups with their stroke-affected wives, I very rarely saw working-age men accompanying their wives. Since almost all support groups were held during business hours, the absence of working age men may be due to the cultural assumption that the man became the sole provider in a family in cases where a double income was not possible or desirable.

All interviews were held at a location of the interviewee’s choice, most often at a local café or in their home. About a half of the interviews lasted one to two hours, while others went for more than two hours. For the longer interviews, participants were offered a break, but all of them preferred to continue talking without a break (except for toilet breaks). I initially planned to conduct multiple interviews with each participant, however I later revised this plan; the length of interviews and richness of data that were gathered meant that data saturation occurred without multiple interviews for each participant. An exception was Will, whose first interview was concluded earlier than expected as he needed to leave for work. I conducted a follow up interview with him two months later.

Interviews were audio-recorded and subsequently transcribed verbatim. At each interview, participants were asked a mixture of retrospective, current, and prospective questions about the nature of their relationships with the partner, other

family members including children, and people in their social networks; difficulties and rewards involved in the caregiving role; formal and informal support systems including welfare support; employment and financial situations; and whether and how caregiving role affected their sense of 'self' (the interview guide is presented in Appendix 2). The interview guide was prepared for the purpose of the ethics application and candidature progress report prior to commencement of participant observation and recruitment of interview participants. It was not used as a list of structured questions; rather, it was only used in preparation for the first few interviews to remind myself of key domains that I wanted to explore in the interviews. Whilst I was mindful to not cause distress, in-depth exploration of topics often considered personal were also imperative in fully addressing the research questions. I was able to balance these two competing desires by providing a safe space for participants to talk about these issues, and using empathetic prompting and probing techniques. Establishing rapport was important in this process; once I explained to them my personal connection to stroke and that I was genuinely interested in their stories, they seemed to have placed a degree of trust in me.

As discussed above, research encounters are situated in time, space and social relations. It was difficult to draw any conclusion based on an unsystematic analysis of the role that the interview venue had on the interview process. However, on the basis of the interviews for this study, the interviews that I conducted in non-public spaces appeared to enable participants to disclose their emotions more intensively than those in public settings. Three participants interviewed in non-public spaces became visibly upset during the interview. They were offered to take a break, or to be interviewed at another time, although they insisted to continue. It was difficult to know whether many participants chose to meet at a public place because they felt safer discussing

potentially sensitive topics in such spaces. For those who had a paid employment, however, it might have been based on a pragmatic reason, as they could meet me on the way home or during the lunch break. Also, meeting at a café rather than home also meant that they could speak about their partner in his/her absence, avoiding eliciting embarrassment or self-consciousness. This may have contributed to their choice, especially for participants who were concerned about their partner's emotional wellbeing. One such participant in particular wanted all communication about research findings sent to her mobile phone rather than their joint email account to avoid her partner accessing them.

Table 2.1: Summary of participant characteristics

Name		First stroke onset	Age of both participant and spouse at stroke onset	Children's age at stroke onset	Metro/Rural	Interview venue	Recruitment	Participants' employment status
Participant	Spouse (person with stroke)							
Abi	Cain	2007	Abi 38; Cain 53	9, 16, 20	Metro	A spare room at a support group venue	Snowball	Abi ran a home-based business before and after Cain's stroke.
Adam		1988	30	Belinda had two children from a previous partnership	Metro	Home	Support Group	Both Adam and Belinda were employed before, but not after, their stroke.
Belinda		1993	31					
Alix	Erwin	2009	Alix 41; Erwin 45	3, 6, and 8	Metro	Library	Snowball	Alex participated in paid employment before and after Erwin's stroke.
Anna	Jason	2007	Jason 49; Anna 44	16 and 19	Rural	Home	StrokeVic	Anna did not participate in paid employment at the time of and after Jason's stroke.
Ben	Amy	2011	Amy 29; Ben 31	No child	Metro	Ben's workplace (After hours)	Support Group	Ben participated in paid employment before and after Amy's stroke.

Elke	Mick	2011	Mick 50; Elke 48	No child	Metro	Home	Support Group	Elke participated in paid employment before Mick's stroke, and returned to her work a few months after his discharge home. However, she quit her job over her own health concerns several months later.
Emily	Ryan	2010	Both 49	17, 20	Rural	Café	Support Group	Emily worked full-time before Ryan's stroke. After his stroke, it took her a few years before she decided to work casually.
Fiona	Matt	2010	Matt 49; Fiona 43	14, 17, and 19	Metro	Café	Support Group	Fiona worked in paid employment until Matt's stroke.
Irene	Lucas	2008	Lucas 38; Irene 34	4 and 7	Rural	Café	StrokeVic	Irene was working casually at the time of Lucas's stroke. A few years after stroke, she returned to work on a part-time basis.

Megan	Simon	2008	Megan 31; Simon 34	No child at the time. A daughter born in 2010	Metro	Home	Snowball	Megan participated in paid employment until Simon's stroke.
Naomi	Iain	2003	Iain 48; Naomi 44	10	Metro	Home	Support Group	Naomi participated in paid employment before and after Iain's stroke.
Neil	Eva	2011	Eva 54; Neil 56	Young adults	Metro	Café	Snowball	Neil ran a business before and after Eva's stroke.
Rebecca	Ned	2001	Ned 44; Rebecca 40	Two teenage children	Rural	Home	Support Group	Rebecca participated in paid employment before and after Ned's stroke.
Tracey	Ted	2008	Ted 47; Tracey 42	13, 18, 20	Rural	Café	Support Group	Tracey participated in paid employment before and after Ted's stroke.
Will	Nadia	2010	Nadia 40; Will 47	2 weeks	Metro	Home and café	Support Group	Will ran a business before and after Nadia's stroke.
Yvette	Chris	2011	Yvette 54; Chris 56	Two young adult sons	Metro	Café	StrokeVic	Yvette did not participate in paid employment before and after Chris' stroke.

I also conducted key informant interviews with five social and disability service workers to obtain contextual information about the relevant services available in Victoria. I met Debbie (pseudonym) at a forum about employment opportunities for people who have had a stroke. She worked at a disability employment agency, and provided with me information about the disability employment services and the funding system. At the time, I was working on the idea that stroke-affected partners obtaining a paid employment enabled some participants to enact a sense of normalcy (Chapter 7), and Debbie's description of the disability employment sector was useful. I met Trish at a support group. She was a personal care assistant accompanying a working age member to the group. She and her colleague Laura provided me with information about respite support services and residential care services, as they have had experience working at those settings. Nellie, whom I met through a stroke support group, was an allied health professional working in a disability service organisation. Nellie and her colleague Sally explained to me the funding system for disability services, and how those services, while targeted explicitly towards people with disabilities, sometimes provided respite as a by-product.

Sampling for in-depth interviews

Purposive sampling, particularly theoretical sampling, was used to investigate the diverse experiences of carers of persons who had a stroke while in their working age (Charmaz, 2007). This approach allowed for a sampling strategy based on concepts, not the representativeness of persons (Corbin & Strauss, 2008); I could therefore maximise the likelihood of obtaining in-depth information from participants, and to capture multiple realities (Charmaz, 2007; Lincoln & Guba, 1985). Initially, I used the following criteria for recruitment. First, to be included, the person had to be a co-residing spouse of a person who had a stroke requiring ongoing care or assistance for

a physical and/or cognitive disability. This criterion was based on self-identification by the potential participants rather than via a diagnostic instrument.¹⁸ The second criterion was that both the spouse and the person who had a stroke had to be aged between 25 and 55. I wanted to examine how stroke, commonly assumed a disease of old age, influenced the spouses' experiences when both were of active working age. In Australia, the official retirement age was 65 (Australian Department of Human Services, n.d.),¹⁹ and people at 55 years of age would be considered in the midst of active working life. 'Young-onset' conditions are typically considered to be those that affect people in later life (65 or over), but they are experienced or manifest prior to this age; while these conditions are understood to be biological realities, the definition of 'young-onset' is entirely social, based on workforce participation. Third, I recruited spouses of people who had their first stroke at least twelve months prior to recruitment. There are suggestions that carers, one year after the first-time stroke in their partner, are more settled in their caregiving role (Bäckström & Sundin, 2009; Bäckström et al., 2010), and this recruitment strategy would therefore be ethically appropriate. It also ensured that people had a chance to reflect on the impact of stroke on their lives. This was important, as people were often stretched thinly in the periods around and after their partner's discharge home (Chapter 5), and they may not have had the time or energy to reflect on the changes that had occurred and were likely to occur in the future.

¹⁸ Throughout this thesis, I attempt to reduce the usage of the vocabulary of medical diagnosis because it reproduces a particular form of problematising conditions that people live with following stroke (i.e. the medical model). However, I do acknowledge that medical terms are sometimes useful in describing certain conditions and bodily processes. Therefore, my attitude is not that of rejection; I made pragmatic decisions where I use medical terms.

¹⁹ From 2017, the retirement age will gradually rise to 67 by 2023 (Australian Department of Human Services, n.d.). Treasurer Joe Hockey proposed in a speech before the 2014 budget that the government will further raise the retirement age to 70 by 2035 (Coorey & Patton, 2014).

My initial phase of data collection served as a launching pad for the future, iterative development of research questions, aims and objectives. As I started analysing the initial interviews and observation data, further questions emerged. Based on my analysis of the data, a sample was selected to examine and elaborate on these questions and their related themes (Charmaz, 2007; Marshall, 1996); this also facilitated the identification of 'gaps' in my emerging ideas and provided guidance for the next step of data collection (a process of iteration). There were several distinct examples of how this occurred. For example, after conducting a few interviews, I realised that I needed to examine experiences of people who lived in rural areas. Similarly, after six interviews, it became clear that individuals need not be living together to be in a care relationship; in response to this data, I attempted to explore meanings of placing a spouse in a residential care facility. I then tried to recruit another participant whose partner was in a residential care facility by asking people I had met in the field. After conducting eight interviews and 10 months of participant observation, the concept of mutuality started to take shape. I invited Adam and Belinda, a couple both of whom had had a stroke, to participate.

However, given the general difficulties I encountered in recruitment, which was at times slow, it was not always possible to recruit new participants who met the profiles that I was seeking. For example, I was unable to recruit people who were partners of, but were not legally married to, a person living with stroke. In fact, almost all of the couples that I met through stroke support groups were legally married, except for a very small number of people who had met after stroke. Also, because most of the participants were recruited through stroke support groups, there was underrepresentation of people who were not receiving this particular form of support. Given these difficulties that I encountered in recruitment, it was more important in

using theoretical sampling to be iterative in my interview questions rather than recruiting new interviewees, although it was sometimes necessary. This circular process continued until 'data saturation' was achieved. Saturation occurred when concepts, their properties and dimensions, and relationships amongst concepts were rich enough, rather than based on their frequency of appearance in data (Charmaz, 2007).

Following initial contact with a potential participant, an in-depth interview was arranged. An explanatory statement and consent form was handed out, providing a project outline, what was expected of interview participants, ethical implications, and how results was going to be communicated. I also attached a list of telephone based support services, such as Lifeline and Rural Support Line, and Family Relationship Advice Line, in case participants required mental health support as a result of participating in the interview.

Making sense of stories: Data analysis

A grounded theory approach based on Kathy Charmaz's work was used in data analysis. This involved four steps, outlined here. After becoming familiar with the interview transcripts through repeated reading, line-by-line analysis was conducted to identify segments of "data as actions" (Charmaz, 2007, p. 48). In this 'open coding' stage, sections of the data (i.e. words, sentences, paragraph, or more generally, incidents) were assigned with a simple label that represented the meaning of the section (Corbin & Strauss, 2008).

In the next stage of analysis, significant and/or frequent codes were identified, and similar codes are grouped together under these 'substantive' codes (Charmaz, 2007). The coding framework was progressively developed as new data were collected, and substantive codes formed a basis for analytical categories that captured

emerging themes and concepts (Charmaz, 2007). NVivo [versions 9 and 10] software package was used during the coding stages. While it was valuable in data and code management, I also found that, without a strategy for flexibility and reflexivity, it could potentially contribute to data fragmentation. I describe below how I attempted to ensure data and my analysis of them remained contextualised.

Anselm Strauss and Juliet Corbin (1990, 1998) previously recommended the use of another layer of coding called axial coding, which specifies the properties and dimensions of a category such as “when, where, why, who, how, and with what consequences” (Strauss & Corbin, 1998: 125). However, Corbin later dismissed the notion of axial coding as a distinctive level of coding on the grounds that the separation between axial codes and other codes was “artificial” to start with (2008, p. 198). Accordingly, rather than using axial coding as a rigid analytic framework, I used ‘when, where, why, who, how, and with what consequences’ questions throughout my analysis to interrogate contextual origins of categories, subcategories, and the links between them (Charmaz, 2007). This contextual information was detailed in memos, and/or become codes.

Data analysis in grounded theory is not a linear process (Charmaz, 2007); rather, analysis involves continuously moving back and forth between levels of analytic stages. Furthermore, any qualitative data, by their nature, are ‘messy’ (Law, 2004). The process of navigating through ‘messy’ stories in my coding process and illuminating relationships between abstract concepts, in order to construct a theory that encapsulates the participants’ worlds, was difficult. In addition to theoretical sampling, two methods assisted my analysis to remain systematic while allowing for flexibility and reflexivity: constant comparison and ‘memoing’. Throughout data analysis, comparisons were made between: data and data; data and codes; codes and

codes; codes within and across interviews and field notes; codes and tentative and established categories; and tentative and established categories. This process is called constant comparison, and this ongoing process ensured that the categories emerged from analysis sufficiently capture experiences of participants. Also, comparing, contrasting and grouping categories allowed me to observe relationships amongst different categories, to examine differences and similarities in their properties and dimensions, and to identify theme/s. Memoing constituted recording of my thoughts about data, codes and categories, as well as my own self-reflection (Charmaz, 2007; Corbin & Strauss, 2008). Memoing was both the process of and means to record my analytical thinking; through memoing I developed my ideas about codes, categories and how they interact with one another, which later became chapters that form this thesis.

While data analysis based on coding and categorisation is valuable in finding and conceptualising patterns in the data, it has the potential also to lead to the fragmentation and de-contextualisation of data (Punch & Punch, 2005). As Coffey and Atkinson write:

Our interview informants may tell us long and complicated accounts and reminiscences. When we chop them up into separate coded segments, we are in danger of losing the sense that they are accounts. We lose sight, if we are not careful, of the fact that they are often couched in terms of stories... Segmenting and coding may be an important, even an indispensable, part of the research process, but it is not the whole story (Coffey & Atkinson, 1996, p. 52).

Memoing contextual information and constantly going back to the original data allowed me to keep whole context in view, and present “the whole story, the whole body of data” (Charmaz, 2000, p. 521).

Quality in qualitative research: ensuring rigour

Embracing constructionism as the epistemological stance has significant implications to the quality criteria for the output of a research project. The relativist assumption informs us that reality is multiple. A researcher may collect a range of data, though they have no inherent meanings; the researcher interprets and represents them. Since it is possible to make sense of the same material phenomena in different ways, the reality enacted in a research report will not be the universal, one-and-only truth. Furthermore, constructionists assume that data and analyses are co-produced by the researcher and participants through their interaction, and that they are situated in time, place, culture, and situation (Charmaz, 2007). However, stating that multiple realities and multiple interpretations of these realities exist, is not to imply “research anarchy” (Smith & Hodkinson, 2005, p. 921), in which any claim to knowledge, regardless of rigour, is attributed to equal credibility. Whilst there can be no ‘true’ or ‘valid’ interpretation of data, there can certainly be ‘useful’ interpretations (Crotty, 1998). This means that the concepts of validity and reliability, often associated with objectivist research inquiries, require a careful consideration in research projects following the constructionist tradition. In addition, the issue of representation requires further reflection, since research processes are inevitably embedded in unequal power relations between the researcher and research participants.

The knowledge practice inevitably involves processes of typification, reduction and abstraction, since it is impossible to observe, memorise, understand, and record every single detail of an individual, event, object and phenomenon.

Selective observation, analysis and representation are thus unavoidable in the works of social researchers. Furthermore, as discussed above, how an individual sees and makes sense of the world is only one of multiple possibilities of enacting reality, rather than the one and only truth. It was quite possible that my understanding of participants' experiences might be vastly different to how the participants themselves perceive their experiences. However, at the conclusion of the project I, as the author, had the authority over the particular reality to be performed. In the following section, my approach to ensuring quality in my study will be discussed.

There is no agreed upon evaluation criteria for qualitative research (Sparkes, 2001), because such criteria depend on who forms them, how 'quality' is defined within epistemological, methodological and disciplinary orientations that a study adopts, and the purposes of the study (Charmaz, 2007). Due to the diversity within qualitative research, it would be difficult, if not impossible, to devise an all-encompassing set of criteria suitable for all qualitative inquiries. Methodological literature discussing the issues around rigour in qualitative research can broadly be categorised into four camps: the replication, parallel, diversification, and letting-go approaches (Sparkes, 2001). The proponents of the replication approach adopt the traditional criteria of construct validity, internal and external validity, and reliability, though these are achieved through procedures different to quantitative research (e.g. LeCompte & Goetz, 1982). The parallel approach advocates for alternative terms such as credibility, transferability, dependability and confirmability (e.g. Lincoln & Guba, 1985), though these criteria are still closely related to the ones used in quantitative research, which are simply translated and fitted into a qualitative research context. The diversification approach encourages re-conceptualisation of validity and rigour by rejecting the notion that certain methodological procedures can guarantee access to

‘true knowledge’. Since the status of true and trustworthy is verified by social agreement situated in certain time and space, diverse conceptualisations of validity are required to suit particular context (Sparkes, 2001).

Lather (1993), for example, presents a reinterpretation of ‘validity’ that is radically different to how the term is conventionally understood. Her concept of ‘transgressive’ validity is concerned with the problematisation of truth claims, each specific to particular research contexts (Lather, 1993). The letting-go approach maintains that the concept of validity is not only uninformative, but also a distraction to ‘good’ research (Wolcott, 1994). According to this approach, alternative criteria are required, since validity does not quite capture the essence of many qualitative studies. ‘Goodness’ in quality qualitative research often extends beyond procedural (i.e. technical, ethical, theoretical and methodological) rigour and entails embodied aspects; it ‘feels right’ when we see it, even if we may not be able to put our finger on some of the reasons for it (Corbin & Strauss, 2008; Smith & Hodkinson, 2005). Part of this may be that ‘good’ qualitative research also demonstrates aesthetic and emotional dimensions; the report of a particular research project often displays creativity and artistry (Finlay, 2006) and is capable of moving the reader at an emotional as well as rational level (Bochner, 2000). My approach to ensuring quality in the present study incorporates elements of the parallel and letting-go approaches.

The criteria I used to determine quality, in this study, drew on works of Charmaz (2007), Corbin and Strauss (2008), Beck (1993), Finlay (2006) and Bochner (2000). My attempt was to apply these to both research procedures and the end product. The first criterion was credibility (Beck, 1993; Bochner, 2000; Charmaz, 2007; Finlay, 2006). Were the methods appropriate for what I was trying to achieve? Does my research demonstrate that I have gained intimate familiarity with the

research setting and participants? Are the evidences presented detailed enough? Are the arguments ‘grounded’ in the data? Do the findings present complex and often ‘messy’ journeys that participants and I go through? In conducting interviews and participant observation, and in writing about them, I tried to pay attention to how interview responses and social actions were produced by participants and I, both of whom occupying specific social and discursive positions, and this was as important as the analysis of the reported reality itself (Dowling, 2007; Manderson et al., 2006).

The second criterion was resonance (Bochner, 2000; Charmaz, 2007; Finlay, 2006). Do I offer a story vivid or powerful enough to move the reader emotionally as well as intellectually? Do my findings resonate with experiences of participants or people who share similar circumstances? Alternatively, are they unsettling, or even disturbing, giving the readers an opportunity to challenge their own taken-for-granted assumptions? Do they inspire the “sociological imagination” (Mills, 1959) in readers, allowing them to draw links between larger institutions and individual experiences?

The third criterion was usefulness (Charmaz, 2007; Corbin & Strauss, 2008; Finlay, 2006). Do the findings shed new light on experiences of carers of people who had a stroke living in contemporary Australia? To what extent does my research contribute to the body of knowledge, and in offering basis for further research in the area of informal caregiving or other substantive areas in medical sociology / anthropology? Is it accessible both conceptually and in its writing style? Does it offer guidance for future policy development, action for potential change, and/or improved practices?

The fourth criterion was sensitivity (Bochner, 2000; Corbin & Strauss, 2008; Finlay, 2006). Do I show respect and sensitivity for participants’ needs, safety and dignity? Am I humble? Do I pretend to ‘know’, and make judgments for how things

should be done, without even trying to understand the contexts? Do I demonstrate reflexivity – critical reflection of my own starting points for thinking and how social and discursive positionings influence my thinking, emotion and embodied experience (Bacchi & Eveline, 2010)? Do I honestly reveal my emotional reactions and vulnerability, including contradictory feelings, ambivalence, and life’s messiness (Bochner, 2000)? Are the issues of power relations addressed? Throughout data collection, analysis and writing, these questions guided my reflection on the quality of research procedures and the end product.

As I asserted at the beginning of this chapter, I intend this thesis to be a political performance. In the chapters that follow, I will present accounts shared by participants that perform particular realities of informal care. Before doing so, however, I will delineate in Chapter 3 the dominant modes of performing informal care.

Chapter 3

Stroke, carer policy and support

Policies are constructed within specific social, historical, and cultural contexts, and are therefore cultural products – that is, they are an expression of the dominant discourses of a given historical time that enabled their production. At the same time, policies also ‘perform’ (Law, 2009): they do not merely represent certain realities about the nature of issues, but they generate ‘problems’ that in turn demand certain ‘solutions’. In doing so, they also downplay, neglect, and ignore alternative modes of constructing ‘problems’. In the case of carer policies, as I describe below, the nature of carers and the government’s relation to them, in the last 40 years, have largely been shaped by various discourses as negotiated effects.

The disability rights movement and population ageing created needs for the government to seek alternatives to institutionalisation, which was considered both inhumane and too costly. In the context of normalised female workforce participation, the carers’ movement has brought to light the extensive and often burdensome nature of informal care. It became increasingly clear that the government could no longer count on women to provide care as a normative aspect of family life. The ‘solution’ to date has been that of recognition: a celebration of carers as heroic, self-sacrificing individuals. This particular mode of recognition allowed perpetuation of carers as economical resources without enacting fundamental rearrangements to existing disability and carer support frameworks. In this chapter, I provide a broad overview of how carer support, as a policy problem, is represented and managed in Victoria and more broadly in Australia.

Carer policy development: a historical perspective

As I discuss below, wider social changes emerged from the 1970s, internationally and in Australia, in the latter case in the context of the election of the Whitlam Labor Government in 1972, impacting carer policy. In 1971, the United Nations General Assembly proclaimed the Declaration on the Rights of Mentally Retarded Persons. This was followed by the Declaration on the Rights of Disabled Persons in 1975 and subsequent proclamation (in 1976) of the year 1981 as the International Year of Disabled Persons (IYDP). These initiatives led to increasing pressure placed on the government to raise awareness in Australia about social, economic, political and human rights for people with disabilities (Australian Human Rights Commission, n.d.). These calls for improvements to living conditions and human rights of people with disabilities became an important political issue. This development in disability rights also gave impetus to deinstitutionalisation of people with mental illness and disabilities from institutional to community-based settings, including community residential units and home (Dunt & Cummins, 1990; Young et al., 1998).²⁰ In Australia, as with other industrialised nations, the definition of ‘community care’ was imprecise in deinstitutionalisation policies, and it was often assumed to be ‘care by the community’ (MacKinnon & Coleborne, 2003). In this climate, a new terminology became necessary to specifically describe those who are today called ‘carers’. Further, despite the government’s expressed commitment to promote action to realise the theme of the IYDP, *Full Participation and Equality*, the existing formal support

²⁰ Many children with disabilities had been placed in institutions irrespective of their intellectual development or presence of psychiatric illness. One such example was Annie McDonald, a Melbournian with cerebral palsy who was institutionalised at age three until age 18, when she won a Supreme Court case in 1979 to claim the right to leave the institution. Until deinstitutionalisation policies were implemented, in Annie’s words in her memoir (Crossley & McDonald, 2010, p. 3): “If you were disfigured, distorted or disturbed, then the world should not have to see or acknowledge you... You were expected to die [in an institution].”

structure was unable to meet this goal. Indeed, until the Australian Bureau of Statistics conducted the Survey of Handicapped Persons²¹ in 1981 as one of the initiatives of the IYDP, there was no national information about the number of people with disability, the nature and extent of their disabilities, or their service needs. The calls for action to improve living conditions of people with disabilities resulted in a search for the means to fulfil these needs. ‘Carers’ emerged as a solution, as I argue in this chapter. Below, I track these developments.

1970s: Emergence of caregiver and carer as terminology

Until the 1970s, the primary responsibility for the care of the sick, young and elderly was placed on women, and terms such as ‘informal caregiver’ and ‘carer’ did not feature in policy, academic or everyday discourses in English-speaking, industrialised nations (Heaton, 1999). Indeed, in terms of its everyday usage, the word ‘carer’ first appeared as an entry in the second edition of the *Australian Concise Oxford Dictionary*, published in 1992 (Hughes et al., 1992); the previous edition (Turner, 1987) makes no reference to ‘carer’ or ‘caregiver’ even under the entry for the word ‘care’.

The word ‘caregiver’ was first used in the context of childcare in 1976. In a speech made to the House of Representatives on 21 September 1976, MP Ian Wilson applauded his leader Malcolm Fraser’s Liberal Government for its introduction of Family Allowance, a welfare payment to the families with children:

It is the policy of the Government to recognise the family as the cohesive force in society, and the Government's aim is to give recognition to the necessity of strengthening its influence... There is in the community a

²¹ The survey is now called the Survey of Disability, Ageing and Carers (SDAC), which has since been conducted approximately every 6 years. I will discuss below the 1993 iteration of the SDAC.

significant and vocal group which believes that the care of children from a very young age should be the primary responsibility of the state. There is, however, in the large silent majority of families a strongly held view that the primary care of young children should be given by their mother in a comfortable, secure family setting... The family allowances that have been introduced will relieve to some extent the economic pressure on families that up until now have faced increasing difficulty in gaining sufficient resources to enable the mother to be the primary care-giver of young children during the preschool years (Commonwealth Parliament, House of Representatives, 1976, p. 1).

In this speech, Wilson reflected various ideological assumptions around gender, care and support provision. First, caring was seen to be a matter for families, which were seen as self-sustaining units; implicitly, caring is not the responsibility of the state. Second, despite this, the state had a responsibility to provide enough support through social security payments, so that women could continue their duty of caring. Third, given that the speech was made in relation to childcare, female labour force participation was seen as hindrance to them fulfilling their maternal duties until their children reached school age. This reflected the tensions between personal economic imperatives – which had also been adopted by the state – and the need for societal reproduction of the next generation of productive bodies. This dilemma is also reflected in the current policy framework, as I discuss below. These assumptions drove earlier development in carer policies, and their influence can still be seen in more recent policies.

Mid-1970s to 1980s: The introduction of financial assistance for carers

In 1972, the Domiciliary Nursing Care Benefit was introduced, with a modest start – \$14 per week – for people who provided care in their own homes for frail aged people requiring a nursing home level of care. Although the benefit was only available to people providing care to family members with disabilities who were aged 65 and older (i.e. aged care), this scheme is noteworthy here for a number of reasons. The persons providing care were not yet considered ‘carers’ in the *National Health Act* enabling the scheme; indeed, they remained rather anonymous, as they were defined in terms of the elderly person’s relationship *to* them. Therefore:

[An application to the scheme would be approved where] the patient is the [co-residing] wife or husband [...or] a parent, or a parent of such parent [...or] a brother, a sister, an aunt or an uncle [of the applicant] (Commonwealth of Australia, 1972, p. 12).

This passage demonstrates how assumptions of care were tied to the kinship relationship *centred* around the person requiring care, who remained the focus, leaving carers to exist “off-centre” (Twigg, 1989, p. 54). In this depiction, carers orbit around the person requiring care, pulled by kinship obligation.²² Second, the scheme was introduced to provide “incentives for people to care for aged relatives in their own homes” because of the fear that overprovision of nursing home places was creating “unnecessary Commonwealth expenditure of \$17.5 million a year” (Department of Health and Family Services, 1998, p. 7).

Hence there were already concerns about the demographic transition and its fiscal implications for the Commonwealth government. The same assumption that underlay Wilson’s speech, quoted above – that care was a matter for families – also

²² This image stubbornly exists today. I explore in Chapter 5 how this assumption renders spouses invisible.

justified and made self-evident the policy rationale for the introduction of the Domiciliary Nursing Care Benefit. It therefore makes sense that there was also a concern at the time that the provision of nursing home places by the Commonwealth was “conditioning a large section of the community to accept it as ‘normal’ for the frail aged to enter nursing homes, whether or not there was a medical necessity” (Department of Health and Family Services, 1998, p. 6). This suggests that there was concern that people stopped seeing the care of ageing family members as a familial responsibility, and instead referred this to the state. This was in the context also of a concern that the ‘traditional family’ was being eroded by the increasing incidence of divorce, and delayed marriage and childbearing (Kahana et al., 1994). Paying a modest amount of money to relatives as incentive was therefore perceived as a cost-effective solution to the financial burden that would be incurred with people’s increasing reliance on the Commonwealth for residential aged care.

In 1983, the word ‘carer’ was used for the first time to refer to people who provide care to younger (non-elderly) people with disabilities in a parliamentary discussion about the introduction of income support, for the first time, for people caring for adults with disabilities, in the form of Spouse Carer’s Pension carers (Commonwealth Parliament, Senate, 1983a, p. 1087).²³ This was initially payable only for co-residing husbands who were ineligible for an aged or invalid (disability support) pension themselves (i.e. because they were in the workforce) and who were caring for wives with a severe disability, defined as requiring constant care on a permanent basis or for an extended period of time. Wives caring for husbands were not eligible for this Carer’s Pension, as they were already entitled to the Wife Pension,

²³ However, the practice of using the word ‘carers’ to refer to unpaid carers did not seem to have yet been crystallised in 1983. In another parliamentary debate about disability assistance programs, Senator Don Grimes used the term ‘carer organisations’ to refer to disability service provider organisations (Commonwealth Parliament, Senate 1983b, p. 2759).

payable to all wives of aged or invalid pensioners regardless of whether or not they provided care. The original welfare payment for wives, Wife's Allowance, the predecessor to Wife Pension, was introduced in 1943, in the midst of WWII, as part of a broad range of new social security measures introduced to make a post-war future appear worthy of sacrifice (Shaver, 1987). The fact that the Wife Pension, unlike the Carer's Pension, did not include involvement in care activities as an eligibility criteria reflected the perception of wives as dependent and that their care work was taken for granted, a normal and natural part of being a wife (Daniels, 2011). The Pension was tied to the assumption that the husband was the only source of income. Therefore, the Spouse Carer's Pension can be thought of as a compensation for husband's lost income, whereas the Wife Pension was a gift to the household. In this sense, carers as a distinctive social group was yet to include women and, at least in these particular legislations, 'carer' status was reserved for husbands who, due to caregiving activities, were unable to participate in paid employment. Women who provided care, on the other hand, were simply fulfilling their duty in the family. The idea that individuals – men in this case – would assume a caregiving 'role' by abandoning or swapping another role seems to have originated around this time.

Mid 1980s to 1990s: Expanding 'carers'

The narrow definition of carer for welfare payment purposes was soon expanded and, in 1985, the Spouse Carer Pension was replaced by the Carer Pension. The Carer Pension was payable to any co-residing relatives who provided "constant care and attention" (Commonwealth Parliament, 1985, p. 4) for an individual on an Aged or Invalid Pension. There was – and still is – no legal definition of 'constant care and attention', and its operational definition has since depended on the guidelines of the administering governmental department. Eligibility gradually widened, extending

coverage of the Carer Pension to non-relative carers in 1988, and to non-co-resident carers in 1991 (although the carer still had to live in close proximity). From 1993, carers were allowed to take time off from caregiving for a total of 42 days per year (up from 28), and they were also allowed to participate in employment, education or training for up to ten hours per week. Like the introduction of the original Spouse Carer Pension and the subsequent Carer Pension in the 1980s, these changes occurred under a Labor government (the Hawke-Keating Government), and were shaped by multiple discourses as I discuss below.

Meanwhile, the Wife Pension as a dependency-based payment became obsolete by the early 1990s due to increased female labour participation (Daniels, 2011), and was phased out on 1 July 1995. By this time, all social security payments have been restructured to emphasise individual eligibility as carers or job seekers. Those who received the Wife Pension before 1 July 1995 could continue receiving it until they started receiving the Age Pension (as of 2014, from 65 years of age), so long as they remained eligible and met income and assets tests. In 1997, the Carers Pension became the Carer Payment, and the number of hours that a carer could spend in employment, education or training was extended from 10 to 20 hours per week. This was followed in 1999 by the introduction of the Carer Allowance, which incorporated the Child Disability Allowance (initially called the Handicapped Child's Allowance) and the Domiciliary Nursing Care Benefit. The Carer Allowance also removed the eligibility criterion regarding the age of the person receiving care.²⁴

The Carer Payment is an income support program currently in place for carers who cannot participate fully in the workforce due to their care responsibilities.

²⁴ However, depending on whether the person receiving care is under age 16, the recipients of the Care Allowance are categorised into either adult or child stream, with different assessment methods.

Conceptually, it is designed as a compensatory measure for lost income generating opportunities for carers. It is means tested (for both income and assets) and, as of 25 October 2014, the maximum rate of fortnightly payment was \$776.70 for a single person and \$1,171 for a couple. Carers who earn an income from paid employment and/or other income sources including financial assets have their Carer Payment reduced when their income level reaches a certain level (currently, reduction applies of 50 cents for each dollar over \$160 for singles, and over \$284 for couples). In addition, carers are eligible to receive the Carer Allowance, not means-tested, which is a supplementary payment for carers to cover the costs associated with caregiving. The current rate is \$118.20 per fortnight.²⁵ Recipients of Carer Payment are also eligible for Carers Allowance. Carer Payment and Carer Allowance recipients can also apply for the Carer Supplement, an annual lump-sum payment of \$600, to cover the costs of care activities. The Carer Supplement may be likened to a bonus payment, and was introduced in 2009 as formalisation of similar but ad-hoc payment bonuses to carers offered from 2004.

The emergence of 'carer' as a distinct social group

The introduction of 'financial compensation' for carers in welfare policies signified emergence of caregiving as a public issue. The establishment of support services such as respite and peer support services specifically targeting carers further cemented the status of carer as a distinct in-need social group in its own right.

²⁵ This is, as commented by the Parliamentary Library staff members more than a decade ago (Daniels & Tapley, 1999: para 29), a "largely token payment [...with a] modest rate considering the level of care provision expected of [eligible] recipients". The rate of the Carer Allowance, after inflation adjustment, has remained unchanged since then. According to the Reserve Bank of Australia's inflation calculator (n.d.), \$75.60, the rate of the Carer Allowance in 1999, would be equivalent to \$114.35 in 2013 after inflation adjustment. This means that there has only been a negligible increase in the rate (to be precise, an increase of \$3.85 per fortnight in 2013 dollars over 14 years).

Apart from defining ‘carer’, for welfare payment purposes, more widely than as ‘husbands caring for wife’, 1985 was an important year in carer service provision. The Home and Community Care Act, the legislation that enables Home and Community Care (HACC) programs to this day, was introduced by Bob Hawke’s Labor Government. In the Act, carers were for the first time specifically mentioned as part of the target population (Commonwealth of Australia, 1985). In outlining the aim of the Bill in the parliamentary debates, then Minister for Community Services Senator Don Grimes, who introduced the Bill, identified carers as a group of people with specific needs, and presented respite care as an appropriate measure to support carers:

We have those [HACC] services provided on a community basis to people either in the home or in a home-like atmosphere, wherever they can be delivered: Firstly, to ensure that they get the care that they need; secondly, to ease the lot of those individuals, but primarily those women in the community, who have borne the burden over the years of looking after relatives who are disabled, ill or aged in their homes... We had hardly heard of respite care beds until the last few years. We are ensuring that respite care beds are provided in nursing homes and hostels for the aged and in the smaller institutions for the disabled in the community. They are vital if we are to keep people at home as much as possible. (Commonwealth Parliament, Senate, 1985, p. 3077)

For the first time, informal caregiving was represented primarily as a woman’s issue. The objective of a state intervention – namely respite services – was to ensure people with disabilities are kept at home. Otherwise, presumably, ‘the burden’ would be carried by the state. The lineage of these problematisations can be observed in current policies and has significant implications, as I discuss below.

Meanwhile, an emerging body of research into informal caregiving led to the birth of the carer movement. Carers Australia (2013) attributes this to a report entitled *Dedication* by Clare Grant Stevenson, then research officer with the New South Wales Council on the Ageing (COTA), which sought to investigate the levels of assistance provided to elderly people living at home by their family and friends. The first study on carers in Australia, the report was based on a survey of 427 carers living in Sydney.²⁶ Stevenson subsequently formed a ‘carers group’ in 1975 – arguably one of the first public uses of the term ‘carer’ in Australia – as a subcommittee of COTA. This group became the Carers Association of NSW in 1980, which Carers Australia claims as the first independent carer’s organisation worldwide (Carers Australia, 2012). A decade later the movement had spread to other states and territories, with carers’ organisations established in Queensland and South Australia in 1989, Victoria and Northern Territory in 1992, and Carers Association of Australia – now Carers Australia – in 1993. This emerging carers’ movement also captured the political imagination, because the carers’ ‘dedication’ converged with commonly held assumptions about the nature of care.

In 1990, ‘carers’ were explicitly discussed as a significant social group in its own right in Federal parliament. In a grievance debate — a weekly speech presented by a Member of Parliament to raise concerns about his or her constituents or other issues — then MP Garrie Gibson spoke about the official opening of the newly established office of the Queensland Council of Carers in his electorate:

This afternoon I would like to talk about a very important group of people in our community, the people who we call carers. [...Carers] care each day because of the love and compassion that they have for other people and

²⁶ A copy of *Dedication* is held at the National Library of Australia.

particularly for their family members (Commonwealth Parliament, House of Representatives, 1990, p. 2292).

In his speech, Gibson felt the need to clarify what he meant by ‘carer’, and did so by quoting a definition used by the Queensland Council of Carers: “a person or family responsible for the care in the home of an individual who needs varying degrees of assistance with the activities of daily living” (p. 2292). He urged the federal, state and territory governments to provide a much greater level of support to carers, because:

[Carers] play a very vital role in our community in helping those who otherwise would have to be institutionalised. The Government would otherwise be required to pay a much more substantial amount of money for their support (p. 2292).

Gibson recognised the importance of carers in enabling the government to achieve deinstitutionalisation policies, and described their efforts as ‘labour of love’. The speech was constituted by and reinforced assumptions of care as a family matter, and of carers as economic resources.

The recognition of carers as a distinct social group was formalised in 1992 when the Federal Government budget allocated, for the first time, funding specifically for carers, worth \$93 million over 4 years, to fund the distribution of a *Carer Support Kit* and established the Commonwealth Respite for Carers Program (Carers Australia, 2012). In a parliamentary debate about the Budget, a Labor MP Carolyn Jakobsen described the Budget allocation for carer support as a “compassionate and caring aspects” of the Budget (Commonwealth Parliament, House of Representatives, 1992, p. 940). In her speech, which was made during the first *National Carers Awareness Week* coordinated by Carers Australia, she managed to amalgamate multiple constructions of carers. First, she portrayed caregiving as ‘burden’ (p.940):

It is an unfortunate fact that many carers experience a deterioration in their own health as a consequence of the physical, mental and emotional strain occasioned by long term care of someone else... It is a sad fact that many families or partners are unable to withstand the rigours, which those sorts of problems [disabilities and chronic illnesses] cause. It often ends up with a breakup of the marriage, which is a very sad thing.

Here, informal care was constructed as a threat to family and marital breakdown due to its burdensome nature. Pointing out that it was the *National Carers Awareness Week*, and indicating the 'I Support Carers' badge that she was wearing, she asserted that: "It is imperative that the Government act to diminish these stresses and strains in every way possible." Like a later Victorian carer policy, as I discuss below, MP Jakobsen assumed the 'naturalness' of the burdensome nature of chronic illnesses and disabilities, and at the same time defined the role of the governments as reducing the burden *caused by chronic conditions*.

In MP Jakobsen's speech, carers were constructed as a hard-working human resource, motivated by a sense of sacrifice and compassion:

Carers are an under-recognised resource in our community. Without these people, we would be up for a lot of money. We would be a less compassionate society if we did not have people in the community who are prepared to put themselves out to assist members of their family and their friends... These people [people with chronic conditions] could not exist without carers (p.940).

This passage demonstrates the *assumed naturalness* of heroic, self-sacrificing nature of carers, in contrast to indifference of others in the general public. The survival of people with chronic conditions, MP Jakobsen asserted, becomes unimaginable in the uncaring society at large. The government's role, according to Jakobsen (p.941), was

to “acknowledge the work of carers, recognise the sacrifices that they make and value each of them as an essential contributor to and component of our society's social fabric,” that is, to celebrate heroic and self-sacrificing carers to give them some moral currency.

The construction of carers as resources was also important in the speech because of the economic context – Australia was in a recession in the late 1980s and early 1990s. As noted above, this Budget introduced measures to allow Carer Pension recipients to participate in education and employment for up to 10 hours without breaching the ‘constant care’ eligibility criteria. While this was introduced as part of the \$93m carer support package, it also constituted Government’s wider initiatives to encourage the general employment participation rate in a bid to promote economic growth. Therefore, MP Jakobsen concluded that:

[the Budget is] much needed to stimulate the economic recovery that we are all looking forward to. I know in my own heart that the most important things for people are jobs and opportunities” (p.941).

While she briefly mentioned housing and higher education policy initiatives in her speech, her speech was predominantly about carer initiatives. Therefore, this implied that employment participation by carers was encouraged, as it was considered to be beneficial both to individuals and to the wider economy.

With increasing recognition of carers in the policy arena, information about the extent and nature of informal care became necessary. The following year, the *1993 Survey of Disability, Ageing and Carers* (Australian Bureau of Statistics, 1993) included information regarding carers. It was an update of its predecessor, the *Survey of Handicapped Persons*, conducted in 1981. The implications of these changes were significant to the establishment of carers as important: carers were no longer invisible

companions of people requiring care; they were recognised as individuals with unique needs who deserve public and policy attention. Indeed, as Hastrich (cited in Savage, 2002, p. 10) states, “prior to this period, the people we now call 'carers' were called parents, daughters, sons, neighbours, aunties, brothers and sisters.”

Coinciding with the trend set at the federal level, state governments also started to include carers as a policy target group in 1990s. In Victoria, the first policy to target carers, the *Strategy for Carers* (now known as *Support for Carers Program*), was introduced in 1996, with an allocation of \$25 million in the annual budget (Parliament of Victoria, 1996, p. 300). It established the basis for programs recurrently funded to this day, such as respite services and case management services. In the words of Carers Australia, in the 1990s and 2000s, “awareness was growing. Governments were taking notice” (Carers Australia, 2012). Continuing this trend, the Australian Institute of Health and Welfare, an Australian Government statutory agency, included carers as a key population group deserving a dedicated section in its key biennial publications on health and welfare of the Australian population: *Australia's Welfare* in the 2009 edition (Australian Institute of Health and Welfare, 2009), and *Australia's Health*, in the 2012 edition (Australian Institute of health and Welfare, 2012).

Recent policy frameworks

The last decade has seen an explosion of policy activities regarding carers both at federal and state levels. By mid 2000s, the recognition of ‘carers’ as a policy target group has grown to the extent that carers were included in the Labor Party’s 2007 election campaign agendas, when promises were made to implement several carer-specific initiatives: streamlining respite services, strengthening support mechanism for carers in paid employment, and implementing a supplementary allowance for

carers, which was later implemented as Carers Supplement²⁷. While the carer-specific initiatives occupied less than one out of eight pages in the election campaign document entitled *Disability and Carers: Election 2007* (McLucas, 2007), this inclusion of carers as a political target for the first time in an election campaign was significant. In the document, Senator Jan McLucas, carrying the portfolio for Ageing, Disabilities and Carers as a shadow minister, justified the election promises (McLucas, 2007, p. 7) on the rationale that:

Without carers, the quality of life of people with disabilities would be significantly reduced and the demand for formal services would rise markedly. Labor understands that one of the most important family responsibilities is caring for a partner, adult child or other family member.

Echoing decades' old statements by various politicians, as quoted above, Senator McLucas's framing of informal care portrays care as familial responsibility while at the same time attributing carers as resources, filling in the gaps left by the existing formal disability support system in addressing demands from people with disabilities. On the latter point, the value of carers was especially important, since the signing of the International Convention on the Rights of Disabled in 2006 (and its ratification in Australia in 2008) made it a national obligation to improve the human rights of people with disabilities.

The elected Rudd Labor Government in 2008 commissioned an *Inquiry into better support for carers*, which resulted the following year in a report titled *Who Cares...? Report on the Inquiry into Better Support for Carers* (House of Representatives Standing Committee on Family, Community, Housing and Youth, 2009). This inquiry, which attracted 1,300 written submissions, identified a number of

²⁷ However, as I noted above, a series of similar but one-off payment bonuses already existed since 2004.

key issues faced by carers, including the lack of recognition about the contributions that carers make, difficulties in accessing information on and support from services, and financial stress as a consequence of reduced employment opportunities, poor government assistance and additional costs of disability and caring. The report provided 50 recommendations, most accepted, at least partially, by the Government (Australian Government, 2009).

However, the Government's responses to the issues identified in the *Who Cares...?* report demonstrate tensions around competing discourses about the problem and possible solutions. Certain issues were neglected, downplayed, or ignored, while others were foregrounded in the responses. For example, in the 60-page document outlining the Government's responses (Australian Government, 2009), women (and men, for that matter) were not once mentioned, making the responses – and consequentially, the problem – de-gendered (Bacchi, 1999). While the Government agreed that carer recognition was important, the recommendation that carers be provided structured advocacy services under the National Disability Advocacy Program, which provides individual, systemic and legal advocacy services, was rejected. Instead, the Government argued that the existing carer support service structure was adequate (Australian Government, 2009, p. 14). This included funding, already budgeted, of \$3.2 million (for 2009) provided to Carers Australia for a Carer Information and Support Service, which mainly provided information and advice about locally available carer support services. A similar position was taken in regards to support group service provision (p.9-10) and case management or care coordination services for carers (p.13). In both cases, the Government agreed with the importance of these services; however, its responses implied that existing support provision structures were able to meet the needs.

One of the most obvious tensions observed in the Government's responses was in relation to carers' participation in the workforce and education. In this area of the document, the Government's responses were shaped by competing priorities of maintaining the carers' caregiving contributions, increasing their paid workforce participation, and curtailing the potential increase in demands on government respite services. While the Government emphasised "the training and skills development needs of carers" (Australian Government, 2009, p. 1), negative responses were offered to recommendations to address lack of choice for carers regarding participation in the workforce and education. These included calls for a legal framework to create the right of employees to request flexible work arrangements (p.46), to amend the '25 hour rule' – the maximum number of hours carers can work or study while remaining eligible for carer income support (p.50) – and respite support services specific to people in paid employment (p.45-46). Instead, the Government offered to strengthen referral services to its carer information and respite service providers to the skills training service provided by state and federal governments under the existing generic training and skills programs (p.47-50).

In these responses to the *Who cares?* report, the Government's solutions entailed better utilisation of existing support frameworks, with additional small scale funding schemes acting as a top-up. In this way, the Government framed the problem as the inability of individual carers to utilise existing formal support structure, due to lack of information. This was despite that information provision about services alone cannot improve living conditions of carers (Clarke, 2001), as I discuss in the chapters that follow. In this way, the Government response (Australian Government, 2009) silenced alternative problematisation expressed in, for example, the submission to the

enquiry by the National Carers Coalition (National Carers Coalition, 2008, p. 3), a parent-led carer advocacy group, which contended that:

What [should already be] abundantly evident from all the research available to the government is that unpaid family carers have – no legal rights, no government legislated entitlements, no family carer advocacy and no voice in policy and planning... The failure of governments and society to recognise and reward families for this work is seen to be both exploitative and abusive.

The Labor Government's responses to the inquiry culminated in the current national carer policy framework. Following the conclusion of *Inquiry into better support for carers*, the Government developed the National Carer Recognition Framework, which comprises of the *Carer Recognition Act* (Commonwealth of Australia, 2010) and the *National Carer Strategy* (Commonwealth of Australia, 2011), which I discuss below. The objective of the Carer Recognition Act was “to increase recognition and awareness of carers and to acknowledge the valuable contribution they make to society” (Commonwealth of Australia, 2010, p. 3). It sets out ten principles of how carers *should* be recognised, respected, and supported by government agencies and other publicly funded organisations. In introducing the Carer Recognition Bill 2010 for a second reading, Senator Nick Sherry (Commonwealth Parliament, Senate 2010, p. 649) made a statement that mirrors others I have already quoted:

Every day [carers] sustain and support the people they care for. And through their dedication and hard work they enrich community life and are an inspiration to us all... No public holidays. No annual leave, no time off when you're sick. Mr Speaker, this Bill recognises in legislation the contribution by

the mums and dads, the grandparents, the sons and daughters, the brothers and sisters and partners who every day get on with the job of caring.

Here, Senator Sherry constructs carers as ‘dedicated’, ‘heroic’ and ‘self-sacrificing’ (Lloyd, 2006). Again, the statement makes it ‘self-evident’ and ‘natural’ that carers do not have any time off; it distracts attention away from the possibility that the lack of time off may be to do with insufficient and inadequate respite service provision, for example. Senator Sherry continued, and attributed the rationale of the Bill to the inquiry:

Last year, carers told us [in the *Who cares...?* report] they wanted greater acknowledgement and increased recognition... [The proposed Act] recognises in law, the valuable social and economic contribution, as well as the many personal sacrifices that carers make (Commonwealth Parliament, Senate, 2010, p. 649).

At the same time, the Act “does not create rights or duties that are legally enforceable in judicial or other proceedings” (Commonwealth of Australia, 2010, p. 8). What the Act provides is largely symbolic recognition. This mode of ‘recognition’ did not converge with the one advocated by carers, according to Maree Buckwalter, a carer and the President of the Carers Alliance, a political party formed by carers of people with disabilities:

Family carers have lobbied for legislation that gives them legal status, rights and entitlements. And what do we get? A Bill that will legislate for us to get a pat on the back... A waste of time and toner. (quoted in "Carers Recognition Legislation Under Scrutiny," 2010)

Parallel to this development at the federal level, in 2006, the Victorian Government, through the former Department of Human Services (DHS), released

Recognising and supporting care relationships (Victorian Department of Human Services, 2006b). This policy framework set the scene for later carer policy and program planning and development in the state, and formed the basis for the *Victorian charter supporting people in care relationships* (Victorian Department of Health, 2010). The key ideas in these two documents are almost identical; in a set of principles mirroring those set out in *Recognising and supporting care relationships*, the *Charter*²⁸ outlines how people in a care relationship and the care relationship itself *should* be recognised, respected and supported by Victorian public service agencies and non-governmental but publicly funded service providers. The principles in the charter were used as a foundation for the *Victorian Carers Recognition Act 2012* (Parliament of Victoria, 2012), which provides legal recognition of the role of carers in Victoria. Like its federal counterpart, the Act also set out obligations of state government departments and care support organisations funded by the government to “take all practicable measures” (p. 9) to follow the care relationship principles and to include in their annual reports how they complied with the principles, although the Act “(does) not create, or confer on any person, any right or entitlement enforceable at law” (p. 8).

In 2009, the administration of health and human services in Victorian public services was restructured, leading to the separation of health and aged care portfolios from the Department of Human Services, and the establishment of the Department of Health (DH) as a new stand-alone government department responsible for these program areas. Disability services remained the responsibility of the new Department of Human Services. Despite these departmental changes, and the change of

²⁸ The target audience of the *Charter* is people in care relationships, whereas *Recognising and supporting care relationships* is aimed at public servants and support service agencies receiving government funding. Given the nature of the document, the *Charter* is much shorter and briefer than *Recognising and supporting care relationships*.

government in November 2010 from the Labor Party to the Liberal-National Coalition, these policies have remained in place and continue to guide policy directions of both DH and DHS²⁹.

These policies, spearheaded by *Recognising and Supporting Care Relationships* (Victorian Department of Human Services, 2006b), are in many respects innovative and aspirational; unlike all other similar state/territory and federal policies and legislations already in place at the time, the Victorian policies focus on the care relationships, with particular acknowledgement given to the multidimensional and dynamic aspects of care relationships. In doing so, they aim to support people in a care relationship to maintain that relationship. Thus, the problem the policy document is aiming to address is represented as people's inability to maintain their care relationship.

The shift towards a relationship-focused model away from a model targeting carers or people who receive care in isolation is justified in *Recognising and Supporting Care Relationships* (Victorian Department of Human Services, 2006b) in relation to demographic shifts. After outlining a projected increase in the near future in the number of people aged between 45-64, and following recognition that most of them are either the spouse/partner or a child of the person receiving care, the policy document states that:

Future provision of informal care to people in this age group could be vulnerable to higher rates of relationship breakdown than has been evident in previous generations... the large proportion of female carers in the workforce highlights the need to consider issues around balancing work and care in the

²⁹ Following the Labor Party's win in the Victorian 2014 election, Departments of Health and Human Services were reunited to form Department of Health and Human Services from 1 January 2015.

ongoing development of carer support programs... [There is a] need to better support the familial and spousal relationships that have traditionally provided informal care, acknowledging the increasing pressures and opportunities of life (for example, expanded career opportunities for women).

(Victorian Department of Human Services, 2006b: 9-10)

Here, increased female participation in the workforce and the accompanying challenges in balancing work and care responsibilities are represented as problematic. The policy framework recognises that caregiving is gendered, and that women may be pressured into taking on a caring role because it is seen as ‘women’s work’ (Victorian Department of Human Services, 2006b, p. 10). The solution, it seems, is to support maintaining the care relationship so that women can do both — engage in paid labour and care for their spouse/family member. The potential solution is not around how to encourage more men to provide care, or alternatives for women providing the bulk of caring. It also maintains the status quo around the current value of paid and unpaid work. What if ‘care’ was considered ‘work’?

Another rationale for focusing on the care relationship is that a functioning ‘care relationship’ is constructed as positive for both carer and the person receiving care. This is exemplified in the opening statement of *The Victorian Charter Supporting People in Care Relationships* (2010):

Carers and the people they care for are the basis of the care relationship. If the relationship is strong, the carer and the person being cared for are more likely to live as well as possible (Victorian Department of Health, 2010, p. 3).

A care relationship is conceptualised as originating in kinship, obligation and/or affection, and contrasted to a relationship based on financial transactions between people (Victorian Department of Human Services, 2006b, p. 11).

Recognising and supporting care relationships also “understands that relationships have histories” (Victorian Department of Human Services, 2006b, p. 2). These representations have two implications. First, by representing a care relationship in contrast to a relationship involving a monetary transaction, possibilities of ‘informal’ caregiving involving monetary transactions automatically shut off. Voices that are silenced in this representation include that of Gary Thorne, a Victorian carer running an online campaign calling for legislatively guaranteed conditions for carers similar to those of a formal employment, such as a carer payment at the level at least of the minimum wage, superannuation, paid holidays, and free education and training (Thorne, 2013). Thorne argues that full-time carers (i.e. those who are entitled to the maximum rate of Carers Payment and Allowance because they do not hold a paid part-time) are provided with financial remuneration significantly less than that of the lowest in the pay scale for full-time personal care assistant jobs, and that well below the minimum wage in Australia (Thorne, 2013). Governments’ unwillingness to provide financial remuneration and ‘employment’ conditions equivalent to those in the paid workforce and protected by the industrial relations law, according to Thorne, is abusive and exploitative. To him, this is especially exploitative because the government is fully aware that there is no alternative for carers:

If all carers decided to give up this responsibility and put it back to the Government to look after the elderly, sick, frail and disabled, the country would go broke overnight. However, the Government know that carers would never be irresponsible and dump their loved ones (para. 5).

He continues that this exploitative relation is maintained by structural silencing of carers:

Carers are isolated and fractured. It makes it extremely difficult to get together and have a voice. The Government know this, so the status quo remains. Even Carers Australia and Carers Victoria will not contact carers on my behalf, simply because they are funded by the Government and have no political will, and fear losing their funding and jobs (para. 6).

Thorne challenges the constructions of care as family obligation and labour of love, as expressed in carer policy. Instead, he constructs care as 'work'. By locating himself in the discourse of capitalism, he attempts to naturalise his assertion that labour of caregiving, as a commodity, ought to be matched by appropriate financial remuneration³⁰. However, this construction does not transmit smoothly against the culturally dominant construction of care as acts of compassion, self-sacrifice and familism, reproduced in carer policies. I first came across Thorne's website (Thorne, 2013) when I was working at StrokeVic as a voluntary office assistant. He sent out a mass email to disability, chronic illness and carer related organisations to promote his cause. The website, however, has been slow in gathering people's signatures for its online petition calling for 'workers like' conditions for carers.³¹ Although intimate and close social relations are in fact based on various forms of economic transactions, this is often masked in everyday lives by the discourses of intimate and spousal relationships (Zelizer, 2000). That is, it is inconceivable in a contemporary society that spousal or family relationships be based on financial payments. Reflecting this cultural assumption, carer support payments are designed more as gift for doing good

³⁰ However, of course, Marxists would argue that all forms of labour are inherently exploitative in capitalist transactions.

³¹ The website was currently offline (as of 28 December 2014). The last time I checked the website in mid 2013, it had attracted less than 30 pledges. The website had been 'live' since January 2013.

deeds, rather than payments based on entitlement or compensation (Rosenman and Le Broque, as cited in Dow et al., 2004c, p. 28).

Second, these representations refer to the carer relationship in isolation from underlying relationships of the carer and the person receiving care, as well as the relationships they have with other people. The assumption here is that the care relationship replaces the previous relationship, and that an individual swaps his/her identity as a spouse or family member with that as a carer. In this representation a carer is only important in their capacity as a carer, and exists only within the 'care relationship'. However, care relationships are deeply embedded in existing personal relationships (Warren & Manderson, 2013) – in cases of spousal relationship, both within and outside the relationship, as I discuss in later chapters.

Carers as 'economic resources'

As outlined above, from the 1980s and at an escalated rate since the early 2000s, carers have come to feature prominently in social security payment and policy arena, as awareness has increased on both sides of the politics about their role and contributions. At the heart of this policy attention, carers are seen as 'cheap economic resources'. Therefore, the rationale for governments' interventions has been driven by a motivation to perpetuate this 'informal' workforce's contribution (Twigg et al., 1994). That is, government spending on carers can be seen as a 'maintenance cost' to prevent greater expenditure in the future or through alternative arrangements. This economic thinking is reflected prominently in a recent report prepared by the National Commission of Audit on the performance, functions and roles of the Commonwealth Government:

The Commonwealth recognises that people who choose (or have no choice but) to care for a relative or friend and forego the ability to earn an income

should receive some form of general income support. It is often argued that, if this form of care was not provided, it would need to be provided formally (mostly by Government) at a much higher cost (National Commission of Audit, 2014, p. 306).

Increasing (but unfulfilled) pressures on the government to realise the right of people with disabilities to live and participate in the community, and the perceived and projected threat of population ageing, created impetus for succeeding governments to harness carers as economic resources. Carers' organisations also use this economic perspective as moral leverage to justify their calls for improvements in carers' living conditions. For example, Carers Australia in 2010 commissioned Access Economics, a high profile consultancy firm, to prepare a report on the economic value of informal care (Access Economics, 2010). Presentation of figures about the economic value of carers has become commonplace in the introductory paragraphs of academic writing on informal care – including this thesis. This, I want to argue, is because the economic discourse has become so dominant in contemporary society that asserting even a moral or academic case now requires to be based, at least partially, on economic rationality.³² In this climate, carers have been constructed as economic resources that allow the existing health and disability services to operate.

In this chapter, I have argued that policy construction of carers emphasise carers' economic values. Another policy arena that carers have come to feature prominently is healthcare participation. The Victorian policies (Victorian Department of Health, 2010; Victorian Department of Human Services, 2006a) emphasise the importance of participation by both carers and people receiving care in care planning, delivery, and evaluation of community and health care services. Similarly, the

³² In Chapter 9, I will revisit this economic rationalisation and locate the participants' experiences in it.

National Carer Strategy identifies that “involving carers as partners in care can have positive results for all.” (Commonwealth of Australia, 2011, p. 19) However, this mode of participation is not always possible for various reasons. In the next chapter, I explore participants’ experiences in the acute and semi-acute settings.

Chapter 4

Stroke as unexpected illness

I sat in the hallways of the hospital at 3am, and I was very numb. I was very, very tired and just eating food from the vending machine, because nothing was open at night. And the carers sometimes get forgotten because you're not the first point of concern for the medical people... I realised I didn't have enough money to put in the vending machine and was sitting on the floor crying, not because I couldn't get a candy bar, but because of everything that was happening. And there was no one around, just completely empty. And then the cleaner walked past and he looked at me and said: "Are you okay, what can I do?" And he went and got me some food — the kindness of a stranger at three in the morning when I was just really finding it overwhelming (Megan, speaking about the night in acute hospital setting).

A sudden medical crisis is shattering. Stroke, especially when it occurs in a younger person, is unexpected and unable to be anticipated, yet leads to profound and rapid changes not only in the lives of those affected, but also in the lives of people around them, often their spouse. Participants provided their insight into the events around the onset of first stroke, including in acute and sub-acute hospital settings, vivid even some years later. The sudden and unexpected onset of stroke, which led to the subsequent hospitalisation of their partner, challenged participants' personhood in terms of their subjectivity located within a spousal relationship. Due to their critical condition, participants faced the threat of losing their 'other half'; in addition and as a

direct result of this, they faced the possible loss of the spousal relationship – of ‘us’. This happened rather unpredictably, as I discuss below. Uncertainties in the course of the medical emergency, and consequent treatment and in-patient rehabilitation, exposed the fragility in participants’ sense of control. They were thrown into fault lines — between informed and uncertain, reflexive and detached, hopeful and grieving, and active agent and passive recipient. In this chapter I explore how the participants of my study understood the time around hospitalisation of their relatively younger, working-age partner.

Previous researchers have focused on the lives of partners and relatives after discharge of working-age people who had stroke (Bäckström & Sundin, 2007, 2009, 2010; Bäckström et al., 2010; Buschenfeld et al., 2009), but have paid relatively little attention to how their participants constructed their experiences around the time of stroke and subsequent hospitalisation in acute and sub-acute hospitals. Although some studies (Banks & Pearson, 2004; Greenwood et al., 2009b; Lutz et al., 2011) explicitly describe partners’ reflections of the time around the stroke event, these are only presented as a small part of their findings, and their participants included older participants. One of few exceptions is the study by Wallengren and colleagues (2008), conducted in Sweden, who focus on the experiences of close relatives and partners; however, most of their participants were adult daughters of relatively older persons.

Sudden hospitalisation

With the onset of stroke, most participants’ partners were engaged in mundane everyday routines and activities, such as work, sleeping, or watching the TV. In other words, the participants’ partners were being the ‘predictive’ self, performing routinised, taken-for-granted activities that framed their identity (Goffman, 1959; Heritage, 1984; West & Zimmerman, 1987). Alix, for example, was in the living

room watching television, one night in 2009. Beside her on the couch was her husband Erwin, who was 45 years old. Their young children (aged three, six, and eight) were already in bed. These facts orchestrated the feeling of just another ordinary evening, but then:

We were just sitting at home... that evening we were watching TV, and it was some detective show. Normally what happens is I fall asleep when I'm watching TV, because it just puts me to sleep. And then, it must have been about 10 o'clock at night, he woke me up, or I woke up, and he was just slurring his words.

Initially, Alix thought Erwin was joking. However, she noticed that it was as though he had lost his control of his body.

He was going like: [Alix mimics slurring sound] j-j-j-j. Well he was speaking like that. And because I was still half asleep, I thought he was maybe joking, or mucking around or something like that. Then he was kind of little bit like, falling to one side, and just trying to speak. He was saying all these strange things.

Unable to make sense of what was happening, Alix tried quickly to locate the possible cause. She first thought of a relatively benign condition that Erwin had been diagnosed with. Soon, however, she realised it was something more serious:

Because he did have a history of a movement disorder, which is like epilepsy – and I'd only ever seen him having an attack once – where [unlike epilepsy] he only gets muscle spasms. So, I thought, 'Oh, maybe it's that'. And then, 'no it's not that, because it looks very different'. He was just looking at me like he was a road kill or something, looking shocked, or whatever. I don't know why,

but I just knew this wasn't normal, this wasn't right. So I rang 000 [the emergency call number].

The abrupt development of an observable physical abnormality sharply contrasted the mundaneness of the activities in which they were involved at the time. Minutes previously, they had been just their 'usual selves'.

As Alix explained, most participants had not had direct exposure to stroke in their immediate social circles, and therefore the occurrence of stroke in their age group was unfamiliar, even obscure and foreign. 'Stroke' and their partner simply did not sit together. Rebecca's husband Ned had a stroke in 2001, and she explained that it had never occurred to her that a stroke could happen to him, given his age (44 years) and his physical condition: Ned was relatively young and fit, a farmer; it would have been more fitting to find him sipping beer with his mates at his local football club – where he had been an active member – than bed-ridden in a hospital. So Rebecca was shocked when he was hospitalised:

It was completely out of blue — he was 44, super fit... he just collapsed one morning... I thought [stroke] was an old people's disease. So that was a bit of a shock. I'd probably heard of people that had strokes... maybe younger people that had had strokes but probably not have taken a great deal of notice of it [before].

Ned was lucky. Rebecca was a schoolteacher, and she was at home on school holidays when it happened. They lived in a rural town approximately two hours' drive from the closest regional centre, and almost four hours' drive from Melbourne. Ned was taken to the district hospital, then transferred by helicopter to Melbourne. This air ambulance transfer service had only started two weeks prior to Ned's stroke. Rebecca

reasoned that, given the remoteness of their hometown, the transfer service probably saved Ned's life and limited the extent of brain damage.

Even after admission to hospital, as their partners' conditions deteriorated, participants were shocked. This was especially shattering, as only a few hours earlier, they had appeared 'normal' in an ordinary, everyday way. Then, things changed dramatically; their partner was bed-bound in hospital, surrounded by medical technology that was not part of their everyday life. Until then, to most of the working age participants, hospital was an unfamiliar environment where others might face the possibility of death, disability or chronic pain; these things were associated only with other, older individuals. Alix reflected:

Because, for me, at this age, relative to people who stroke normally happens to, [we are] quite young. When you go to the hospital, it's for a day. You get something done, it's a day, a night, you are home in the next day, because [usually] there's nothing seriously wrong.

Anna agreed. Anna's husband Jason was 49, when he complained on the way home from their holiday in Tasmania that he could not sleep due to a headache. After he felt unwell for a couple of days, she took him to the hospital, where he was given muscle relaxants for neck strain. They reasoned that it must have been the pillow he was been using while away on holidays.

The following day, he had prolonged hiccups and difficulties swallowing, and Anna took him to a general practitioner (GP) out of hours. The GP did some blood tests and concluded that Jason had a very low blood sugar level, and suggested that they get some lemonade on their way home to redress this. Jason tried to follow the 'prescription', although the fizz made his hiccups worse. Anna woke up next morning to find Jason slurring his words and unsteady on his feet. When she called the doctor,

she was told to take him to the emergency department straight away, as they lived near the hospital. Almost six hours later, he was diagnosed with stroke. Even then, it did not seem like an urgent medical emergency to Anna. The doctors did not act like it was:

I remember leaving him [at the hospital] in the evening, and by that time they'd given him some aspirin and things like that. And they'd done all his blood pressure [measurements] and they said his blood pressure was slightly raised but nothing that they would be alarmed about.

Neither Anna nor Jason had ever had serious illnesses, and she expected that the hospital, on the basis of the medical knowledge transmitted within it, would promptly intervene. This was not the case:

When I went back [to the hospital] the next morning, he just seemed a whole lot worse. I thought, they've given him this [aspirin] and he's in the hospital, I'll go back in the morning and it'll be a bit better, but he seemed worse than ever, and I remember bursting into tears because he wasn't getting better and he was in hospital, and you think if somebody goes to hospital they make you better, don't you?

Unfamiliar sections of the hospital, such as the emergency department, Intensive Care Unit (ICU) and operation theatre, medical jargon and equipment, that might have been a better fit in a TV show – and, for many participants, hours of waiting and transfer to and from different hospitals and sections within the hospital – highlighted to Anna, and to other participants, that a medical emergency that was nothing but ordinary. As Irene recalled, “you are in this situation, that's just totally unreal. You sort of almost become a bit distanced from it... Sort of, ‘is this really happening to me?’”

Irene's husband Lucas was 37 and a very fit amateur athlete when he was hospitalised following stroke in 2008. Her story began with events two days prior to his hospitalisation. It was an Australian Rules Football (AFL) grand final day, and Irene, Lucas, and their young children (ages 4 and 7) went to a local sports club after watching the game on the television. After a "great night out," Lucas woke up the following morning with a headache; despite this, he completed his morning training session. They then went to Irene's parents' beach house. Lucas's headache persisted, and he developed 'flu-like' symptoms such as coughing and shivering. Since the children had recently had a bout of influenza, they assumed it was the same viral infection.

Lucas took some paracetamol tablets and went to bed. Because he was coughing heavily, Irene slept in a separate room. As a result, she did not know that Lucas had a stroke in the middle of the night. When one of the children went into their bedroom in the morning, Lucas was unable to move or talk. Having taught Physical Education and Health as a schoolteacher, Irene recognised this as signs of stroke, and called 000 straight away. What followed was agonising delays at the emergency department, transfer to another hospital, and an anxious wait during neurosurgery, as I discuss later. What appeared as a relatively ordinary start to holidays – despite Lucas complaining about his headache and flu-like symptoms – developed into a medical crisis. Irene was devastated when she saw her husband bed-bound following surgical de-clotting, which she was told was his only chance of survival:

He was pretty bad, when we got to [a major metropolitan hospital where Lucas had been transferred], he just pretty much couldn't move at all, and he was really bad. [After the operation], they moved him to the ICU, and I waited

and sat with him through the night, and he just didn't wake up... It was pretty full on. All these thoughts go through your head, you know, kids, what am I going to do [with them], and it was horrible.

Irene was distraught that she might lose Lucas, her husband and father of their children: she was devastated because it would mean that she was no longer a wife – she would become a widow, and a single mother. The marital and intimate partnership would dissolve, and Irene's subject positions were threatened and rearranged.

At the same time, the stroke led to financial and economic uncertainties: Lucas has been running his own business. Without him, it was not sustainable, as Irene “had no idea what was going on in the shop. I've never been involved in the shop, so it's always been his domain.” This meant that she faced the financial necessity of return to paid employment, from which she was on extended family leave while their youngest child was still at kindergarten. The unexpected loss of a partner would have cascading effects, with financial, parenting and social implications. This potential loss disrupted not only the present, but also their assumed future.

Like most people their age, participants made their plans based on the foreseeable future, taking into account their current and predictable circumstances. The potentiality of sudden and unanticipated change of circumstances, such as the loss of an income source, was felt as impactful and had possible rippling effects on various domains of life. Alix, for example, had her mortgage structured, because it had been based on her and Erwin's joint income when it was negotiated. Ben, who I introduce later, made a marriage proposal to his partner Amy well before she had a stroke, based on the circumstances surrounding them at the time.³³ People tried to

³³ Without mortgage protection and now with Erwin's lost income source (he had no income protection) and Alix's reduced hours at paid employment, the fortnightly repayments became unachievable. She had no choice but to sell the house. Alix, Erwin, and their children had to

eliminate or insure against risks as they were recognised, or perceived as significant and realistic enough within the context in which they were placed. While some participants had income protection insurance and/or mortgage insurance, others did not. Elke, whose husband Mick had a stroke in 2011 at age 50, was grateful that Mick had income protection. However, having worked in the superannuation sector, she was also mindful that this was not the case for many working age people: “Some people don't want to pay the insurance premium, because they say that ‘I don't want insurance, I don't need it because nothing will happen to me [due to their relatively young age], I don't get sick’.”³⁴

The sudden onset of stroke opened up possibilities previously bracketed off from an assumed ordered life, one that provided a sense of continuity and predictability. This possibility of departure, from a culturally intelligible, ‘common sense’ narrative of ‘living a healthy, happy family life’, threatened Irene’s sense of “ontological security” (Giddens, 1991: 35-69) – senses of order and continuity in individuals’ biographies that allowed them to make sense of their world as stable. In this way, the medical emergency of stroke disrupted a sense of confidence in a taken-for-granted, stable reality, and cast doubt on the realisation of a stable and routinised sense of identity, a ‘normal’ identity, both for the present and into the future. The following few days – or weeks or months for some participants – was a long period filled with uncertainty.

temporarily move into a friend’s house until they found a smaller property that was within their altered budget. In contrast, Ben and Amy, who were engaged at the time of her stroke, married within a year from the onset of stroke. These will be discussed in later chapters.

³⁴ In Australia, people have the option to fund income protection insurance premium payment through their employer-contributed superannuation. Elke explained that many people were unaware of this, or felt no need to have income protection. This mechanism of purchasing income protection through superannuation also does not apply to self-employed people who choose not to make superannuation contributions.

Being on ‘tenterhooks’

Advancements in acute stroke treatment, especially for ischemic stroke has been heralded in the literature as maximising outcome (Donnan et al., 2008; Sacco et al., 2007). However, most participants’ partners experienced varying degrees of medical complications. This was partly due to the fact that diagnosis and treatment often did not commence until hours after onset (confirming national and Victorian trends: National Stroke Foundation, 2011b). Delays occurred between the first presentation of suspected signs of stroke and the time of arrival at the emergency department of the nearest hospital, and/or during early assessment at the hospital. For people living in rural areas, it was especially difficult; for example, when Ryan first presented suspected signs, Emily found it hard to get an appointment for him with a GP due to a shortage of practitioners.

Emily and Ryan were both 49 when Ryan had a stroke in 2010. A few days before he was hospitalised for stroke, Ryan had soreness in his neck and was not feeling well. Initially, he attributed this to sailing the previous weekend; he dismissed this as a simple muscle strain. Even so, upon Emily’s insistence, Ryan tried to make an appointment to see a doctor, to no avail. Emily was philosophical about this ‘missed’ appointment:

At the beginning [we tried] to get a doctor’s appointment because Ryan felt funny in the neck, and I’m wondering whether they would have found something then, and being able to prevent the stroke happening. Whether it was that or not, I don’t know; nobody will ever know.

The complexity of stroke signs in many cases, especially at early stages and in certain localisations, such as the brain stem, meant that it was often difficult even for medical professionals to make a diagnosis. Therefore, initial signs of stroke were often

dismissed as a neck strain, migraine, or headache caused by dehydration or as a natural occurrence. One example of the latter was Will's wife Nadia, who had a stroke at 40, two weeks after she gave birth to their daughter in 2010. She complained of headaches, however her doctor assumed it was just part of recovery after giving birth. Will's accounts about Nadia's stroke onset will be discussed later in this chapter.

Where stroke presented as headache or migraine, which was very common, it was often not taken seriously, by the person who had a stroke, his or her partner, or their medical professionals such as the GP. When Yvette's ex-husband Chris called and asked her to come over, he had a severe headache. After she tried to give him a paracetamol tablet, she realised that he could not even lift his head up to take the tablet. Realising that something serious was happening, she spoke to his brother, a medical professional, on the phone. Upon his suggestion, she called an ambulance. Although the ambulance arrived within 10-15 minutes, and a family history of aneurism was communicated to the officers, considerable time elapsed before Chris was taken to the hospital.

I don't know, maybe because his symptoms are not really very obvious. So they stuffed around with him for quite a long time, you know, they were probably there for maybe an hour before they actually finally took him to the hospital. I don't know what they were doing but, you know, they did a lot of tests and everything before they took him.

For some participants delays occurred even after their partner arrived at the emergency department. These delays disrupted the above-mentioned previously held assumption that 'once a patient presented at hospital, all will be fine'. The wait was particularly extended for Irene, who described her time at the emergency department as a "circus." After being taken to the hospital in an outer suburb by an ambulance,

Lucas was initially and tentatively diagnosed with meningococcal disease and viral encephalitis. This was due to the initial CT scan not showing a stroke, and to the fact that he was displaying ‘flu-like symptoms’ such as shivering, in addition to the more classic symptoms of stroke, including headache, loss of movement on one side of his body, slurring, and his mouth drooping. Based on the assumption that it was a viral infection, emergency physicians initially started an antibiotic treatment, but to no avail. Irene observed this process with a growing sense of frustration and reservation:

They [the physicians] didn’t seem to, they were not hurrying things up much...

In the back of my mind I still thought it was a stroke. But I had to go through all the procedures to find that out.

Six hours after admission, Lucas was finally given an MRI, which confirmed a stroke in his brain stem. After this was confirmed, Irene became desperate at the lack of action in getting prompt and apparently meaningful treatment for Lucas:

I tried to do what I could to try and get him a bed, just kept asking and asking, but there's not much you can do, sometimes, you know, as a patient, it's sort of limited. That was terrible... I was actually told that, if they couldn't get a bed, probably they [would] have to let the nature take its course.

There was further delay in securing a bed at another hospital with a stroke unit, and 12 hours passed before Lucas was transferred to the second hospital in an inner suburb.³⁵

The delays that were experienced – not only for Irene and Lucas but also for other couples – meant that some participants’ partners were not able to receive the benefits of thrombolytic therapy, the use of time-sensitive, ‘clot-busting’ medications

³⁵ The neurosurgeon at the second hospital was furious about the delay. This reaction seemed to allow Irene to develop a sense of trust in him and his decision-making. Later in this chapter I discuss how participants perceived specialists.

for ischemic strokes within the recommended three-hour time frame from the first signs of stroke, which have been shown to positively influence both survival rate and long-term stroke outcomes (Boddice et al., 2010). Acute stroke treatment through surgery and/or medication was often unsuccessful, or only partially successful; even when thrombolytic therapy, in cases of ischemic strokes, was conducted within the recommended timeframe, there was no guarantee that it would work. Suitability of treatment options depended on individual factors such as the type and location of stroke, and based on the various and different degrees of risks inherent in any surgical and medication treatment. Neil's wife Eva was given an anticoagulant medication soon after she was admitted to the hospital when she had a stroke in 2011 at the age of 54. He recounted his state of shock when she was hospitalised, and his anxious wait:

She could have another one (stroke) straightaway. She could die, you know...

It's like a car accident in some way. "Are they okay?" "How seriously were they injured?" The only difference with a stroke is that it's like a ticking time bomb, so you don't know until treatment is sort of under way and [seeing] how they are coping. Because some people don't cope with the drugs. There is worry in terms of delay time in getting them treated, delay time in how successful the drugs will be and how she will react to those. So you are always on tenterhooks, I suppose.

Neil's sense of uncertainty – as well as his concern for Eva's life – dissipated as it became clear that Eva's stroke was relatively 'mild' and her condition improved rather quickly. However, the partners of the rest of my participants did not follow such a neat clinical pathway. For example, Alix's husband Erwin was given rt-PA (recombinant tissue plasminogen activator), a drug commonly used in thrombolytic therapy, within the recommended three-hour time frame, for what initially appeared

as a relatively minor stroke. After spending the entire night in the emergency department and with stroke symptoms seemingly disappearing, Erwin was going to stay for a further week at the hospital only for precautionary observations. However, by the time Alix had gone home to feed their young children, who had been looked after overnight by a neighbour, and had gone to the shops to buy Erwin pyjamas and toothpaste, his condition had deteriorated rapidly:

I rang his mum and said, 'look, this is what happened, but he's alright now, he's gonna be at the hospital for a week, but they'll just check it out'... I think my phone was busy, but kind of ignored it anyway. After I'd done all the shopping and stuff, I see that my sister-in-law was trying to ring me at home. She goes, 'you've gotta go to the hospital'. I said, 'Oh, why? What happened?' She goes, 'well, they said they tried to call you, and they were just asking me all these questions about things that I just don't know the answer for. You just have to go there, they need you'. So I went there, and he wasn't anywhere to be seen. And then the special doctors came and wanted to talk to me in a room, so I went to that room.

The drug proved to be ineffective, and Erwin's MRI scan showed a collapsed artery. An attempt at dissolving the clotted artery was unsuccessful, as was stenting the collapsed artery. Erwin underwent decompressive craniectomy³⁶ because, Alix was told, as a young person – paradoxically, a usually positive trait in stroke recovery – Erwin hadn't had as much cerebral atrophy, or brain shrinkage, as an old person, and so there was not enough room in his skull for the brain to swell. He was transferred to another hospital within Melbourne where decompressive craniectomy could be conducted, and, after waiting for his blood pressure to stabilise, a section of his skull

³⁶ Decompressive craniectomy is the surgical removal of part of skull to relieve pressure inside the skull, caused by the swelling brain squeezing against it.

was removed. Following the operation, he was taken to the ICU with “tubes and everything like that”. After spending more than 24 hours at two hospitals, Alix went home, exhausted. The following day, while being driven to the hospital by a neighbour, who was worried about her driving in such an exhausted and distressed state, she received a phone call from the hospital. Erwin had been taken to the operation theatre again, because his brain started to swell:

[I was told that swelling] had an impact on [the section of] the brain that controls all your heart, lungs, and ... So, it was AGAIN long waiting [and I was thinking], ‘oh my god, oh my god’, so basically they removed his temporal lobe — they actually took a chunk out.

Alix’s experience of Erwin’s treatment was characterised by unexpected turns, anxious waiting, and perceived ineffectiveness of the different treatment strategies used.

Fiona’s husband Matt also experienced complications. He was 49 when he had a stroke in 2010, as he was stretching in his room after having breakfast, to prepare for a long drive to visit a client in a rural area. They lived near a major metropolitan hospital with a stroke unit, and Matt was taken there promptly. He received thrombolytic therapy within the recommended timeframe. However, his condition did not improve:

Matt was taken to the hospital and there was quite a bit of concern at the time because the swelling [of the brain] wasn’t going down, it was increasing, [so] they thought he might have to have a craniotomy. He was there within an hour so they administered the clot-busting drug and they said to me, ‘in 97% of cases we’ll see a dramatic improvement and reversal of the stroke effects

almost instantly,’ and nothing happened so, I guess, Matt was one of the 3% that the drug didn’t work for.

Successful or otherwise, once an attempt at early stroke treatment was made through surgery, thrombolytic therapy, or other means (which often involved simply monitoring and stabilising blood pressure and preventing or responding to complications), it became a stressful and dangerous waiting game. Uncertainty over their loved one’s life was looming, and there was nothing that spouses could do to improve the condition. Megan’s husband Simon, who had a stroke at the age of 34 in 2008, did not receive any medical treatment, as the delay in his diagnosis prevented the use of thrombolytic therapy. At the same time, the localisation of his stroke in the brain stem made surgery almost impossible due to thinness of the artery affected:

[The doctors said] ‘we can’t guarantee that even if we did operate that we would be able to make anything different [due to stroke localisation]’... I guess it was a little bit helpless.

There was nothing that Megan could do to alleviate Simon’s critical condition, and she could not count on the doctors, the experts, to save the day.

As both Anna and Alix indicate, without the experience of chronic illness in their biographies prior to their husbands’ strokes, their understanding of the role of the hospital was of *curing*. They expected that, in the face of a serious medical event, acute care would *fix* the medical problem – or at least ameliorate it – and that the omniscient doctors knew the answers. However, as time in acute care progressed, with various complications looming, and in some cases with early misdiagnoses, the limitations of medical knowledge and practice became evident.

Medical knowledge and trust

Parson's conceptualisation of the 'sick role' (1951) has become somewhat of a punching bag. Although still widely cited, medical sociologists conventionally now argue his oversimplification of medical encounters and the obsolete assumptions the concept carries, rather than its conceptual utility. Today, especially in the context of chronic illnesses, sick persons are portrayed not as passive patients, but as active and empowered participants, who negotiate and give meanings to their illness experiences and treatment. However, as Rier (2000) details in an autoethnographic piece of his own experience in the ICU, patient-doctor relations in an acute, critical medical encounter are often reminiscence of the Parsonian world.³⁷ Despite the ethos in contemporary medicine of patient empowerment and participation in decision-making, patients in acute, critical care are typically too weak and sick to be an active partner in choice making. This also applied to their significant others, who did not have the time, technical expertise, or emotional energy to make an 'informed decision' that may or may not have contradicted the doctor's recommendations. As Irene explained:

I was told that [a new, still rather experimental surgery procedure] was his only chance [of survival], so it wasn't a really a decision to make... They thrust things at me to sign, and pretty much said 'sign this', so I just signed it, and ... I trusted [the surgeon].

Was it trust that made you sign everything, or was it out of desperation?

Well, there was no choice. Never ever was there a choice. It was pretty much this, or —. "This is his best shot, his only shot". There wasn't any other option.

In the face of the potential death of their partner, participants had no choice but to 'trust' – or, more accurately, hope – that doctors would make the right

³⁷ Hyndman (1985) also provides accounts of assuming Parsonian 'patienthood' role in a serious but not critical medical encounter following a motorbike accident.

decisions: there was no alternative. Given the critical situation, there was neither ‘consumer choice’ nor rejecting doctor’s control (Haug & Lavin, 1981). However, this was not quite the world illustrated by Parsons more than half a century ago. Firstly, contrary to the assumed technical competence of doctors in the Parsonian world, there were limitations to what the medical system was capable of in terms of diagnosis, prognosis, and acute treatment. Further, many participants were not mere, passive objects; passivity would conflict with the autonomous and agentic subject constituted in contemporary Western societies. Instead, participants actively sought from doctors and other sources, such as the Internet and relatives and friends who worked in the medical field, information about the condition and the prognosis for their spouse. As Neil explained:

[The best way to deal with uncertainty was] action, you know. For me it was getting the right advice. [I was telling myself] I've got to get to a doctor, I've got to get to a doctor, I've got to —. You concentrate on doing that rather than just collapsing in a heap, you know. I think action and time take care of things.

Neil was impressed with how the doctors at the private acute hospital were able to articulate Eva’s condition and projected trajectory. Where he did not understand medical jargon that the doctors used, he searched for its meaning on the Internet, using phonetic spellings of the terms. Given Eva’s relatively mild stroke, it was perhaps easier for medical professionals to provide a detailed prognosis. For other participants, the complex nature of the brain injury from stroke often meant that medical professionals did not have an answer, and the medical knowledge on which they drew did not help them. Megan’s account illustrates this:

The first question I had was what is the research on this type of stroke and they said that it was a very rare occurrence and they obviously were trying to

give a reason why it had happened and they said basically that there was no reason... They said ‘unfortunately we don’t know why, it’s just happened’...

In the first three days that he was in intensive care, there’s not a lot of information that they could give us.

Megan’s account implies irony; while she tried to be an active participant in a medical encounter, this very act rendered her powerless and ultimately passive in the face of uncertainty.

Similarly, Alix recalled the two-week period of uncertainty while Erwin was in the ICU. With a section of temporal lobe resected and a large part of the skull missing from decompressive craniectomy,³⁸ Erwin appeared on the verge of death. One of Alix’s close friends happened to know the head of the ICU through her work. After Alix was frustrated with the lack of information about Erwin’s unfolding illness trajectory, she enlisted her friend’s help to find out more information, to no avail:

It was all touch and go. So, she went to [the head of ICU] and just said, 'look, what's the story, what’s going to happen?' Because there were several times we had meetings, you know, those family meetings in a room, [in which they just kept repeating, without much detail] “we just think this person might die”.

As these accounts illustrate, participant’s attempts to find out meaningful information or exert any influence on procedures and processes were a dead end, at least in relation to surgery and the ICU. Furthermore, in cases of medical complications during stroke treatment, participants seemed to think the blame, if any, was to be placed on initial misdiagnosis and/or delay in the diagnostic process,

³⁸ The removal of her husband’s skull was such a surreal experience detached from everyday life for Alix, she was curious to find out what was going to happen with the skull. She found it almost comical when the doctor told her that the skull would be kept in a refrigerator. Her next question to the doctor was: “What, next to your sandwiches?”

conducted by their GP or by medical professionals at the emergency department, rather than the actions or inaction by neurological specialists after diagnosis. In other words, they believed that the specialists who provided the intervention were operating within the limitations of the currently available acute stroke treatment technology, and did not question their authority, knowledge or competence. To participants, the damages to the brain could not have been helped, although they would have been mitigated or minimised by prompt treatment.

Tracey's husband Ted was 47 in 2008 when he had a haemorrhagic stroke, following complications that arose towards the end of chemotherapy for cancer, involving collapsed veins and an adverse reaction to an anticoagulant. When Tracey dropped Ted off one morning at hospital on her way to work for one of his last chemotherapy sessions, she had already noticed something was wrong; Ted was struggling to use his right hand. Concerned about him, she called his mobile phone from work during the day. When he answered the phone, she was unable to understand a word he was uttering – or try to utter. She “put down the pen” and went straight to the hospital. She found him in the corridor; the nurses sent him to have a CT scan on his own. When she saw him, he was severely disoriented. He did know where he was going and could not even tell his name.

This bleed on the brain was initially not detected; even when a CT scan was conducted after he reported paralysis of limbs followed a seizure, it did not show the bleed. Nonetheless, he was initially placed overnight in an ICU, then in a general ward, for observation. The following morning, a MRI scan was conducted upon insistence from a locum oncologist (his regular oncologist was on holidays), who came down to his bed to check up on him to find him displaying severe clinical signs of stroke. The scan confirmed that he had had a haemorrhagic stroke (Tracey

described it as “huge... the size of a fish”), but no surgical procedure was conducted. Despite the inaction on the part of the specialists after diagnosis, Tracey understood that the resultant damages to portions of Ted’s brain were inevitable due to the type and cause of the stroke. Thus, she told me matter-of-factly:

Because he was on [anticoagulant] and his blood was so thin, they couldn’t operate... I don’t know what the hospital could have done anyway to lessen the effect. I don’t know. You can’t just stop a stroke, can you, if you’ve got a bleed? I don’t know what you could do to stop the bleed. It wasn’t like a clot caused it [which could potentially be dissolved]. And they had to just wait for the blood to drain away naturally. So they left him in an induced coma for about 10 days, while they waited for the blood to re-absorb itself. So during that time, that’s where his brain has died, because it was flooded.

Tracey could not do anything to effect change, and neither could the specialists. The only thing that could make a difference to Ted’s condition was the brain itself – if it ‘naturally’ stopped damaging itself. While still in the emergency department, at least the participants could actually do something; they often tried to attract attention in cases of a long wait, or attempted to contest the diagnostic process in cases where the initial (mis)diagnosis was more benign than stroke. However, once their partner was in the hands of specialists, the participants were dependant on them, and forced to hand over decision making to them in a “leap of faith” (Brownlie & Howson, 2005; Manderson & Warren, 2010). As I have discussed above, although they were sometimes critical of medical professionals such as GPs, emergency physicians and nurses, who did not detect or misdiagnosed the signs of stroke, there was implicit, institutionalised trust (Manderson & Warren, 2010) in the neurosurgeons who carried out critical care, as well as the specialist knowledge

system including treatment procedures, techniques, equipment, and medications. That is, partners and those who had had the stroke subjected themselves to medical knowledge and authority.

This trust in neurosurgeons was not a blind faith that specialist medicine was able to fix the problem, despite the initial generalised belief that the hospital was able to deal with the partner's symptoms. Perhaps medicine's assumed capacity to 'fix' correlates negatively with the seriousness of the illness. The more serious the partner's condition, the more sophisticated and technical the treatment became, and the more complex the treatment, the less likely partners felt that the medical professionals could 'fix' the problem. In the latter cases, the experts were 'the best they've got' and if they couldn't do anything, nothing else could be done. Also, different neurosurgeons were placed on different places in the hierarchy – so, Ben, whose accounts I introduce below, was critical of the neurosurgeon who removed a cyst in Amy's brain in a Middle Eastern country, based on comments made by a surgeon in Australia, who said that the cyst would have been benign, and that the surgical removal itself might have caused the stroke. Also, the trust in the specialists transcended the trust placed on the medical knowledge itself – the trust extended to the person, as Emily explained:

Doctors had to explain to me about [that] – because the de-thrombolising drug is very powerful, because it thins your blood that much – it can cause a haemorrhage in the brain. And they said, 'but a young fellow this fit, he could still bleed, but the thing is if we don't get rid of the clot it will cause more substantial damage'. So I said, 'well what would you do?' and he said, 'at this stage I would say go ahead and do it', and I said, 'is that your personal opinion as well?' and he said 'yeah'. So I gave my consent.

On the surface, it appears that the partners of the person in a critical condition handed over, or consigned, their agency to medical professionals. Stripped of their autonomy, they were reduced to mere passivity, incapable of meaningful action and subject to the dominance of medicine. It is fair to say that participants did not have any choice but to subject themselves to expert medical knowledge, because the consequences of doing otherwise could have been deadly. However, far from being passive observers, participants undertook ‘work’ as a spouse, however successful it was. In other words, the very event that was threatening the existence of the marital partnership also highlighted their subject position as a spouse. They acted as the messenger to other relatives and their wider social network, notifying them of their spouse’s hospitalisation, gave consent to medical treatment, and sat with their spouse in the ICU, a restricted area only accessible to close relatives. Being with the critically ill spouse in the hospital was in and of itself an expression of spoushood. That is, family members of a critically ill person were able to demonstrate their love for and commitment or obligation to the person in a critical condition by witnessing the efforts made by the medical professionals, to encourage the affect person to ‘hang on’ (Vandall-Walker & Clark, 2011).

Medical crisis and spousal relationship

The unfolding medical crisis created tensions in previously taken-for-granted assumptions about participants’ sense of self, as I have argued above. The medical emergency challenged the autonomous subject, as participants were forced to hand over a degree of control to medical professionals and to the element of ‘luck’, exposing them potentially to a position of helplessness. At the same time, the potential death of their partner had implications for participants’ subject position located in the spousal relationship. As I discuss below, this challenged the notion of

'us'-ness. Stroke also seemingly diminished participants' partner's personhood. All of a sudden, stroke rendered previously autonomous individuals in a dependent, precarious position. This was evident when Tracey recounted the time when Ted was in an induced coma for ten days:

He was on a tracheotomy because he couldn't breathe on his own. So that was pretty awful too. And he was on a feeding tube... I mean there's nothing more degrading than that, is there, going from a proud man who was 47, to suddenly overnight having a nappy on and nasal feeding.

The shift from managing 100 people at work prior to stroke, to lying in bed, unconscious, incapacitated, and powerless not only highlighted the sudden nature of the situation, but also exposed Tracey to an 'ontologically insecure' position (Giddens, 1991). She explained to me that their marital relationship had largely been based on more or less traditional gender roles. During Ted's hospitalisation and the subsequent period while he was in coma (and in the months and years following these events), there were many occasions when she felt vulnerable, such as literally getting lost while trying to make her way around a large and unfamiliar city:

I was like the wife who looks after the children — that was my role, looking after the children and house. And he did all the negotiation of things and doing all the driving and stuff. When he was airlifted down [from their regional centre to Melbourne], we [Tracey and the children] drove down an hour later. My God, I'd never driven to Melbourne – never. So that was terrifying for me. And our car was broken into and the sat nav [satellite navigation system] was stolen while he was in the coma, so, then I had no sat nav. I didn't know my way around Melbourne. That was absolutely awful.

In their intimate relationship, Tracey had always drawn comfort and a sense of assurance in being the wife of the proud, strong, and confident man that Ted was. With him in an extended coma, she felt exposed: “Suddenly you’ve lost your partner and you’ve lost your support. You’ve gained everything [in terms of everyday household and parenting responsibilities]”. Similarly, there were many occasions where other participants felt vulnerable while their spouse was in the hospital. Moreover, their taken-for-granted ‘us’-ness could be disrupted by various events. When Tracey contacted the insurance company after their car was broken into, she was reminded that, despite their unity in the marital relationship, they were still two, separate individuals, at least in legal terms.

[The car insurance] was in Ted’s name, and the finance company wouldn’t have anything to do with me because they wanted to talk to Ted. It didn’t matter how much I told them that Ted had a stroke and he was in serious condition in intensive care, they refused [to discuss with me] and I had to keep paying for something I didn’t have.

This separateness of each partner in practical terms was at least partly shaped by the length of relationship: Ted and Tracey had been together for more than 20 years. In contrast, Megan and her husband Simon had been married only for 10 months when he had a stroke. She explained that, even though they were together for four years before their marriage, they still had separate bank accounts and had never shared the exact details of each other’s financial matters. There was “no impetus” to do so, because they were “both healthy people, and you don’t expect something like that to change”. After Simon, whose income was much larger than that of Megan, was hospitalised, Megan realised that she would not be able to pay for everyday costs on her income alone. Not knowing what was going to happen with Simon’s income both

in the short and long term, she hurried to his bank to access his savings account. Just as occurred for Tracey with the insurance company, the bank made Megan realise the fragility of their us-ness of the spousal relationship.

Within a day of [stroke] happening, I was at the bank and I was crying and I didn't know how to access his money. I'm his wife and I didn't know anything, so that was a big shock for us.

These events challenged the previously unproblematic integrity of 'we' and the enmeshed nature of intimate partnerships. According to Dew and Wilcox, the Western notion of marriage in recent decades has increasingly emphasised emotional intimacy and expressive components such as personal growth and self-fulfilment.³⁹ The fragmentation of us-ness threatened participants' sense of self, which was invested heavily in their subject position located within their marital relationship.

Expressions of personhood

Even after the condition of their partner became stable enough to indicate that he or she would live through the stroke event, the sources of uncertainty did not cease for participants. In fact, the nature of uncertainty turned from black-and-white questions of survival to more complex concerns. Participants started questioning the severity of consequent disabilities and the extent of recovery that their partner would be making. It was no longer the question of 'is my partner going to survive?' but, instead, 'would my partner still be/get back to the person that I know?' Such questions highlight the importance of personhood, particularly whether their partner's personhood had been preserved, or if it would be restored. This was described by Rebecca, who remembered when her mother was trying to cheer her up: "My mother was saying to

³⁹ However, Perry-Jenkins & Claxton (2011) question such a generalising statement about meanings of marriage as it differs across ethnic and social groupings.

me, 'be grateful you've still got him' and I thought 'well, have I still got him or is it someone different?' but at that stage we didn't know."

The importance of personhood was especially highlighted by Ben, who was living in the Middle East with his now-wife Amy, 29 years of age when she had a stroke in 2011. Doctors were initially unable to provide any useful prognosis. When I asked Ben whether they spoke English, he said: "They weren't great with communication. That was quite difficult. So it was hard to get information off the doctors." This created a great deal of uncertainty in Ben's mind. Visibly sick in the ICU, unable to produce speech and with a nasogastric tube inserted, Amy did not resemble the bubbly and outgoing person she had been only a short while ago. Not knowing the outcome, Ben was not sure whether to hope for Amy's recovery, or grieve for the loss of her as the person he knew and loved. When I asked him what was going through his head when Amy was in the hospital, after a long pause, he answered:

I was pretty upset that Amy was never going to be the person I originally fell in love with... Initially I thought I'd lost Amy, especially those first few weeks, [when] she was very – I'm not sure if it's the right word, but quite vegetative – she was quite, really brain damaged. And I just thought I would be caring for her for the rest of her life, really. But also at the time we had no idea where the finish would be, we didn't know if this is as good as she'd get or if she'd make a full recovery or —. I didn't know how much had gone. There are a lot of unknowns, so you sort of didn't know how much to grieve, I guess... And no-one sort of knew the answer because they didn't know how much the brain's going to recover.

In trying to make sense of these competing emotions, Ben contrasted the brain damage following stroke to a physical injury where one would lose a limb.

With some injuries... if she might have lost her legs or something, you know exactly what's happened, [in terms of prognosis and loss] whereas this... You hear all the time that the brain is plastic and parts can recover, and it can work around it and new connections can be made, and all different things can happen, so you don't know how much recovery is going to happen.

For him, a physical injury, even the permanent loss of a limb, would have offered a more clear-cut picture of what had been lost, and could be regained. In other words, it would have been easier to grieve and move on from what had been lost, and look towards recovery and/or readjustment. At the same time, he felt that there would have been clearer and prescriptive treatment and rehabilitation pathways laid out in front of them.

When his friend introduced Ben to the concept of brain plasticity, he, a schoolteacher, had enough scientific understanding to appreciate this technical knowledge. His knowledge of brain plasticity ignited hope because, even though Amy appeared 'vegetative' at the time, neuroplasticity meant that she might regain her functioning and, more importantly, her personhood. At the same time, it generated uncertainty: as an abstract concept, brain plasticity could not provide any prognostic or prescriptive pathway. This meant that Ben felt stuck in a liminal position: between grieving for the loss of Amy as the person he knew, and moving on from the loss to focus on her recovery. Whether or not the personhood of Amy could be restored depending on her brain's ability to repair itself. When I asked him if there were moments when he felt he could not take anymore, he responded:

Maybe in the first week or two, when I just thought that she would be a vegetable for the rest of her life and I'll just be caring for her for the rest of her life, full-time, and doing everything for her, caring for her completely. That was probably the hardest time, I think.

I asked him if he thought of placing Amy in residential care:

I guess it did. Because I figured that I was going to have to work — there's no way I would be able to survive and care for Amy full time without working. So, that possibility did go through my head a few times. A lot of these sort of residential care places are more for older people, so she would always be stuck in an old person's [nursing] home, I guess, because there's not many places like that for young people. It was a concern that definitely went through my head quite a bit. A lot of times I thought that [since] I'd have to work, someone else might have to look after her during the day and then I'll come home and look after her during the night, which was quite a scary prospect, doing that for the rest of your life — a very scary prospect to contemplate.

Ben and Amy's spousal relationship at the time of stroke was based on working abroad together. Therefore, their economic participation was a prerequisite for the spousal relationship. However, as Amy's prognosis remained uncertain, Ben was unsure of his capacity to be a caring husband (then fiancé) to Amy while at the same time performing as an economically productive citizen. That is, these subject positions now caused great tension, and the thought of having to reconcile them, and the possible permanency of loss of this status, distressed Ben.

Further contributing to the sense of uncertainty was Amy's inability to communicate. Given that the ability to communicate is often considered the foundation of personhood (Young, et al., 2010), absence of communication not only

threatened Amy's personhood, but also the existence of spousehood; they were unable to share the tough moments together, and support each other:

I knew she's still the same person underneath but she wasn't able to communicate at all [for so long] which made it sort of hard to realise what's she feeling or, sort of hard to work out what she's thinking, or what she's going through.

Despite Amy's incapacity to communicate, Ben kept talking to her. Not doing so, perhaps to him, implied not acknowledging her personhood. Besides, he was desperate to find signs hinting at the presence of 'the Amy he knew'. He described an incident that happened within a week after she came out of her coma. He was re-telling a childhood story that Amy had told him; it was an embarrassing story about her auditioning for a role as sheep in a school play. He had always thought it was funny, and liked to tease her about it. As he was poking fun at her attempt at acting as sheep, the moment he remembered as a defining moment happened:

I was just teasing her about her auditioning process. And she was lying in bed, she was still not able to talk or communicate and she was just lying there and all she did was just stick her finger up like that at me [Ben mimicking her giving the finger, with a laughter]... So it was a big milestone [to know] that she knew what was going on around her, and that probably deep down it was still her.

Another big milestone for Ben was when she kissed him for the first time since her stroke. She was still unable to speak, and had not shown much physical recovery. While his account of the kiss was much briefer, he still vividly "remember the kissing, and I was really happy and satisfied and amazed with [it]". Along with the event I described above, this moment gave Ben a glimpse of hope that, despite the

loss of speech and uncertainty surrounding prognosis, her personhood – and their spousal relationship – might be regained.

Fiona also described the time of uncertainty while Matt was in the ICU. After initial concerns about a dangerous level of brain swelling had subsided, and thus the invasive procedure of decompressive craniectomy was avoided, Fiona was told by medical professionals that they were unsure of the extent of Matt's brain damage and the potential for recovery.

He was in intensive care and he was very, very sick. It happened on a Thursday and I think it was on the Friday night. The doctors in intensive care called me in and sat me down and showed me all the scans that had been taken and they told me that it was a devastating stroke. And that at that point they really didn't know what the outcome was likely to be at all. That was pretty tough.

Unlike Ben, Fiona realised from an early stage that Matt was not going to be the 'same' person again. For her, grieving over the loss of Matt's personhood was relatively unambiguous:

It was pretty clear fairly early on that Matt would never be able to go back to work, so that was a big thing... I think for me there was always that knowledge that Matt is never going to be the person that he was. No matter how much he improves, his brain has been injured and he's not going to be the same person, so I think it was that, just incredible grief and sadness.

This realisation was no doubt upsetting, but Fiona felt that she did not have time to dwell on the loss, at least in front of the others, particularly their children (then aged 14, 17, and 19). Rather, she felt that she needed to take control of the situation to minimise the impact of the devastating situation on their children:

It was a shock, but I remember feeling I needed to be in control. I guess because we've got kids and I just thought it was really important for me to help them obviously, because it was a huge shock for them. Our second daughter was doing Year 12 at the time, in August, so she was getting near to the end of the year for her [and the final exams looming]. So it was pretty tough... I think for the kids I just felt it was important for me not to be breaking down all the time.

In the midst of this disruptive event, Fiona performed her parental role, which involved minimising the impact of the stroke on their children. While Fiona was performing parent subject, there was another subjectivity that she was performing: that of a spouse.

It was important for Matt, even though in the initial stages he wasn't able to communicate – obviously he had no speech at all – and I just thought it was important for me not to be breaking down in front of him. I didn't want him to be worrying about me. I wanted him to put all his energy into himself and getting himself well. So I didn't want to upset him that was part of... why it was important for me to be as positive as possible.

In contrast to other accounts where participants struggled with disruptions to the previously taken-for-granted notions of us-ness, seeing Matt in a vulnerable and dependant state prompted Fiona to display resilience. She felt that she had to keep going for their children, and Matt:

I guess partly for me too was that whole thing of, now I've got to step up because our marriage had very much been a collaborative one — we did things jointly. Matt had things that he did, I had things that I did and it was

suddenly, ‘okay this is me, this is up to me now, I’ve got to take on all of that, all of what Matt was doing’, so it was a whole range of emotions I think.

This ‘stepping up’ was partly out of necessity: no one else in Fiona’s life could do household chores, parenting, and paid employment for her and Matt. At the same time, Fiona, and several other participants, were able to establish a sense of control over an otherwise unpredictable and scary situation. However, this was nuanced. It was not about seizing total control over aspects of their lives; rather, it was more to do with fending off perceived uncertainty that threatened their sense of ontological security, by attempting to put some domains of their lives in order, where possible.

Continuing ‘normal’ everyday life

The mundane-ness of the situation at the time of onset, sudden and quick deterioration of the partner’s condition, the unexpectedness due to absence of stroke in personal or family biography, and the assumption that stroke was particular to older people, exposed participants to a ‘surreal’ world. All of a sudden, they found themselves in foreign, unexpected territory, as Irene recalled:

I don't know if I really believed [what was going on] actually. I was still in a bit of disbelief, I was thinking, no, it can't be... You are in this situation, it's just totally unreal. You sort of think that you almost become a bit distanced from it. You are, like, in some weird movie all of sudden, or in some TV show, and you are thinking ‘is this really happening?’

While the medical crisis was unfolding in the ‘surreal’ bubble of the hospital, ‘normal’ everyday life continued outside of it. Children still needed to be cared for, household chores had to be completed, and for some participants, obligations from paid work continued to mount. Although daily routines were disrupted by the pull of

hospital life and a sudden loss of contributions in everyday tasks from the person who had a stroke, participants attempted to manage most — if not all — of these responsibilities in order to maintain ‘normal’ family and other social functions. Fiona explained how this was a demanding task:

You obviously had to keep functioning, you’ve got to keep the house going, you’ve got to keep meals happening, and the washing and the ironing and all of that has to keep going and I was in at the hospital virtually from first thing in the morning till last thing at night.

Many participants mentioned how their own feelings and thoughts of despair and hopelessness were suspended while the condition and prognosis of their partner was uncertain. They felt that they had no time to reflect on what was happening, or to “just collapse in a heap” (Neil). There were too many things that needed to be dealt with:

Emotionally I just felt like I had to keep it together and everything was happening so fast and so constant that there was no time to feel, so you put it in a pocket and deal with it later. Because you’re functioning, it’s a functional time. It’s a luxury to feel and think at that time because you just have to keep everything together. (Megan)

For Anna, demands of everyday life had to be met, regardless of what else was going on. Anna and Jason’s child Julian was still at school when Jason had his stroke. Jason’s sudden hospitalisation did not alter the fact that Julian required someone to take him to and from school, and nor did it change the drop off and pick up times:

Jason was staying at the hospital and I stayed until about 8, 8:30 each night and drove home and then I went back [to the hospital next morning]. Julian was at school at that point, so I would drop him at school at 8.30am and then

go off to the hospital and spent all the day there and then come back in the evening so it was pretty hard work.

Enabling keeping functioning: Support network

In recent years, efforts have been made to ensure acute stroke patients are admitted to a stroke unit either directly or indirectly through the transfer from another hospital with no stroke unit (Boddice et al., 2010). As a result, in 2011, the majority (65%) of patients in Victoria admitted to a hospital were treated in a stroke unit (National Stroke Foundation, 2011b). However, this did not effectively translate to the stroke units' coverage in rural regions, which remained rather limited (Baldac & Groot, 2012).⁴⁰ Thus, rural-dwelling individuals in the acute stages following stroke were transferred to a major hospital in Melbourne with a stroke unit, especially where a specialised surgical procedure was required. This often necessitated long and frequent trips for spouses who lived in rural areas. Irene and Lucas lived in Middleton, a regional centre more than 100 km away from Melbourne. Irene was fortunate that she could stay with her parents, who resided in an outer suburb of Melbourne, when Lucas was admitted to a stroke unit at a major inner city hospital. Still, it was not easy for her, especially with their young children:

I was staying with my parents... so it was quite good. It was school holidays, so we – the kids and I – stayed there for about a week, until school started.

And I went in [to the hospital] every day, sometimes I went in with the kids

⁴⁰ There has been significant development by 2014 (mostly since 2012) in stroke unit coverage in rural regions. However, at the time that participants' partners underwent acute treatment for stroke, there were still large gaps in the stroke unit coverage in the rural regions. Also, the fact that there was a stroke unit in the local area did not mean that there were vacant beds. Furthermore, almost all non-metropolitan hospitals with a stroke unit (except for the one in Geelong, which is a large regional city within one hour drive from Melbourne) still did not provide neuro-interventional and neurosurgical services (National Stroke Foundation 2011a; Victorian Stroke Clinical Network 2013).

for a quite few hours, then went [back to her parents' place] to take the kids, and I went back in [to the hospital] and things like that, but I went in every day.

Once school started back, Irene and her children had to move back to Middleton, although she continued to travel daily to and from Melbourne to see Lucas. Her friends helped her by picking up the children from school:

I would catch the train down because it got a bit hard to drive in all the time, [because] I just got really tired... And I had a lot of help looking after the kids. I needed it too. Especially when I went to see Lucas and then the train got back later than the school pick up time, [the kids would] go home with [friends], and I'd just picked them up from [their place]. It was really good.

Support from others perhaps speak of the benefits of rural life: Irene's friends also organised a food roster to prepare meals for her and the children in the first three months after Lucas' stroke. They also helped her with other practical tasks, such as garden maintenance, which would have been time consuming given the size of their block and the time of the year – spring – when Lucas had a stroke. This support freed Irene's time and energy, from fulfilling household and parenting responsibilities, so enabling her to continue the daily trip to the hospital – so she could fulfil her spousal commitment.

I didn't even need to cook for three months... it was amazing actually. [Food] would just turn up! I remember one time, I'd got back from the hospital and one of the kid's friend's mum had left this whole thing on the back table, like lasagne and dessert, and whole plates of food. It was so nice. So I had a [very full] freezer. And we've got an acre block, so we had a lot of people come and

everyone mowed our lawns for us, which was really good. And just things like that made things a bit easier.

For Irene, being able to fulfil all of her roles and responsibilities was only possible with considerable help, which also enabled her to maintain many of familiar routines.

In contrast, Will's 'keeping functioning' required learning new skills to fill the void created by his wife Nadia's hospitalisation following stroke, two weeks after she gave birth to their first and only child, Sarah. At that time, Will, as a new father, was still learning how to care for the baby. Nadia's sudden hospitalisation meant that he had to take on the parenting tasks that he had previously assumed would be undertaken by her. He recounted the state of his stunned confusion after the ambulance took Nadia to the Bell Hospital, the local major hospital a few suburbs away from their home.

After [the ambulance left and Will notified relatives of the event], I was in the kitchen with Sarah in a crib, and I was — Nadia had, the day before, bought some powdered milk [infant formula]. Thank God she did. I was boiling some water and I was learning — reading the label on how to make powdered milk.

Infant care is gendered. Not only do new mothers provide more direct, instrumental care to babies than fathers, who tend to act more as 'helpers', they also invest more time and energy into thinking and worrying about babies, interpreting their behaviours, and planning care tasks (Fox, 2009; Walzer, 1996). When Will was confronted by the necessity to step into the role typically considered maternal, he was presented with a challenge of doing fatherhood differently to that which he had anticipated. This was a task too great for him to face alone. Fortunately, his father was a medical professional, and he knew some people working at the Bell Hospital, and was able to negotiate with them accommodation for Sarah while Nadia was there as

an in-patient. Will explained how his father “pulled a few strings” to organise Sarah to be admitted to the maternity ward in the Bell Hospital with her mother:

Subsequently after [Nadia’s condition became stable enough to signal her survival, the question was] what we were going to do with Sarah. I couldn't really look after her on my own, [so] dad spoke to the maternity people. And they said, ‘Okay, we'll take her into boarding for a couple of weeks,’ and that way I can learn how to look after her. You know, they’d look after her in a crib, and then I just go in every day to learn how to change a nappy, or to make powdered milk, or to bathe her. Just to get me to learn how to look after her... But also, you know, what to look for in Sarah, feeding her, when I had to burp her and what-have-you. Because it could be a bit of a —.

He paused. Perhaps Will was about to say that he needed to learn how to care for Sarah because, as a man, he was not naturally equipped to do so. However, after a very brief pause, he continued: “No, I suppose anybody can do it – caring for her – [but] you had to learn all about that.”

For Will, the transition to parenthood turned out to be quite different to that which he (and Nadia) had anticipated. The transition relied on a network of individuals and things. First of all, if it were not for Will’s father’s social and cultural capital, it would not have been possible to co-ordinate Sarah’s stay in the maternity ward. I doubt the idea of asking for such an arrangement would occur to most individuals unfamiliar with the running of a hospital, especially in the midst of such an emergency situation. Nor would such an arrangement usually be permitted unless it was paid privately. The maternity ward staff were able to accommodate Sarah, and to teach Will things that new mothers would culturally be expected to have picked up in the first two weeks of their infant’s life, if not before. The cultural assumption about

new fathers not being as equipped as mothers, at direct care, especially in relation to feeding, and sympathy around a new father having to take on these seemingly unnatural ‘maternal’ duties, could have enabled this arrangement. Without access to expressed breast milk, infant milk formula also allowed Will to perform parenthood. In fact, the prospect of placing Sarah into permanent foster care was very real for Will when the outlook for Nadia’s recovery was still uncertain. To raise Sarah – even if it was going to be on his own, should Nadia not recover – was a conscious commitment for Will:

Actually I made the decision. Because it was put to me whether to actually foster Sarah out, but I said no, I wanted to raise her. The time came for me to bring Sarah home – although she did go to the maternity unit at [the semi-acute hospital] where Nadia was transferred, at first. But after about two weeks, the decision was either to take her home or foster her out, so I brought her home and tried to look after her on my own for that time being, and [with] other people's help. My parents then stayed with me for about maybe two or three weeks, just helped me look after Sarah. And then Nadia’s mother moved in for about one month or so.

With the support of others, Will was able to perform the subjective position as parent. Furthermore, Sarah staying at the same hospital as Nadia also ensured that Will was not sacrificing his spousal responsibility to be around Nadia. Further, once Nadia was well enough, nurses would take Sarah to her, enabling her to parent when she was still largely confined to bed.

“Suddenly, I have to do everything”

For many participants, their partner’s stroke and hospitalisation did not exempt them from paid work obligations. Within a short while after the onset of their partner’s stroke, typically a week, they were back in paid employment. It would be an oversimplification to say that they were forced to, or chose to, go back to work while still dealing with uncertainty around their partner’s recovery, as various motivations and a sense of responsibility were at work when participants resumed their paid employment.

These competing demands were clear for Ben and his partner Amy, who were living and working in the Middle East when she had a devastating stroke. Even after her stroke, Ben was contractually bound to continue working, and it was several months later that he was finally able to finish his employment overseas and relocate back to Australia. He thus had a period of physical separation from Amy, which created tensions between his legal obligation and his desire to be with her to witness and to support her through the crisis. The employment obligation robbed him of opportunities to perform his spousal subject position, and this was painful for Ben:

The stroke happened in October and we were probably in hospital in [the Middle Eastern country] for four weeks. I think I might have taken a week off or something. But I was still working [the rest of that time] and then we flew home together and I stayed in Australia for maybe a week over Christmas, and then flew back [overseas] to tie everything up and get all our stuff and I had to work for another couple of weeks. So I was probably over there until mid or late January. But I was over there for a few weeks tidying everything up and getting everything sorted out... It was quite hard. It was hard to concentrate on working while something so much more important was happening outside of

work, while your wife's – I guess in a way – happy life sort of hung in the balance... [But] they didn't want to give me much time off at all. They wanted me to keep working as much as I could.

As Ben told me, going through a medical crisis in a healthcare system different to Australia, with virtually no rehabilitation facilities, unable to spend much time with Amy due to work, was difficult. Ben also found himself dealing with an employer who was neither flexible nor compassionate. It was emotionally draining.

[The workplace in the Middle Eastern country] that we were working for was not particularly thoughtful or understanding of the situation – they were quite harsh really. They weren't particularly forthcoming with Amy's entitlements. They knew she was leaving but they owed her holiday pay and a few other things but they weren't particularly forthcoming with that. So I had to chase them, really fight for that actually, so that was quite hard. Yeah so that took quite a bit of energy... Yeah it was difficult. And depressing. You've got so much going on with the stroke and that was taking so much of my energy and my emotion, and having to spend time fighting for that money and fighting for time off — it was just an extra stress that I didn't need at the time. So it was hard to cope with.

Although Ben's account may appear as extreme, the 'pull' for participants to remain *productive* in the midst of a medical crisis was not uncommon. For example, Tracey continued working part-time while Ted was still in the hospital, partly because "I was worried [that she would lose her job if she took an extended leave]. I wanted to keep my job". Similarly, although Megan received some paid personal leave, financial uncertainties forced her to continue working:

I had to still go to work. My work only let me have five days off work. They said “take as much time as you want, you poor thing, but you won’t be paid”, and because we didn’t know what was going to happen with Simon’s salary and his salary was a lot bigger than mine, so the concern then became how do I pay for everything? How long is he not going to be at work? [So I had to continue working].

Immediate financial pressures — for example, Tracey and Ted were still paying off their mortgage — and uncertainty about future finances pushed many participants back to paid work once they had exhausted paid carer, personal or compassionate leave entitlements. While the work obligations often prevented people’s capacity to act as a partner, for some participants, these were not mutually exclusive. Even though Ben and Megan felt uncomfortable having to put work ahead of being with their spouse, the pull from work was not always a bad thing. Tracey and Ted were migrants from the UK living in Hakea, a regional centre two hours’ drive from the metropolitan hospital where Ted was staying; they did not have the extensive social network to which some other participants had access. Tracey explained that, at work, she had listening ears:

I kept working then, kept going, to sort of keep myself distracted... It gave me my sanity. It kept my mind occupied. You can’t do anything. I mean, while he was in Melbourne, I couldn’t drive down every day so I needed to just keep my job going and keep myself going and talk to people, because I haven’t got any family here. I haven’t got parents, grandparents, I’ve got no one. Ted was my only adult partner and then I had three children, so the only way I was talking to people was going to work. [Colleagues] were good. Yeah, they were very good. They knew exactly what was going on

Unlike Ben and Megan, work commitments enabled Tracey to maintain her sense of control. Similarly, children provided Irene with a sense of control and a degree of normalcy. She described them as “anchors” that stopped her from “drifting around”.

I guess I had something to live for, and to, you know, having a family life, something [for Lucas] to get better for as well, having two young sons... Having children, you have a bit of a routine, something to keep going for, something to distract you, I guess, as well. Kids were a sort of distraction, I suppose, in a good way, really for me, because you sort of forget about things for a moment, and think “I've got to make lunches, and I've gotta do this”, and school stuff and readers, and all that stuff. It's a reminder that life still goes on, and something that's still normal. But everything else is sort of totally not normal.

Although a feeling of ‘having to do everything’ could be overwhelming, it also provided people with a sense of coherence in some domains of their lives. What was happening in the hospital was largely uncontrollable; however, home and work places were domains in which spouses could potentially maintain a sense of control.

The sudden and unexpected onset of stroke in their partner threatened the participants’ sense of identity, which was previously taken-for-granted as stable and centred, both in the present and into the future. They tried to preserve their sense of personhood in the face of uncertainty in multiple ways and settings, under high demands from various sources. This involved negotiating different subjective positions. While these subject positions sometimes competed against one another, at other times they complemented, and even depended on one another. For Ben, for example, being a responsible employee was incongruent with being a supportive

spouse, not only at an ideational level, but also because of geographical separation. For Tracey, working in paid employment was both a financial necessity and an outlet for emotional support. ‘Staying strong’ for Fiona, during the medical crisis, was her performance as parent and spouse, and this helped her to manage everyday tasks and duties that would otherwise not get done.

Negotiating various subject positions at times enabled participants to maintain a sense of autonomy and empowerment in acute and sub-acute settings. In other words, empowerment – catchphrase in medical settings – was often performed in settings outside the actual hospital. Ironically, it was precisely because participants were unable to attain a sense of empowerment within the hospital settings that there was a need for them to enact a sense of control elsewhere. In hospital, they often felt lost, passive and futile. In other domains of their life, however, they were able to gain a sense of control. In the next chapter, I will explore how the participants experienced the impact of their partner’s discharge home – a domain over which they felt a degree of control while their partner was at the hospital.

Chapter 5

Your whole world's turned into chaos

You go through the medical emergency, you go through the acute medical emergency side, and then you go into rehab, but that focuses on your general day-to-day needs, being able to go to the toilet, being able to shower, being able to feed yourself, being able to dress yourself, being able to make yourself a cup of tea. It goes through the basic functions of life. But then there's after. It's going home, and sure when you're in this rehab environment, everything revolved around rehab, and then all of a sudden you go home and you've got to change from this mentality of three or four sessions of rehab a day, to 'normal life', which is not normal anymore, it's not normal to what it was. So you've got to readjust. That is difficult, because it's not physical, it can't be seen, and it's a whole new change of life (Emily).

The time around discharge was chaotic. During and after this hectic period, partners of people who had a stroke became invisible. In the preceding chapter, I argued that the occurrence of stroke destabilised partners' taken-for-granted assumptions about their selfhood and the sense of 'us-ness'. Their world became divided into the 'hospital world', where their partner was treated, and the 'everyday world', where many aspects of life continued as usual. This distinction allowed them to maintain a sense of control in some domains of their everyday world.

However, their partner's discharge home from hospital terminated this separation of the two worlds. I focus in this chapter how the re-introduction of the person who had had a stroke into this 'everyday world' impacted upon the spouses'

lifeworld. As outlined in the previous chapter, the sudden and unexpected nature of stroke left them little or no time to prepare themselves for changes necessitated in their life, or to deal with uncertainty surrounding their partner's recovery. Furthermore, as I discuss below, the lack of appropriate and sufficient formal support meant that participants were often left on their own to manage care duties, as there was an assumption that once their partners were discharged, they were 'functional enough' to smoothly reintegrate back into the community. As I will show, these assumptions rendered the participants invisible. At the same time, various and dramatic changes that were introduced when the person who had a stroke returned home fractured spouses' lives as they once knew them prior to stroke.

Anxiety about discharge and lack of communication

The time around discharge home was marked by anxiety, for many participants. Their partners last lived at home 'able-bodied', several weeks prior; now they were coming home with multiple stroke sequelae of varying degrees of severity, including combinations of mobility, functional, communication, cognitive, and emotional difficulties.

Disappearing safety net

The sudden removal of the safety net provided by the hospital environment compounded participants' sense of anxiety as their stroke-affected partners returned home. While many participants expressed some dissatisfaction with various aspects of care delivery during their partners' hospital stay, their partner was at least in the immediate reach of nurses, doctors, and other healthcare professionals to seek their assistance and support, should another stroke, other medical complication, or injury (such as from a fall), occur. Being in a hospital was especially re-assuring for those

whose partners had no obvious prior risk factors of stroke – hence, no clear way of eliminating them in an effort to manage risk and prevent reoccurrence. When their partner was discharged home, the reality of living with a stroke-affected person hit home for participants; the 24/7 access to immediate medical attention and nursing support at the hospital was no longer available:

When they actually said he was coming home I was really worried. I thought, when he's in the hospital, if something happens, he's in the right place, but what if he comes home and something happens again, sort of thing? (Anna)

This fear was especially pronounced for participants who lived some distance from hospital, such as Rebecca, who at the time lived in a small rural town two hours' drive away from the closest regional centre:

When you're in rehab, you're in a very protected environment – you've got the physiotherapist and all those [other health care professionals] that [constantly] come in. And suddenly you get home, particularly where we were, you're by yourself. There's just you, your family, your friends and you don't have that professional backup... So it was a bit scary really because you think if something went wrong in hospital, we had someone there to fix it but where you are, you haven't. That was really, quite scary.

The urban sociologist Jane Jacobs (1961) once theorised that the eyes on the street – the gaze and, more importantly, the felt presence of local residents – created a sense of security in both residents and visitors in urban settings. She continued that self-appointed and trusted public characters, who need not possess special qualification or knowledge but are frequently present on the scene, are integral to this. While anyone who is in regular contact with a wide social circle in the area, such as a shopkeeper, might serve as a public character in a Jacobsian neighbourhood, within a

hospital environment, it is the medical and healthcare professionals who are bestowed with trust by virtue of working in an institution and representing the medical and clinical knowledge systems (Manderson & Warren, 2013a). In this way, they provide the ‘eyes’ that instil a sense of safety. While ‘clinical gaze’ is an expression of power relations that has depersonalising effects, through the separation of the individual’s body — along with clinical signs and symptoms — from their personhood (Foucault, 1973), supervision by medical and healthcare professionals in a relationship based on a degree of trust can foster a sense of security and hope (Fox & Chesla, 2008; Manderson & Warren, 2010; Warren & Manderson, 2008). This sense of safety may also extend beyond the bounds of the hospital, as demonstrated in cases of cancer patients and their carers who received regular home visits by registered nurses (McKenzie et al., 2007). Here, however, as the person who had a stroke returned home, the omnipresent eyes of healthcare professionals in the hospital environment were no longer available and, without schemes involving frequent and regular visits by healthcare professionals, a sense of uncertainty was introduced into the home that was once a safe space in their life. Home now seemed like an unknown territory, as I discuss further in Chapter 6.

Further contributing to this sense of uncertainty was that people often were not equipped with a ‘back-up plan’ (O’Sullivan et al., 2012) – a concrete contingency plan in case another stroke occurred. Instead, information and support provision at the point of discharge often focused on clinical information about brain and stroke, rather than practical and situation specific materials, confirming previous research findings (Almborg et al., 2009; Cameron & Gignac, 2008; Lutz et al., 2011). In this context, a sense of anxiety arose out of feeling inadequately prepared to take on the caregiving role in addition to their busy ‘normal’ everyday life at home where there was no

immediate medical attention and supervision. There was often no provision of sufficient and appropriate information, training, and other resources to ameliorate this sense of anxiety either at the time of discharge or on an ongoing basis.

At acute and sub-acute hospitals, the focus of daily life was treatment and intensive rehabilitation. Nursing care provided at the hospital, including continence management and medication administration, largely eliminated the need for participants to provide much of care activities themselves. Rebecca explained that Ned's six-week stay in the rehabilitation hospital was "the easy part because someone [else] was looking after him, someone was controlling his life," before adding that "when he came home, that was probably the worst part." In the rehabilitation hospital, daily life was organised according to the rehabilitation program, which some participants likened to a school timetable – consisting of blocks of regular sessions and killing time in between them. During this time, their concerns were focused largely on the functional and physical recovery of their partner. With discharge home, most, if not all, care activities were suddenly to be borne by the partners. Naomi's husband Iain was 48 when he had the first of multiple strokes in 2003. Naomi recounted the time shortly after her husband Iain's discharge home when he still had continence problems, which was confounded by mobility and cognitive issues:

When he first came home from hospital, he was incontinent and some nights, I was washing, bedding and showering him [in the middle of the night, because of urinary leakage. And some mornings] I'd have a flooded bed – we had drainage [a urinary drainage unit] on the bed and he'd obviously pulled it off. He wouldn't realise that he did it.

She hinted here that this unplugging of drainage bag was due to cognition problems, but then she immediately dismissed this by normalising it, perhaps in an attempt at

preserving Iain's dignity: "I'm not — like, it just would happen or other things". She then continued:

By jingo, those first few weeks were a bit of a nightmare. And it was very difficult for him because it was hard for him to make the toilet all the time, because he was incredibly slow walking and very [urinary incontinent] – so the signalling [i.e. bodily signs to urinate] wasn't going as well. So it was all pretty tricky. Especially because Iain was on fluid tablets to get the swelling down in his legs, but the trouble was that means you've got to go [to the toilet] more often.

This meant that Naomi had to manage Iain's incontinence – both the consequences of the urinary leakage and prevention of it. This 'bodywork' or 'dirty work' (Brittain & Shaw, 2007; Cassells & Watt, 2003; Twigg, 2000) had wide-ranging implications for her. The need to wake up during the night to clean up, or incorporating this task in the busy morning routine before going to work, led to sleep deprivation and exhaustion.

Managing Iain's incontinence included planning his day while she was away from home, and planning their day together, to incorporate frequent toilet breaks. Planning the daily activities was especially difficult outside home (Manderson, 2011), where immediate access to toilets was often not possible due to lack of availability and this was compounded by Iain's slow movement. It also meant that the out-of-home activities were intermittently interrupted by frequent toilet breaks, interfering with the rhythm of everyday life.⁴¹ Incontinence management also included odour control for both Iain and the house. Suddenly having to assume this work, culturally

⁴¹ How care activities interrupt the rhythm of everyday life will be further discussed in Chapter 8.

associated with a low status and low paid job (Brittain & Shaw, 2007), was both draining and undignifying.⁴²

Lack of meaningful communication

Most participants had not had any experience of providing extensive and complex caregiving equivalent to domiciliary nursing care, let alone stroke care, prior to their partner's stroke. Therefore, the prospect of shouldering direct care provision was daunting and created great anxiety. This was especially so, because of the lack of a definite time frame due to uncertainty regarding recovery. Tracey's husband's (Ted) mobility and speech were still severely restricted at the time of his discharge, and he also suffered continence problems. Ted's determination to get better, together with his recovery that went beyond the initial, rather pessimistic prognosis, gave Tracey a sense of hope for his further recovery in a semi-acute setting. Nonetheless, she dreaded his release date, as she felt terribly unprepared to provide the care that Ted required at home. This was especially so, because she still held a part time job. She reflected:

I was petrified about him coming home. I'm not a nurse, and he was on all this medication, he had a catheter, he was in a wheelchair — I didn't know how I was going to manage all that.

Tracey's anxiety was also exacerbated because the hospital staff did not consult with her regarding Ted's release date, nor did they discuss with her about her own support needs:

⁴² While Iain's incontinence "gradually settled down" in the first few years, the subsequent stroke recurrence over the last few years made the continence problem worse, amongst other deteriorations. How this affected the spousal relationship will be further discussed in Chapter 8.

I saw in his notes that they had a release date in October, which freaked me out because nobody said anything. And I said to them ‘I work, I don’t know how I’m going to cope’. Basically I got no support at all.

The assumption underlying Ted’s release date being reported only through his notes was that Ted, the patient, rather than both he and Tracey (as a couple), were the focus of consultation. Further, initiating familial care was assumed to be unproblematic, as was the idea that families expected to take their family member home. Perhaps it was also assumed that this information would somehow be relayed to Tracey by Ted, notwithstanding his severe speech difficulties at the time. I do not wish to create a one-dimensional picture of the staff at the rehabilitation unit where Ted stayed, as some positive aspects of Tracey’s visit at the unit also featured in her accounts. However, as also reported by other participants, a lack of communication and support was common, despite the fact that many rehabilitation hospital staff may perceive otherwise. A national audit of stroke rehabilitation services (2012b: 28-30) found that almost all rehabilitation hospitals (93%, or 25 out of 27) in Victoria reported that they incorporated provision of ‘patient education material’ in their regular discharge procedure. The same audit also identified that, according to the clinical notes completed by the hospital staff, just over three quarters of primary carers of people who were discharged post stroke from Australian rehabilitation hospitals received ‘training’ and ‘support needs assessment’ (78% and 77%, respectively) as part of the discharge preparation procedure. However, the feeling of being neglected during and after their partner’s discharge home was a common theme amongst participants. In their lives after stroke, the partners of people who have had a stroke (the people who are central in this study) become ‘invisible’ – not in a literal sense but ‘seen but unnoticed’, often pushed out of the public consciousness. For

example, as I was preparing to interview Elke at her home, she asked her husband Mick, who seemed to want to stay nearby while the interview took place, to go to his room and listen to a CD, adding: “well, for a change, it’s not about you, only somehow.” The assumptions about the ‘naturalness’ of partners managing and providing care and ongoing rehabilitation to the person who had a stroke, and expectations that they would do so unproblematically, created this invisibility. Also contributing to this was that, as I mentioned above, the main focus of clinical and care service interactions largely remained on the patients, rather than carers or dyads, as has been reported elsewhere (Brereton & Nolan, 2002; Gustafsson et al., 2010; Lovat et al., 2010).

In fact, the lack of information and services that are designed to prepare the person who had a stroke and their family members for their return home was a common theme among the participants in my study. This persists despite numerous international studies establishing that appropriate and effective information provision to carers during the discharge period was one area that requires much improvement in stroke clinical (Almborg et al., 2009; Brereton & Nolan, 2000; Brereton, 1997; Cameron & Gignac, 2008; Cecil et al., 2011; Forster et al., 2012; Gustafsson et al., 2010). Indeed, the importance of carer support around this period is acknowledged in the clinical guidelines (Boddice et al., 2010) widely used in Australia. In cases where ‘education material’ or an ‘information kit’ were provided, participants felt that they were too busy at the time attending to different needs outside of ‘caregiving duties’ to read them, or were not in the right mindset to take in and comprehend the information provided to them. Naomi’s account below exemplifies the difficulties in these written information materials achieving their intended outcomes, in the context of so many competing demands:

I'm sure I've had brochures but [having the] time to actually follow it up is another thing. I was raising a kid, I was trying to work full-time, I had my dad [who was gravely ill at the time], and I had Iain. I needed to give some time to all those people. To find time to read a whole pile of stuff [was difficult] and I was thinking, 'how am I going to action it?' You get a whole lot of information and, in the end, it just sort of feels like a blur, and you think, 'I don't have the energy for all of it.'

Yet, clinical notes for these cases would have indicated that information was provided in a timely manner, and they would be counted in the statistics as 'adherence to the guideline'.

In the audit cited above (National Stroke Foundation, 2012b), there was no documented record of 'training' and 'support needs assessment' provided to the carers in one quarter of cases at the time around discharge. Abi was one of these cases when at 38, her husband Cain, then 53 years old, had two strokes. Cain was severely affected physically by the first stroke, and cognitively by the second stroke that occurred straight after he was discharged following the first stroke. Entirely unfamiliar with stroke until this time, she knew nothing about stroke, its causes and outcomes, and its implications. When Cain returned home, she was ill-prepared for caregiving, due to the absence of sufficient and appropriate information. She recounted her struggles after the first discharge:

The hospital did not explain to me what a stroke was. So they did not explain the behaviour [changes], what he could not do or why he couldn't do it, what part of the brain was affected, why he was not walking. They did not tell me that it was caused by the brain [damage]. They did not give me any information. ... I did not know anything [about stroke]. Nobody, not even,

social worker, [told me anything] – nothing, nothing. I was just given this person. I didn't understand anything about stroke, I've never experienced it, never seen it, and I now had to deal with this person, by my own.

Elsewhere in the interview, Abi likened her experience immediately after discharge to having been tasked to build a house without any training or experience in construction work: “Really, it's like you've never been a builder, and suddenly given this huge house [to build]. So you don't know how to start”. Without understanding about stroke and its implications, she struggled to empathise with Cain's physical and emotional struggles, and to accommodate his needs. In the absence of information about how a stroke might affect a person, she depended on her prior understanding of Cain to make assumptions about his behavioural changes. For a few years prior to his stroke, Cain had seemed withdrawn socially – she described him at the time as “very bad, very angry and very upset” and “not caring about himself or family” – which caused great strains on their marital and family relationships. Abi only now attributed those behaviours to depression, the diagnosis of which Abi has been made aware since his second stroke. However, she was unaware of his suffering from depression at the time around his strokes. When Cain returned home with physical and functional disabilities, including hemiplegia and difficulty swallowing after the first stroke, she interpreted them as an extension of the behaviours that he was showing prior to stroke:

Because he was lazy in the past, I assumed he was just being lazy to get my attention. So I used to force him to do things... because I did not understand how someone could be walking [before stroke], and suddenly that his body can't [after stroke].

Following his stroke, Cain acted in ways that Abi could not make sense of: “Like, not swallowing food and I didn’t understand why, and he was snappy – like he’d get very angry, so I did not understand why.” Her frustration was exacerbated by the fact that their marital relationship had been problematic prior to stroke. In response, she became angry when she could not make sense of his behaviours, and decided that by being forceful and often shouting at him, Cain would behave like a ‘normal’ person:

[We would] go for a walk, and I’d force him and [say] ‘you can do it’ to him... If he was trying to get in the bed, I would just say to him ‘you can just lift your legs up and put them in the bed!’ And he said, ‘I can’t!’, I said, ‘yes, you can. You are just pretending. I am not going to do that for you’.

Without access to the clinical notes for Cain, it is difficult to determine whether Abi was given some sort of information materials but was unable to take notice of these, or to recollect this happening, given the chaotic and stressful time around discharge. However, this factual detail is irrelevant; regardless of whether information was provided, her acknowledged lack of understanding about stroke at the time demonstrates that it was not communicated effectively. In addition to the absence of previous exposure to stroke, being a migrant who came from a CALD (culturally and linguistically diverse) background may have also contributed towards Abi’s lack of prior knowledge about stroke, or her capacity to access information herself (e.g. by searching Internet resources), and potentially also shaped how she responded to his behaviour changes. Perhaps, her excellent command of everyday English language also masked her lack of understanding about medical terminology, as healthcare professionals could have assumed and overestimated her comprehension of basic medical knowledge.

As public health campaigns target people's knowledge about recognition of stroke signs, risk factors and prevention, evaluations about these programs self-evidently measure the target population's awareness about these domains (for some Australian examples, see Cadilhac et al., 2007; Sug Yoon & Byles, 2002; Sug Yoon et al., 2001). These campaigns and evaluations that focus on specific and technical aspects of stroke, however, inherently assume singularity of stroke, and that stroke is something that everyone already knows about. It also appears that the hospital staff made the same assumption about Abi. While cultural competency has become recognised as a prominent part of clinical practice, its operational conceptualisation is often ambiguous and sometimes reduced to stereotype-laden 'check lists' (Kleinman & Benson, 2006). In such practice, a false dichotomy may be constructed, based on an assumption that people either operate on the familiar, 'mainstream' medical model, or an exotic, foreign explanatory model. What then get obscured is nuanced understanding about how people may draw on multiple explanatory models to construct their understanding of illness.⁴³

Even at the time of the interview, five years after Cain's strokes, Abi still had difficulty understanding what 'stroke' is and what its effects are. She understood 'brain injury' as a different entity to 'stroke', but also regarded a brain injury as one type of stroke. Therefore, physical and functional disabilities were caused by stroke, whereby cognitive deficits and emotional difficulties were consequences of a 'brain injury'. When I asked her to talk about Cain's first stroke, she responded: "The first stroke, he didn't have a brain injury, so he was fine." Rather confused, I asked her if the first stroke was a minor one. She clarified:

⁴³ In fact, western medical professionals also operate on different models of a disease. For an exploration of the multiple ways through which a disease is enacted in medical settings, see (Mol 2002).

It was still a big one, like, he was paralysed on the side, but he did not have a brain injury. So I found that the stroke is not a problem, but we have a stroke and brain injury and it is more harder. Because the stroke is just physically [affecting the person]... the brain is still working. But when you have a brain injury, it's very hard, you lose memories, and change personality, and who you are. So, yeah, the brain injury is worse. But when he had a stroke it was ok.

These responses may almost make the first stroke sound trivial. However, further prompting and probing revealed Abi's story of the time between the first and second strokes, with struggles and feelings of frustration seeping out, as I have described earlier with her analogy of building a house. This might not have come out in a superficial, surface-level conversation. Chances would be much less in a clinical conversation, in which the focus was on Cain rather than Abi. It may be that she was retrospectively downplaying the first stroke, despite the hardship she faced at the time, due to the greater perceived impact of the second stroke. That is, in telling her story about Cain's stroke, the greater significance of the second stroke may have foregrounded its impact more prominently in her narrative. Similarly, a greater emphasis was given to the hardships following later strokes in an interview with Naomi, whose husband Iain had multiple strokes, the second of which was considered the more severe. In any case, Abi's account illustrated a lack of comprehensive assessment of her support needs.

Drawing conclusions about a causal link between ethnicity and lack of carer support provision at the time of discharge is beyond the scope of my study due to the limited sample. However, Abi's account provided a glimpse of subjective experience at the time of discharge that augments claims made by Mackenzie et al (2007) that

carers in the UK from ethnic minority groups were often inadequately supported in terms of receiving information about stroke and its consequences.

This lack of support is not limited to people of ethnic minority groups. More broadly, previous studies have identified factors preventing effective information communication and training provision to carers. These include time constraints placed on healthcare professionals, over-reliance on written materials, lack of active and engaging information communication tailored to the carers' individual needs and personal situations, a focus on the patient rather than the carer during discharge planning procedures, a lack of awareness, knowledge and/or skills regarding carer needs assessment, and an absence of interventions designed to prepare new carers (Brereton & Nolan, 2002; Denby & Harvey, 2003; Gustafsson et al., 2010; Perry & Middleton, 2011; Rodgers et al., 2001; Silva-Smith, 2007). Various elements of these were observed in my participants' experiences as described above. In fact, effective communication in the rehabilitation wards should extend beyond mere information provision. As demonstrated with amputees (Manderson & Warren, 2010; Warren & Manderson, 2008), it involves fostering confidence in patients about their capacity for living their lives with an altered body after discharge, and instilling trust in patients and their families that rehabilitation staff are supportive in this process during and beyond the initial clinical context. Participants' accounts that I discuss above illustrate that, in some cases, 'information provision' was neither practical nor meaningful in developing a sense of confidence for participants in managing their partner's stroke-affected body and various consequences of it in their lives post-discharge. These contributed to the participants' sense of feeling neglected, or being 'invisible'.

Discharge as inevitability

Even though many participants felt that they were under- or unprepared to take on the caregiving role at home, the release date was to eventually arrive. The healthcare system and funding arrangements explicitly discourage (see Victorian Auditor-General, 2008) and implicitly penalise acute and sub-acute hospitals for continuing to provide beds to patients for a long-term stay (see Appendix 3 for the funding arrangement for rehabilitation hospitals). At the same time, there is a lack of temporary transitional or permanent alternative options for younger people following discharge. This meant that participants did not have a choice — despite the rhetoric of ‘choice’ in health services — but to accept discharge at a date specified by the hospital staff as a natural and inevitable step.⁴⁴ However, the lack of information about stroke and its implications meant that participants were ill prepared for the transition, as I have described above. Alternatively, some held a rather optimistic assessment about their spouse’s condition and recovery progress, which they had only observed in a controlled, rehabilitation setting rather than in everyday life situations.

Many participants were actually keen for their partner’s return home when notified of the discharge date by the hospital staff. For Fiona, Matt’s discharge home was a major milestone in his recovery – after regaining basic speech and ability to walk – that gave them a sense of hope. This was against the backdrop of a pessimistic and uncertain prognosis given when he was in a critical condition at the acute hospital:

The doctors said to me [initially]: ‘look, will Matt ever walk again? Will he ever talk again? Will he even go home? We don’t know.’ So, it was pretty

⁴⁴ However, many young people with disabilities (especially from an acquired brain injury) do end up in residential care services for older people (Dearn 2011; Winkler et al., 2006), including Belinda, a participant in my study. She was placed in a residential care service until she met her now-husband Adam in her early 40s. Their story will be discussed in Chapter 8.

major that the doctors were even saying that he may never go home. Coming home was a huge milestone and that was fantastic.

For some participants, their excitement about their partner's return home was also based on more practical grounds. After several weeks (or longer in many cases) of visits to the acute hospital, followed by rehabilitation hospitals, the travel had become very exhausting for them. As Cain had two periods of hospitalisation within a period of four months, Abi found that visits were getting cumbersome. She had school-aged daughters — one in primary school (age 9) and another in high school (age 16), which made incorporating the visits to and from a hospital located approximately 20km away into her daily routine difficult. It necessitated her to drive to at least three different destinations, not all in the same direction, across several suburbs and through the traffic. So, after Cain's second stroke, she "requested to bring him closer to my place [for outpatient rehabilitation, so that] they didn't keep him that long at the [inpatient] rehab".

The trips demanded especially strenuous efforts for those who commuted to a metropolitan hospital from a rural region. For Irene, keeping up with the frequent long trips and concurrent parenting responsibilities for their young children was overwhelming. She recalled the time when she received a phone call from the hospital staff, notifying her of Lucas's discharge home:

I said [in an excited voice] "Oh. Yeah, yeah, yeah!?" The thing is, [initially] I was coming up every day from Middleton, but I was actually, at that stage [towards discharge], coming up every second day because it was just getting too hard, travelling, because it took me two hours each way, and plus I had kids. I'd go when they went to school, so I drop them off at school, then go

down [to Melbourne], and then pick the kids up and meet them back down, so it was pretty hard to juggle everything, you know.

Moreover, most participants explained that their partner was eager to be out of the hospital and return home, as many of them found life in the rehabilitation hospital to be boring, depressing, or otherwise unsatisfactory. This was evident when Anna told me about her husband Jason's over-enthusiasm to return home: "all he wanted to do was to go home [...] I had to keep, sort of, tying him down to get him to stay in the hospital." Similarly, Irene explained that Lucas was missing the 'normal life' outside the walls of the hospital — his children, his business, and being at home:

He really pushed to come home because he had a couple of things [that he wanted to attend]. Sam [son] had a school concert coming up, and we had a birthday that was [coming up] soon.

Matt's and Lucas' determination to return home coincided with Fiona's and Irene's excitement about this too, at least at the time of discharge. As I discuss later in this chapter, Irene's excitement quickly dissolved when Lucas returned home, and she realised that his discharge was organised too early.

Not all participants shared their enthusiasm for their partner's return home, however. In some participants' eyes, their partner's condition obviously warranted more time at the hospital with further intensive rehabilitation programs. However, the day of discharge arrived, seemingly hastily. This led them to feel abandoned, as they were aware of their partner's unmet rehabilitation needs that were then to be taken up on their own at home. Elke explained to me, with a sense of resignation:

[After the initial intensive rehabilitation program, sessions] sort of slowed down. It was more in the beginning than in the end. Then at some point they say, this is all we can give you. This is all we can provide you with. We have

other patients on the list. So slowly it gets less and less and less and then they discharge you, basically. Although, at that point, rehab is not finished. Then you are on your own, basically, you have to continue.

Elsewhere, Elke – like other participants – mentioned that she had to become the spokesperson for Mick, who could not speak to mediate communication with healthcare professionals at the acute and semi-acute settings. While she interpreted for Mick, she also observed rehabilitation sessions that allied health professionals conducted with him. This was partly to provide him company at the repetitive laborious rehabilitation sessions. However, she also intently observed the sessions in order to learn rehabilitation exercises so that she could conduct them with Mick. As her comment above illustrates, she noticed that rehabilitation sessions were becoming less frequent as the time went, despite her advocating for more sessions, and realised that she needed to assume this role to augment what was being provided by the health care professionals at the hospital and in the community settings after discharge home. This will be further discussed in Chapter 6.

Due to chronic underfunding (an example of the implications in Victoria can be seen in Carlyon, 2013), the healthcare system was running at the full capacity and the shortage of beds was a common story. In this climate, discharge was regarded as a potential choke point for patient flow that needed to be kept as clear as possible. Under the current funding system (Victorian Department of Health, 2012), it did not make financial sense for hospitals to continue providing intensive rehabilitation services to patients, especially those considered ‘slow stream’⁴⁵, but also ‘fast stream’ patients who had already reached a certain functional recovery. In order to

⁴⁵ Slow stream patients’ long-term stay in the hospital was typically spent on waiting for a vacancy in a residential care facility, rather than participating in meaningful rehabilitation programs, the cost of which the rehabilitation hospitals could not afford.

maintaining the patient flow, limited available resources were allocated to patients who could potentially make enough recovery to return home within a short period of time — thus, providing the best ‘bang for the buck’. Patients were discharged as they appeared ‘functional enough’, with further rehabilitation to be undertaken in the ‘natural’ community settings.

Discharge and choice

The apparent inevitability of discharge home created a void for partners as a choice-making subject. For Tracey, Ted’s discharge was not as exciting as it was daunting, and I have described above her anxiety about Ted’s return home. The fact that the hospital staff did not consult with her led to her feeling without a choice about the release date. Confounding this was a sense of moral obligation as a wife. She explained:

He was determined and he wanted to come home... I couldn’t say anything because Ted was so desperate to come home. I can’t say ‘you can’t come home’, can I?

‘Choice’ has become a buzzword in healthcare, intertwined with the neoliberal ideology. It is assumed that, as ‘rational’ consumers, health service users and their carers are capable of exercising informed choice, and that having opportunities to do so will empower them. However, this is an oversimplification. The choices available are shaped, constrained and limited by the various contexts within which individuals are placed (Arksey & Glendinning, 2007; Funk & Kobayashi, 2009; Lupton, 1997). At the same time, choices by different actors may be in conflict in some circumstances and yet they may coexist in a different context, which causes dilemmas in cases of informal family caregiving (Moran et al., 2012). However, a certain

'choice' may be driven, in the name of efficiency, by systemic and institutional needs (Carey, 2009; Dow & McDonald, 2007; Teasell, 2011). From systemic and patient perspectives, Ted and Lucas' desire for early discharge home may have been celebrated as cases of respecting their choice, and at the same time solving the bottleneck in the healthcare system. For Tracey, this was much more nuanced. Ted's eventual return home would certainly have been her 'choice'. After all, people, appreciate living with close family members with a chronic illness and/or disabilities in arrangements that replicate a degree of reciprocity that was previously available at their own home (Manderson & Warren, 2013b). However, her desire for Ted's return home was provided that there was a sufficient support system in place that enabled her to feel confident about Ted's reintegration into the everyday life and community rehabilitation.

Sudden changes to 'everyday life'

When their partner returned home, participants were required to accommodate various changes to their everyday life. The 'deficits' became more obvious as the stroke-affected partner was removed from the hospital environment and reintegrated into the home environment. It was a rude awakening for those who thought their partner had made a sufficient recovery for everyday, 'normal' life. And it was a crude confirmation for others who feared their partner was not ready for life at home. It was during this period that many participants faced the potential chronicity of various changes in their life, as I describe below.

The stroke-affected partners' return home did not signal the reinstatement of the 'normal' life. In the months that they were in the hospital, many aspects of life had changed. For Emily, who stayed near the acute and rehabilitation hospitals while

Ryan was there, home felt familiar, yet different after his discharge. This was because discharge home coincided with other events that marked changes:

When we did eventually come home, it was good to be home but it was strange. It was very difficult because we didn't have the dog [who had to be euthanised while Ryan was in hospital]. Everything was totally different, everything was really quiet, and we missed [the dog] very much, because we'd just about always had dogs since we'd been married [...] Because our children had shifted down to Melbourne in the January to early February, and Ryan had had his stroke in that March, so when we came home the Friday before Easter, we came home to an empty house — no kids and no dog, neither of us working because I was looking after him, and he couldn't work. So our whole life was turned upside down.

The events that coincided with Ryan's discharge home left symbolic markers that reminded them of the changes brought about by his stroke. The absence of the dog, perhaps more than any other changes, emphasised the changes in the dynamics of their marital relationship. However, these changes were more than symbolic. The presence of their children, who were already young adults by then, would have provided 'eyes' to an extent, should Ryan require immediate attention in Emily's absence. In fact, direct or indirect supervision was an important ingredient in maintaining a sense of stability in the home environment (Chapter 6). The practical implications of these various changes became more obvious as the person who had a stroke settled back in the home environment. So Ryan's discharge home was somewhat bittersweet for Emily. It had some element of excitement, but it was accompanied with a sense of loss, uncertainty, and change.

For Ben, Amy's stroke brought a complete change of scene, and the sense of uncertainty was immense. Following their return to Australia once Amy's condition became stable (see Chapter 4) and while she stayed in the semi-acute/rehabilitation hospital, Ben moved into Amy's mother's house. Notwithstanding the weeks when Ben returned to the Middle East, they remained in this house for a year after Amy's discharge. Unlike Emily and other participants, who were still at least located in the same physical home space as before the stroke, Ben literally experienced a 'new life'. After the hectic time shuffling between overseas and Australia followed by Amy's discharge, his life seemed completely different: it involved living in the house that wasn't his 'home' and living with an in-law, while his partner was still physically and communicatively affected. Together, these generated a great sense of uncertainty:

It was just hard adjusting to a new life without Amy being able to do all the things she used to be able to do. Initially she was unable to do lots of things. ... Emotionally [for Ben], it was probably still getting used to what's been lost and what's not been lost, and trying to work out if there's still improvement to come or if that's where she's going to finish recovery-wise. Deciphering [Amy's condition and the potential future], that's probably one of the hardest things I guess.

As I discussed in the previous chapter, while their partners who had a stroke were in the acute, subacute and rehabilitation hospitals, the participants were focused on juggling their visits to the hospital and other, everyday duties and responsibilities, and their attention was directed at functional recovery. Their partners' discharge home marked the first occasion where participants had to seriously face the meanings of their partners' stroke, the resultant disabilities and long-term outcomes, and what

the future might hold. The reality of living with a stroke affected person hit home. As Irene explained:

It was the realisation, on both of us, that this has happened, and it's not going to go away — It's not something that's going to be fixed, overnight. It's going to take a lot of time. And the life has to go on, but it was — everything was a lot harder.

Like some of the sequelae of stroke including cognitive difficulties, the impact of stroke on participants' lives was 'invisible' until it was experienced. As noted in the previous chapter, the relatively young age and absence of notable chronic illness in their biography prior to their spouse's stroke meant that participants' understanding of acute and semi-acute medical treatment was mostly limited to that of 'cure'. For some participants, this understanding still lingered during the stay in rehabilitation hospital. In these cases, it was expected that discharge home signalled complete or near-'cure'. Megan found out quickly that it was not the case when Simon returned home, with sequelae of stroke still very obvious:

You expect, for some reason, someone to come out of hospital healthier than when they went in, and I couldn't see any difference in the time that he had been there. He was still needing to be assisted to do everything.

These expectations were not restricted to participants who were unfamiliar with the health system. Emily had previously worked as a nurse, mainly with infectious disease patients but also with stroke patients. Even then, her experience was confined to that of the acute health system. Until Ryan was discharged home, she still held the 'medicine as curative' assumptions. When Ryan returned home, she quickly realised the chronicity of his condition, and that the implications spread much wider than the brain of the 'patient':

I must admit when I was nursing, you didn't see this side of it. ... Once they come home, that's when the shit hits the fan so to speak, because you really come down with a thud, that there's no quick fix. It's not like, when you have a blocked artery, you go and have a scan and an angiogram and they put a stent in and you're fixed. There's no quick fix, it's a long-term project. And it takes a while to process that. It is a whole change in life.

Stroke does not simply affect a person's brain. It effects changes in many aspects of the person's life and of people around him/her. And, as I argued in the previous chapter, these changes happened unexpectedly and suddenly for the working age participants.

Many events that are culturally considered 'life changing', such as becoming a parent, career change, property purchase, and marriage, involve a degree of planning and occur gradually enough to leave some time for preparation.⁴⁶ However, due to the unexpectedness of stroke for the relatively young participants, there was little time afforded to them for mental and practical preparation to adjust to the changes following stroke. As Emily continued:

And the thing is, a lot of your [other] changes, if you change jobs or you shift house or something like that, you plan ahead for all of those things, so you're aware of all [things required, and consequences]. But a stroke, you don't expect it to happen, and it happens all of a sudden, and all of a sudden you're thrown into the deep end and your whole world's turned into chaos, and you've just got to cope. And the person that's had the stroke can't [be relied

⁴⁶ Of course, many life events — especially those involving a sense of loss — do happen abruptly. People do not plan for miscarriage, having their employment suddenly terminated, or being involved in an accident. In cases of chronic illness, an onset and/or diagnosis may be experienced as a sudden disturbance — or “biographical disruption” (Bury, 1982).

on], because they can't, they're physically, absolutely exhausted, it absolutely drains their body of energy as well as the physical problems that they have because of it.

Participants held assumptions that when the person who had a stroke returned home, their life would pick up from where they left off. In the acute and rehabilitation hospitals, they actively attempted to pick up positive signs of recovery. The focus was on what their partner could still do, or functions that they were getting back. However, at the time of, and the period shortly after discharge, and in everyday home life situations, attentions were forcibly brought to what their partner could no longer do, and other bodily and practical changes that were considered a loss or limitations. Many aspects of life and necessary re-adjustments to home life reminded the participants of various changes to their spouse. As Emily explained above, fatigue was one of the 'invisible' changes that became obvious as Ryan re-adjusted to everyday life. Anna's husband Jason made a good functional recovery to an extent that he found the rehabilitation programs at the hospital too basic and not challenging enough. However, Anna quickly found out, once Jason was at home, that there were more implications of stroke than his limp and weakness in one hand:

[At the rehabilitation hospital] I was rushing about here, there and everywhere, and he just seemed to get on and do [rehabilitation sessions]. Then it was when he came home that was when I was upset, you know, when he was back and the reality of what has happened hits you. In the evening, he would go to bed early because he got really tired, so I just sat on my own... and then you're left to ponder with your thoughts and think what's going to happen from now, sort of thing. So it just gave me a bit more time to think about it... I

think that was the time when we realised – [the changes, and potential chronicity of them].

For those whose partner still displayed severe physical disabilities, the focus remained on ongoing physical and functional rehabilitation, except that it was much harder to organise and receive rehabilitation sessions now that they were outside the hospital system. As Alix explained:

In that early period, you very much focus on the physical rehabilitation. You are not thinking about the cognitive damage, the change in your life, or the permanency of it all. You are just thinking and focused on, ‘ok, when’s the next appointment, ok, we’ve got to go there, why do we have to wait so long, why can’t... you know, you are constantly battling to get appointments and stuff like that. So, you are just doing that all the time. So you are very much focused on the physical aspect of things.

Far from a smooth transition back to home, life remained hectic. The activities that were relatively easily completed in an organised rehabilitation setting became problematic in everyday settings at home. Even what may seem trivial, such as going to the toilet (which happened frequently in cases of incontinence), putting on clothes, or getting ready to go to a rehabilitation appointment, took a much longer time. Irene recollected the time immediately after her husband Lucas’ discharge, which happened earlier than expected. Seeing him struggle while walking around the house dampened her excitement about his discharge. They had two young children, and avoiding the little toys that they left on the floor while walking had not been part of the rehabilitation sessions:

[The hospital staff] said, ‘well, actually, he can come home.’ and I thought, ‘Oh, ok, he must be right!’ But... probably in the hindsight, he probably

should've stayed for a little bit longer, because, he wasn't really great when he came home. Like he couldn't walk very well and little toys that kids left lying around was a big hassle and things like that.

Similarly, Will's wife Nadia found that, after three months of hospitalisation and rehabilitation, there were many things that she still could not do in everyday life, such as using the toilet without a toilet frame, cooking, or even putting on a bra.

It was time to discharge her and bring her home. I think at first it was a bit frustrating for Nadia because she discovered she just couldn't do what she normally did in the past.

Moreover, the activities she was no longer able to do were not limited to those that used to be her daily routine. There were new practices that she was missing out due to her stroke sequelae, such as hemiplegia and poor balance. As Nadia had become a new mother to their baby Sarah less than two weeks prior to her stroke, it was particularly frustrating that she could not engage in the activities that were expected of a new parent, such as getting her daughter out of the cot and changing her nappy. Also, Will explained that, due to fatigue, Nadia "really slept like a baby. And sometimes, it would take a long time for her to wake up". This meant that feeding Sarah overnight and early in the morning was difficult for Nadia.⁴⁷ So, Will continued feeding Sarah, the practice he picked up immediately after Nadia's hospitalisation:

You virtually have to be there every two or three hours to feed her. Every morning I got up, boiled the milk, and she'd have her milk every morning.

With many things in everyday life that reminded them of their 'deficits', these even mundane activities were incredibly frustrating for people who had a stroke. Irene

⁴⁷ During the 12 day period between Sarah's birth and Nadia's hospitalisation, Nadia was breastfeeding her.

told me about Lucas' emotional struggles that arose out of his frustration over seemingly simple things in everyday life that he could no longer do.

Emotionally, he found it very hard to deal with things... If things didn't go right, he found that hard, like, he'd get a big mood swing, things like that.

Because, he just found it hard to control those sort of things, you know?

Irene understood Lucas' frustration, and wanted to cheer him up. She told me that she attempted to eliminate negativity, such as pessimism, stressful events, sadness and sense of loss over his stroke. Instead, she pretended an air of optimism around him:

You go through a stage where you just sort of got to try and act like everything is fine. You know. 'You will be right, it'll be fine'. That's pretty exhausting as well, after a while, to do that.

Is it especially when, in your mind, you were still uncertain [about recovery]?

Yeah, that's right, exactly. You've got to put a bit of an act on I suppose, that everything is fine. Yeah. A lot of it. Because you don't know it yourself. So, you've just got to act like everything is fine.

Irene felt she needed a degree of blind optimism in order to encourage a sense of hope in Lucas, and at the same time protect herself from a sense of uncertainty. Hochschild (1979, 1983) coined the term 'emotion work' to capture acts of attempting to change an emotion or feeling and their degree and quality, to suit a given social situation.⁴⁸ She argued that emotion work is stipulated by "feeling rules" (Hochschild, 1979, p. 560) – social norms about appropriate feelings in a given situation. In the informal caregiving context, this emotion work can be done to

⁴⁸ In her conceptualisation, emotion work is distinguished from 'emotion labour', on the basis that emotion labour is conducted in interactions involving payment, whereas emotion work is done in non-commercial interactions. This conceptual distinction can, however, be blurred in a health care context (Allen & Ciambone, 2003).

encourage the care-recipient to conform to the feeling rules, and also to manage their own feelings, in order to comply with socially and normatively appropriate feelings as a carer (Olson, 2011; Simpson & Acton, 2013; Thomas et al., 2002). Discursively available feeling rules when facing serious and chronic illnesses in contemporary western societies are largely derived from ideologies of survivorhood and positive thinking: staying strong, brave and stoic in the face of hardship (DeVolder, 2013; Little et al., 2002; Wray et al., 2007), and adopting positive outlooks and attitudes in conquering negative emotional experiences and the pursuit of ‘happiness’ (Christopher & Hickinbottom, 2008; Held, 2002). Furthermore, this emphasis on a rational self – the mind – overcoming negative emotional experiences and feelings of distress reflects the mind-body dualism (Reeve et al., 2010). That is, embodied emotional experiences are to be managed cognitively. However, as Irene’s account shows, emotional work was not easy; it was exhausting and stressful, and sometimes seemingly impossible. Furthermore, what was discursively available as ‘appropriate feelings’ were not always congruent with phenomenological, embodied feelings, and a degree of difficulties ensued in reconciling these tensions. Irene explained:

I think sometimes I probably acted too much of that [positivity and encouragement], now looking back in hindsight, because Lucas would just go really quiet, then he just combusts a bit and goes, “how can you be so happy about it all” sort of thing, you know what I mean? For him, he’d wanted me to be a bit more openly distressed about it.

Anna had a similar experience with Jason’s ‘mood swings’. Her description of Jason at the time illustrates her difficulties in knowing ‘appropriate feelings’, and the delicateness of achieving emotion work:

I felt one day he'd be up and positive and the next day he'd be really down and there was no talking to him, that sort of thing, so it was just a bit like a rollercoaster ride [...] like walking on eggshells. Well, it's not that I didn't know what to say, I was scared what to say in case I said the wrong thing and upset him. Even just a statement that you wouldn't think anything of, you know, he would either take it the wrong way or read it the wrong way and it would upset him.

She gave an example of statements that would upset Jason:

It was like people would say to him, 'you're looking a lot better,' and that would just make him feel worse because he probably was looking better but he wasn't feeling better inside so just that little statement – you're looking better – would make him feel ten times worse.⁴⁹

The culturally dominant 'feeling rules' in response to an illness also dictated how other people understood how participants should respond to their spouse's illness. Rebecca told me about a time when she was 'cheered up' by their family financial advisor:

I had to ring up our financial advisor when Ned was still in the hospital because I had to sort a few things out, like insurance claims and stuff like that. And he said 'you're a strong person, so you'll cope' and I thought 'that is the last thing I want to be told, that I'm a strong person and I'll cope.' I just thought 'I know what you're saying — yes, I will cope but I just don't really want to be told that.'

⁴⁹ Incidentally, I once made a similar — what I now consider was insensitive — comment to a stroke support group member in the first meeting that she attended since being discharged from the hospital following a stroke recurrence. The sad expression on her face is not something I will forget any time soon. She was kind and polite enough to explain to me she was still not feeling well.

Similarly, Megan spoke of her embodied feelings of loss, pain, suffering, and isolation that stemmed from her realisation that people often did not understand what she was going through:

I felt like I had just a giant foot on my chest the whole time. I felt like I couldn't breathe and I think that was the hard thing, especially for me at work because people couldn't see Simon and they couldn't see him as sick.

She spoke of a passing comment that someone at work made to her soon after Simon's discharge home.

My boss had seen a picture of Simon at Christmas on Facebook and said to me 'Simon looks fine, what are you complaining about?' But that picture was of just his face and he didn't realise Simon — still to this day — cannot feel anything on the left side of his face, the right side of his body and, of course, that makes a difference even still now. But Simon had just been released a day earlier from rehabilitation and to have someone just carelessly say 'there's nothing wrong with him, he looks fine' — I don't know whether he was trying to jolly me along or whether he was just — but the lack of understanding. I think some people just thought I should suck it up and get on with it.

Friends and acquaintances were often well meaning, and the examples above perhaps show their way of engaging in emotion work. However the culturally dominant 'survivorship' and 'positive outlook' discourses were embedded deeply within their subjectivity, and these ideals, when expressed verbally, were not necessarily consistent with personal feelings of the participants and their partners. Furthermore, these discourses underlined expectations that individuals ought to carry on with their life — their personal quest — rather than 'dwelling on' their lives after stroke. This further exacerbated invisibility, since caregiving then was constructed as an individual

issue, as I discuss later in this chapter. That some of the stroke sequelae was not obvious to casual observers also contributed to this.

‘Invisible’ disabilities

Stroke often resulted in various sequelae that were not as visibly apparent as mobility issues. Communicative, cognitive, continence, fatigue, and emotional issues were not as obvious to people, including medical professionals, who did not spend daily life with the persons who have had a stroke. Mobility issues were easy to recognise, and also attracted much sympathy/ empathy because they were immediately noticeable. However, participants felt that the ‘invisible’ sequelae were very difficult to manage at times, yet often people did not understand the hardship. Alix’s husband Erwin had mobility and cognitive issues, including deficits in executive function. She felt that people around her failed to recognise how difficult care provision was, especially as this mostly involved supervision. This made her feel alienated and as though her caregiving work was invisible:

The thing is, these [cognitive deficits] are all the things that other people do not see, and do not experience. What they see, what they focus on, is his mobility. So when he gets out of his wheelchair and walks to the toilet with his stick, it’s like ‘God is in the room, walking on water!’, you know, it’s a miracle that has happened. People say to me, ‘Isn’t it fantastic, he’s doing so well!’ and I just think, ‘you know what? I’d rather he was a paraplegic, and had his brain, than he was who he is now, walking with a stick. If I had the choice, that’s what I would [want]. If he was a paraplegic, he would be at work, he could do his work. His work was just at a computer...”

People's enthusiastic appraisal of the progress that Erwin made rang empty for Alix. Her struggles and hardship went beyond managing Erwin's physical body. Stroke had fractured the Erwin she knew, the spousal relationship they established, the life they built together, and her sense of personhood.⁵⁰ She told me about the time when Erwin, she and their children went away on an overseas trip to see Erwin's mother, who lived abroad and did not see him very often.

His mum said, 'oh, he's doing really well. Look, he could live on his own, he just needs help with a few other things, and well, he is not as intelligent as he was in the past, but he copes really well, blah, blah, blah'. And I just thought, 'so, are you saying that I complain too much? Or, I should be grateful, or what?' And having someone for 5 weeks is a bit different to having them permanently, having to deal with everything, every issue that comes up...

Erwin's safety was a particular concern for Alix. He had an accident on his electronic wheelchair during the trip, although it was not surprising for her. She told me that, due to deficits in his executive function, Erwin sometimes engaged in potentially dangerous wheelchair driving.⁵¹ Fortunately, the accident resulted only in damage to the wheelchair and Erwin was not hurt. She thought that the incident would have been a good case in point to demonstrate to her mother-in-law the severity of his cognitive deficits. She was disappointed, and felt her struggles undervalued yet again, when her mother-in-law dismissed the seriousness of the accident, and normalised Erwin's behaviour:

I have to say, I was actually glad that he crashed into something, wrecked his wheelchair, [so that Erwin's mother] saw that he couldn't solve the problem

⁵⁰ This will be further explored in Chapter 8.

⁵¹ About one year after this interview, she told me that Erwin was in the hospital for a broken leg from another wheelchair accident.

about how to repair the chair. And I said, ‘he shouldn’t have been driving his wheelchair at night time in the dark without anybody, because he can’t see, he doesn’t look, he just goes really fast, because he’s just thinking I wanna go home. And she goes, ‘oh, yeah, but you know, I went and had a look after it happened, and it’s really, really hard to see [the object Erwin crashed into] – it’s very difficult for anybody to see that’. And I’m just thinking, ‘yeah, but he would’ve been going really fast for such a big chunk of steel to crack’. And she was just still even saying things like ‘oh, it could’ve happened to anybody’.

Not only do the assumptions around spouse’s role in care provision reduce the caregiving tasks into just an extension of a normative and pervasive aspect of spousal life, but the invisible nature of many consequences of stroke also make partners feel their work unrecognised and undervalued.

Assumptions about ‘moving on’

‘Time’ also masked individuals who had a stroke and their spouse. After a certain time had passed from the onset of stroke and subsequent discharge from the hospital, they became invisible. In the absence of structured, regular follow-up programs, they ‘disappeared’ from the healthcare system as the out-patient rehabilitation programs offering post-discharge services waned after a certain time.⁵² The economics of the funding system dictated that once individuals reached a certain functional recovery, they were seen to be yielding diminishing returns, and the resources were reallocated

⁵² The National Stroke Foundation has run a telephone follow-up program (stroke survivor and carer needs assessments over the phone at 6, 12 and 20 weeks post-discharge) on a pilot basis in WA and Tasmania, with positive outcomes (National Stroke Foundation, 2012a). The organisation has received a grant from the Queensland government in 2013 to run a similar program (National Stroke Foundation, 2014). To my knowledge, there was no such program implemented in Victoria, although the Victorian government was currently funding ‘pathways from hospital to community support’ programs, with a broad focus on information provision and strengthening referral mechanisms.

to individuals in an earlier stage of recovery. This was despite recognition that the recovery process continued long after discharge home, even after formal rehabilitation services had been completed. The prospect of long-term recovery was considered particularly futile for younger individuals. Emily told me that healthcare professionals were adamant that rehabilitation be continued long after discharge, as persons who had a stroke, especially young individuals, continue to recover, albeit at a slowing rate of progress:

The doctors were saying, because Ryan's body is still young, he was fit, his body copes better at repairing things and learning. But the older folks have to re-learn something, and of course your brain doesn't function as well when you're older [...] They said, they used to use a word 'plateau', which means people get to a certain stage of re-learning and then that's it. And they said, a lot of the doctors now, I think the rehabilitation doctors and the specialists in strokes, don't like that word 'plateau', because it gives the sense of 'that's it, you get to that stage and you'll get no better'. Whereas the thinking of today is that you never really get to that stage because you are always progressing.

This clinical realisation of, and aspiration for, the ongoing nature of stroke recovery and rehabilitation conflicted with the reality of the economics of funding in the healthcare system. The current healthcare system did not have resources to provide ongoing rehabilitation services that could facilitate long-term recovery. This meant that the person who had a stroke and their partners (and perhaps rehabilitation professionals) were stuck in two, seemingly competing logics: that long-term rehabilitation is possible and desirable; and that allocation of funding and resources to long-term rehabilitation is economically unsound. The message was thus: your partner

will get better with ongoing rehabilitation, but it is your job to provide it because no one else can. Elke explained:

At the point [of discharge], rehab is not finished [but] then you are on your own basically. [But] you have to continue. Their argument is [that], ‘there are other patients they have to take on board’. If your progress in recovery is not as big as it was in the beginning, all of a sudden your progress slows down, then it’s time for them to say, ‘oh, this is how much you progressed with our help, you are not progressing as much now, it might stay like this’, but that’s not correct. Because you will always make progress in your stroke recovery. It might slow down, yes, but you have to continue with rehab in a way, because there’s still more to gain in stroke recovery over years. But obviously they can’t keep you on the list for years. But then for some people, it’s hard to continue [rehabilitation] if they don’t get the support elsewhere.

Without a mechanism in place to ensure post-discharge recovery and wellbeing of the persons who had a stroke and their partner, they became forgotten and lost in the system. It was up to partners to manage the needs of their spouse, and to provide ongoing rehabilitation in the ‘natural’ environment of their home. Their capacity to do so, however, depended on various factors, such as their availability of time, their level of knowledge in stroke rehabilitation, and access to financial resources. Emily felt that her nursing background helped her in comprehending rehabilitation techniques and exercises. However, she had to quit paid employment so that she could dedicate her time to Ryan’s recovery and other needs:

The speech therapist told me what I needed to teach him, the physio was showing me what we needed to do, and because I’ve got that bit of a background [in nursing] where I had an idea medically, that I was able to

follow. Because I was willing and able and had the time – because I had to give up my work to spend with him – he progressed. But if you don't have anybody pushing on your behalf, or able to do all of that stuff at home, then you don't get the intensive therapy that you need.

With their partner being relatively young, a hope of further recovery was there. However, the availability of ongoing rehabilitation through the public health system beyond the first few months post discharge was rather limited. During the interview, Alix repeatedly mentioned the absence of appropriate services, especially activity-based support services, for Erwin in the community setting, and she attributed this to the lack of funding for long-term rehabilitation and support programs:

The disconnect between what you receive when you are an inpatient, and then what's out there when you are in the community, is just appalling. Lack of funding — yeah, it's ridiculous. We are lucky in this country in a way, that we have all those other things, I guess. If he was in a different country, he would have just died. He wouldn't have had intensive care, and if you go to intensive care, you are not allowed to die. It doesn't matter how disabled you are going to be, you are not allowed to die. They will do everything to keep you alive. I don't know why, just because they can, right? And they get money to do it. I just think like, well, you guys invested all this money on him, keeping him alive, putting him through [inpatient] rehabilitation — well, there wasn't enough, and it wasn't intensive enough — and now, nothing. It doesn't make sense!

Furthermore, in the community health settings, many rehabilitation therapists were generalists and not necessarily specialised in stroke rehabilitation. There were also general shortages of therapists in certain disciplines. According to Nellie, a

speech pathologist I met during fieldwork, who worked in a disability service organisation, this was due to a combination of related factors around funding and staff recruitment and retention. She told me that there were difficulties recruiting speech pathologists (and more broadly, allied health workers) in the publicly-funded disability sector, because “disability isn’t [thought of as] a particularly ‘sexy’ field.” In this context, staff retention was also an issue, due to the perception that the financial remuneration was not matched adequately to the workload, compared to the other fields or the private sector. This had implications for access to rehabilitation services. As Elke explained:

[Accessing] speech therapy is really difficult for us in the [area of Melbourne where they lived]. It’s understaffed. The speech therapist [at the in-patient rehabilitation hospital] wrote a referral to [a local community rehabilitation centre]. But there’s only a part-time speech pathologist, not full-time [in the area]. And she’s got so many people on the list, so she only gave us 5 or 6 sessions, one hour, once every fortnight. And then she gave us a referral to [a community health service centre] and it’s a speech group [session], once a month, where we are going now... but we’ll run out of [allocated sessions] soon, so we won’t continue forever.

The lack of on-going rehabilitation services did not only affect persons who had a stroke, but also their partner. Waning formal rehabilitation services in the public system meant that the slack was to be taken up by someone else, and this often led to a drain on personal time and finances on part of participants. The culture of the government-endorsed push towards the private medical insurance was still a relatively new phenomenon in Australia and, although almost a half of Australians purchased a private health cover in 2013 (Private Health Insurance Administration Council, 2013),

many relied solely on the public schemes. Furthermore, there were different levels of cover amongst those who had a private health insurance, and the level of protection was largely affected by various contextual factors including the perceived level of health risk exposure at the time of purchase (Chapter 4). This meant that some of the costs beyond the initial acute and semi-acute care and out-patient rehabilitation services immediately post-discharge were not covered by neither public or private schemes.

These expenses could add up, and some activities were very costly. When I visited Elke and Mick's home, Elke brought out a seemingly endless array of rehabilitation equipment (one item of which was priced at \$2,000) and exercise books that she purchased online, many of which were imported from overseas and paid out of pocket.⁵³ The billiard room in their house had been turned into a 'rehab' room, and Elke became a quasi-rehabilitation professional in that section of home (Chapter 6). Time, costs and effort involved in this 'rehab at work' was considerable, however there was little support and compensation for this care work (Dow & McDonald, 2007; Essue et al., 2010). Will had neither knowledge, time, nor specialist equipment to make the most of Nadia's potential for further recovery. He had to rely on services available outside the public health system, and it cost him and Nadia money out of their own pocket.

We've lost a lot of the services now because time has gone on a bit. But stroke is a long-term illness, and it can't be just ignored, even as time passes – like two years after the event and Nadia still has her condition. I mean Nadia's

⁵³ Many specialists and purpose-built equipment needed to be imported. A member of a stroke support group, in her early 30s, resented her old, generic walking frame because she thought it was age-inappropriate. She imported, and paid out of pocket, a "funky" walking frame from Sweden that looked stylish and had a drink holder for her morning latte (café latte). I discuss in Chapter 6 how Nadia resisted wearing a personal alarm system that was designed for elderly people.

stroke was quite a powerful – it was quite a big one. I am sure there will be more recovery as time goes on, being a young person. But a lot of the services have all gone now. And the only thing we can do is we privately fund her to get taken to a gymnasium in [a suburb 15 minutes' drive away on a taxi] where she can do a bit of machine weights. And some Tuesdays she does hydrotherapy. But I am looking into further [services] – Getting a possible physiotherapist to actually do one-on-one training with her and give her electrical impulses and what-have-you. I am sure what's happening is helping but [we have to pay for it ourselves because], all the government services have just totally gone now.

Everyone else moves on

It was not just the public health care system that participants felt had deserted them. Participants spoke of various supports they received from their social networks immediately after and over years since their partner's stroke. They also mentioned however, that their friends and family members assumed that they would naturally be the ones responsible for providing care to their partner. For example, Elke observed that: "I think, once you are home, they think. 'Oh, yeah, they'll be alright'. Then it's sort of back to normal for them". This was partly because people in their social networks operated on the 'medicine as curative' assumption. Anna explained:

People said "well at least he's out of hospital now and he's better," and I was so annoyed by that statement because people assume that when you come out of hospital you're 100% recovered but really you'd only started on the road to recovery, you weren't at the end of it.

It was also difficult for people who did not have the experiential knowledge to understand the extent of on-going difficulties that participants faced. Megan elaborated that it was as if time was flowing differently for her compared to people around her and her husband Simon. People moved on rather quickly and resumed their busy daily lives, but she was somehow stuck in the temporal space left by Simon's stroke.

I remember everyone's very genuine and sympathetic when it first happened, but it's like a death in that everyone turns up to the funeral, but then when you're a widow or a widower three months down the track, you're still dealing with everything. You're dealing with the grief of what's happened and the life that you have then, but people have moved on. And that's fine because they're not living it, but there's no appreciation or sympathy or empathy once you've got to that stage [a few months after her husband Simon's discharge home], so I think that was the hardest point. Life has changed for me, but everyone's moved on.

Both the healthcare system and extended circle of family and friends operated on the same assumption; that is, it was taken for granted that it was the job for the partners of people who had a stroke to take on the sole responsibility for management of the long-term support for their partner. Furthermore, it was assumed that it was done unproblematically. In this framework, participants often became an invisible 'sidekick'. Indeed, spouses lived life like a 'shadow' (Wallengren et al., 2008) and were treated like one. "People don't do it intentionally", Rebecca offered, before continuing:

They think 'how's Ned going? How's this going? How's that?' but they never think 'and how are you going?' They don't ask that question, they just assume

that everything is going wonderful. And that's human nature, they haven't been through it themselves.

If people had actually asked, Rebecca had a lot to tell. She would have spoken about delicate acts of managing her husband Ned's emotional difficulties, despite his physical and functional recovery going seemingly well — albeit still with limited mobility. She would have also mentioned the difficulty of balancing caregiving tasks and her career aspirations. Ned was identified as suffering from depression at the semi-acute hospital, which she understood as “caused by the fact that he's got a lot of brain damage”. Although he initially resisted, he eventually started taking anti-depressants after discharge home. This was upon the recommendation of a doctor at the rehabilitation hospital, who said “[these medication] will give him more energy, sometimes [anti-depressants] work that way”. However, they made him drowsy: “it was horrible. He lost a month of his life and just sat there like a zombie.” Ned's depression was subsequently managed with another anti-depressant that his local GP prescribed, which was “a very mild dose but it's just enough to keep [him on an] even keel [i.e. balanced, with fewer ups and downs]”. Still, Rebecca found out that his depression became out of control if Ned was left on his own at home:

When he first came back and he couldn't do anything... he was still coming to terms that he couldn't do [many things] and that he probably wasn't going to get better. [... When he was alone] he just kind of thought about it too much and got a bit frustrated.

Rebecca went back to her full-time job as a teacher soon after Ned's discharge out of financial necessity, although it was not well perceived by extended family members. Initially, she assumed that the anti-depressants would take care of Ned's depression, but she soon found out that it was not the case:

I went back to work and I got criticised for going back to work, but staying home doesn't pay the bills either. So I went back to work full-time and that didn't work in a lot of ways because Ned wasn't coping that well at home and I didn't know.

Rebecca realised that, in order to keep his depression under control, Ned needed company to keep him busy at home. At the time, she had already been acting in a temporary senior leadership role at the school, and the job as a permanent position was hers for the taking. However, she gave up this career opportunity because accepting it meant she had to leave Ned alone at home:

I probably had a position that I could take up as principal but I didn't because I was a carer as well. I've realised now I can't work full-time because if I work full-time, the wheels start falling off at home and depression starts kicking in with Ned.

Instead, she now worked part-time as an integration aide at school and as a private tutor in a program for children recovering from a serious illness. She also did occasional shifts as a casual relief teacher (emergency teacher), and all of these jobs provided an income source and allowed her to stay involved in teaching (Chapter 7), while ensuring she had time to spend with Ned.

The assumption that persons who had a stroke unproblematically reintegrate back into their everyday lives upon their return home neglects the extent of work conducted by their spouses. The assumption also that spouses 'naturally' knew what to do, how to provide care, and were able to provide this care, masked the fact that 'getting over' a partner's stroke was not easy. Assuming and engaging in a stroke caregiving role were indeed difficult tasks

I have so far argued that carers become invisible. This seems contradictory to what I argued in Chapter 3: namely, an increased awareness about carers in the policy and public discourses. However, this divergence in recognition of ‘carers’ on one hand and invisibility of spouses in my study on the other, I want to argue, is precisely because of the way ‘carers’ are recognised: an economic resource. Stroke and its resultant disabilities are constructed as ‘burden’, and ‘carers’ as a social group are to provide an economically rational solution. This framework does not adequately capture individual and personal experiences of being a spouse of a person who has had a stroke, and they, in turn, become invisible. Furthermore, the cultural assumptions reflected in and reproduced by policy that frame family as a self-contained unit and carers as self-sacrificing saints silence their voices. People did not want to be seen as ‘burden’ by continuously ‘complaining’ about the situation that they were in. I again quote Rebecca here, to illustrate why she might not come out of the ‘shadow’ (Wallengren et al., 2008) when people asked her about Ned.

The two of us [Rebecca and Ned] sat down and said: ‘this is our problem, we’ve got to deal with it. We’re not burdening the world with it, we’ve got to get on with it’... You can’t burden your problems onto everyone else. They just get sick of hearing about it after a while.

Invisibility of lives after stroke

The development of new medication and ‘miraculous’ therapies, including ideas of cure offered by stem cells treatment, attracted media attention (e.g. Baxendale, 2013; Medew 2014; Townsend 2014), and the promise of prevention through public health campaigns captured policy makers’ imagination. However, scant attention was paid to people’s lives after stroke in public, clinical and policy discourses. Public health messages in the media were filled with the idea that a ‘healthy lifestyle’ will

‘eradicate’ stroke. When ‘breakthrough’ in stroke was discussed, it was almost always regarding prevention through anti-hypertensives and acute treatment. This focus on prevention and acute treatment created a vacuum that rendered absent people living with after-effects of stroke, including the individuals who have had a stroke and persons around them. While I was conducting fieldwork, I encountered numerous events that exemplified this.

One night, I attended a fundraising event for cardiovascular diseases including stroke. Among various silent auction items, there were three donation options for people to contribute towards a specific cause, namely: life-saving research (i.e. research into acute medical intervention); early recognition and prevention; and supporting survivors of cardiovascular disease. While the first two options immediately attracted donations as the night began, the last option finally received the first donation when the evening’s proceedings were well into the night. The trend continued and, at the conclusion of the event, it attracted a relatively modest sum of donation compared to the first two options.

Supporting individuals who had already had and are living with the after effects of stroke was not a very obvious idea when people considered a societal response to stroke as a ‘disease’. Furthermore, stroke, seen in the popular imagination as an ‘old person’s disease’, did not attract a high profile as a charitable cause in the community. I met the wife of a person who had a stroke in a community forum about living with stroke. At the time, she was raising funds to develop an information kit for long-term community resources and support for individuals who have had a stroke. She admitted that, despite her professional background in fundraising, she was finding it difficult to raise the money required, because “stroke isn’t a ‘sexy’ cause in the public.”

Another example occurred during one of my visits to a stroke support group. It was an election year, and the group received a visit from a local politician. The politician started his speech by declaring his passion in the field of stroke due to his father's passing from the disease. "He was a heavy smoker and diabetic, and he had a stroke because he didn't listen to the doctor", he claimed in front of his audience, consisting of people who had had a stroke and those who accompanied them to the group. He continued to explain that his party understood the importance of prevention and was trying to put the message across, because "stroke costs a lot of money, the money that could otherwise be better spent on building roads and hospitals, and on getting more teachers." One of the group members – the wife of a person who had had a stroke – whispered to me: "well, he wouldn't be interested in talking to us, then. He's interested in prevention, not people who's already got it!" After his speech, I had an opportunity to have a brief conversation with him. After I explained to him my research project, and as the conversation turned to the healthcare system, he proudly said, "I'm trying to put those people out of job by eliminating stroke!" Presumably, then, he sought to create a world without people who have had a stroke.

The politician was refreshingly frank, honest and passionate, and the large amount of money piled in at the charity fundraising event spoke volumes about the attendees' compassion. What I am interested here is the discursive ordering that enabled actions that I described above on the part of those individuals, and how such discursive effects created a vacuum where individuals who have had a stroke and those who provide care to them were relegated to relative anonymity in political and public health arenas. Patients in many cases were hurried back home and to paid employment without adequate support. Their spouses were expected to be able to manage care provision and to assist their rehabilitation in 'natural environment'.

Naomi reflected on what she now considered unrealistic advice from rehabilitation staff that Iain could go back to work six weeks post-discharge, and the expectation on her to manage the life after discharge.

I don't believe he really coped. So, in lots of ways, I don't really think he should have gone back to work at all. And certainly not unless he'd had a significant amount of rehab and maybe he should have then. I really didn't get it and understand that he probably needed the physical rehab, the intellectual rehab that, you know, wasn't available to us. But, yeah, rehab at home wasn't the answer, because it wasn't rehab really... And you really are very much expected to – you very much have to manage your own health, or whoever you're caring for's health.

When people became invisible, they had to yell out to get noticed. This is, of course, if they had the time, energy and resources to do so — all of which were consumed by care provision. It was not always possible for spouses to speak up, and very few people were able to advocate on their behalf to challenge the status quo. As Alix summed up:

It has been constant advocating, battling! And then you realise, that the only reason why government and the whole system and the bureaucrats, can get away with it is because you just get exhausted. And you just realise, you are fighting a hopeless, useless battle, because you say to the OT, 'that's ridiculous', she goes, 'oh, well, that's the way it is'... I suppose that it's like any of those sectors that aren't sexy, that aren't getting all the money [they need], they just have to battle on with what they've got.

Facing a sense of injustice, Alix decided to be vocal – she wrote a letter to her local representative and relevant ministers to “complained about the system, how all

the costs [fall on to individuals], and the lack of the case manager.” She did get a case manager some days later, but she was also aware of the limitations of ‘individualised’ solutions to systemic contradictions.

The only way you are going to get an attention is to complain, and to complain to as high up as possible. But at the same time thinking, it’s unfair that it’s the squeaky wheel that gets things done, because at the same time I’m thinking, what about all those other people who don’t have the education, English is their second language, or don’t understand how the system works, or how it doesn’t work, and don’t know that they can [write letter to a politician]. So, you know it’s not fair.

Time around their partner’s discharge home, for participants, signalled fundamental changes in their lives, and was marked by uncertainty about the future. They experienced waning support, and gradually buried under the ‘shadow’. The assumptions about naturalness of home care, conducted by spouses were contributing to this. I now turn to *how* care is done at home. The sense of uncertainty continued long after discharge of the person who had a stroke. In Chapter 6, I illustrate how this sense of uncertainty was managed at home, a domain traditionally associated with safety and stability.

Chapter 6

Orchestrating home

Now we are at home. But home does not pre-exist: it was necessary to draw a circle around that uncertain and fragile centre, to organize a limited space. Many, very diverse, components have a part in this, landmarks and marks of all kinds... The forces of chaos are kept outside as much as possible, and the interior space protects the germinal forces of a task to fulfil or a deed to do. This involves an activity of selection, elimination and extraction (Deleuze & Guattari, Félix, 1987, p. 311).

The space of the home has become an important site of health care delivery. Since the 1970s care within community settings, in the name of ‘community care’, has become an explicit focal point in welfare policies (Chapter 3). More recently, it has become common both internationally (Mayo et al., 2000; Pearson et al., 2012) and in Australia (Anderson et al., 2000; Dollard et al., 2004; Dow & McDonald, 2007; Dow et al., 2004a, 2004b; Walters et al., 2010) for most rehabilitation following intensive in-hospital treatment to take place in domestic settings – sometimes provided by formal services but mostly by informal carers.

This trend of early discharge and decreased in-patient time has been based on assumptions that home-based care is cost efficient for the public health care system, and that it is clinically beneficial to function and social and emotional wellbeing (Martin et al., 2005; Williams, 2002). The shift to home care has also been driven by changes in understanding of rehabilitation. While rehabilitation in much of the 20th

century focused on medical intervention within hospital to increase physical capacity, the concept of ‘person-centred’ care, popularised in the last few decades, has promoted a more holistic understanding of rehabilitation. This has facilitated the idea that service users should have greater choice of services and that the role of rehabilitation is to foster the control of individuals over their own lives in their preferred environment (Bonner et al., 2009).

In this climate, home is commonly seen as an ideal and desirable place of rehabilitation and long-term care for people with care needs, such as those with disabilities; this view is often held by people with chronic conditions and their carers (Manderson & Warren, 2013b; Shepperd et al., 1998) and healthcare professionals (Boddice et al., 2010; Statewide Stroke Clinical Network, South Australia, 2012). Given that ongoing care for chronic conditions such as stroke can continue long after discharge, health policies and practices that emphasise person-centred home care rely largely on informal carers for the provision of care. As I discussed in Chapter 3, carers in policy are seen as the cornerstone of this notion of ‘home as a preferred site of care’. Such understanding enables, for example, a Victorian government informal care policy document to state that: “[informal] carers are acknowledged as critical to enabling people with care needs to remain at home” (Victorian Department of Human Services, 2006b, p. 8).

Home in this framework is represented as an *a priori* entity that *naturally* provides continuity and stability. This understanding also takes for granted the responsibility placed on carers to maintain therapeutic qualities within the home environment, and external interventions are provided only insofar as they prepare individuals with disabilities to ‘return’ home. Therefore, rehabilitation services are provided to get patients ‘well enough’ or ‘functional enough’ to live at home, with the

expectation that the rehabilitation process continues ‘naturally’ at home. Furthermore, the nature of rehabilitation itself changes with the shift to the home setting (see, for example, Pollack & Disler, 2002). It is no longer something specialised: as I discussed in Chapter 5, many allied health professionals in community settings are generalists. With this, rehabilitation in community settings focuses more on self-directed rehabilitation and self-management including lifestyle adjustments and at-home rehabilitation activities (Dow, 2004; Essue et al., 2010). It is also assumed by healthcare professionals and the persons receiving care that these activities are supported ‘naturally’ by family members, especially the spouse (Burton, 2000; Dow & McDonald, 2007).

The assumption that care at home somehow results in better rehabilitation and health outcomes compared to other places, most notably institutional settings (Milligan, 2003), derives from the notion that home is more than just a dwelling; it carries cultural meanings of safety, security and nurture. Home is considered a safe, protected place where individuals feel in control and are able to express or experience their sense of self (Milligan, 2009). Home is the site of authenticity. Yet, home is more than a symbolic representation of self, as various embodied and affective performances and practices take place (Foley, 2011). Moreover, the meanings of home are shaped by social, cultural, economic and biographical factors (Williams, 2002). In fact, it is a rather elusive concept due to its multidisciplinary and multidimensional nature (Mallett, 2004).

Home is a setting of healing and recovery, resonating with the idea of ‘therapeutic landscapes’, spaces associated with healing and recovery. These are formed through a “dynamic, constantly evolving process, molded by the interplay, the negotiation between, physical, individual, and social factors” (Gesler 1992, p. 743).

While originally intended to describe landscapes of healing and recovery from illness, it may provide conceptual utility to describe the maintenance of health and wellbeing in a home environment for informal carers (Williams, 2002). However, sites of potential therapeutic meanings or outcomes for one person cannot be assumed to provide the same values for another person. The therapeutic potential of a site is a relational outcome, since an individual setting may or may not be therapeutic – or even detrimental – depending on the person’s relationship with – and within – the particular site (Conradson, 2005). In the context of the home as a potential therapeutic landscape, the physical place of home does not guarantee an affective experience of home. In fact, the home can be a space of struggle and pain for some (Wise, 2000), especially for informal carers who shoulder continuous, round-the-clock caregiving (Williams, 2002), often for many years. It is not the home space per se that provides therapeutic potentials, but it is the sense of ‘being at home’ – with all of the emotive dimensions that accompany that idea – that may be therapeutic.

If it is the sense of ‘being at home’ that provides the therapeutic property, what is it to be at home? And more importantly, what kind of process is involved in this? The work of Hand and Shove (2004) is relevant here. Tracing the historical development of kitchens in the UK, they explore how social, material and practical elements coproduce the experience of place. Rather than viewing the kitchen as a pre-existing container in which individuals act in accordance with cultural norms, they conceptualise the kitchen, and other domestic and ordinary places, as an “‘orchestrating concept’ in which materials, images, and forms of competence ‘hang together’ at different points in time and space” (Hand & Shove, 2004, p. 235). ‘The kitchen’ involves a dynamic process through which the experience of it constantly emerges and re-emerges out of relations amongst materials, meanings, and practices.

That is, choreographies amongst the constitutive elements are continually being made and re-made and, therefore, the experience of place is the dynamic outcome of a resulting configuration in a certain space and time. Therefore, new elements do not simply 'replace' existing elements; they may or may not be appropriated into the existing configurations depending on how they 'fit' with other constitutive elements. Using this approach in thinking about changes in the experience of a space diverts the analytical focus away from each constitutive element (e.g. meanings of the place) in isolation; it allows one to view selective and reproductive processes through which constitutive elements 'fit' with one another in order to maintain the integrity of the place as a coherent entity.

Sudden onset of stroke and the eventual discharge from formal rehabilitation of the person who had stroke often forces spousal carers to reorganise their lives in a short period. In this chapter, I explore how carers' experiences of home change as it becomes reconstructed as an important site for post-stroke recovery and following bodily changes to their partner as a consequence of stroke. I focus not so much on how the home as a site for the provision of care operates; rather I pay attention to how activities and practices produce home as potentially therapeutic, spatialised experiences. Following Wise (2000, p. 300), I understood home as "the creation of a space of comfort [...the] comfort-effect that is home, not the house necessarily". Therefore, home is an outcome of a dynamic and never-ending process, in which its meanings are recursively constituted and reconstituted. While the nature of home is necessarily transformed into a locus of long-term recovery following stroke, this is not an unproblematic, smooth process, nor is it without impacts on spousal carers. As I demonstrate in this chapter, home is not a self-contained healing place as often portrayed by healthcare policy and practice, but rather, it is an outcome of delicate

and dynamic orchestrating efforts by networks of transformed and transforming material, personal, embodied and social relations. Responsibility for creation and maintenance of home, therefore, rests on far-reaching individuals and institutions.

Changes to home

Participants' partners lived with various degrees of medical, psychosocial, and physical sequelae following stroke. Their realisation of such changes to their stroke-affected partner's body was made more concrete around the time of discharge (Chapter 5). Having lived together, often for a long time, their partner had become 'part of the furniture', comprising a crucial component of home as a seemingly stable entity. Changes to the partner's body after stroke, therefore, had pronounced effects on what home became and what it will become in future. These changes, when re-introduced at the time of discharge (Chapter 5), interrupted the perceived 'naturalness' of home as a site of stability and security. Home was assumed to provide refuge from the forces of chaos, but with stroke, it became the centre of chaos: the protection from potential threats or sources of uncertainty was no longer offered by home. Instead, the partner's stroke-affected body prompted reorganisation of the home space in various ways. First, home had to be able to accommodate immediate adaptations necessitated by bodily changes, by modifying the physical home environment, and rearranging and changing the use of and organisation of spaces in domestic settings. Below I present some examples.

Changes to the nature of home spaces

Various technologies of care were integrated into the physical space of home. These included extensive bathroom modifications, widening the doorways and passageways, and installing and/or placing specialist care equipment in different spaces in the home.

These physical modifications, particularly when associated with the purchase of aids and equipment not covered by the public subsidy scheme, were expensive. The Victorian Aids and Equipment Program (A&EP) provided subsidised aids, equipment, home, and vehicle modifications (see Appendix 3). However, due to its various limitations – the most significant of which was funding constraints and a complicated application process – it was unsurprising that participants mentioned their struggles to fund these care technologies. Affording them was particularly difficult with reduced household incomes, when the partner who had a stroke no longer working. As Alix explained:

Everything just costs. It's like your wedding [where] everything, like a bunch of flowers, are now going to cost you five times more! You say 'disability' and it's the same thing. Everything is just ridiculously expensive. [You] get a lifetime grant of \$4000 to modify your home. It costs you \$1500 to widen the doorway. Now, to renovate the whole bathroom, you are looking at \$10,000. Then if you move, well, bad luck. You can't do it again [because it is a once-off grant] (Alix).

As I discuss below, Alix and Rebecca had to move house following their partners' stroke. The additional cost of home modification on top of the costs involved in moving house was significant. For Naomi, Iain's stroke recurrence and subsequent deterioration over years meant that the maximum funding available through the subsidy scheme was nowhere near enough to cover the costs required. Furthermore, the application process was slow and complicated:

Last year we put in a bathroom downstairs for him [because he couldn't come up and down the stairs]. [We] had to move the shower, move the bathroom. Apparently the government will give you some money towards alterations, but

you have to have it approved before it happens. And we got an architect, who did a design. But [because] Iain was coming home [from the hospital], I couldn't wait [for the approval process] for \$4,000 worth of funding. I had to actually make the alteration [out of her own pocket] so Iain could live at home... I spent probably \$40,000 altering the house, and buying additional equipment, because every physiotherapist wants something different... I was [also] paying for all his drugs. Although I earn a reasonable income, I was still supporting our son at uni and it was on one income.

Moreover, the A&EP did not subsidised over-the-counter aids and equipment such as shoes (people often purchased Velcro shoes to eliminate the process of tying shoelaces) and braces.

For some participants, the uncertainty around the health of the person who had stroke was another complication involved in installing care technologies in the house (and paying for them). A decision was made a few weeks prior to the interview that Naomi's husband Iain was to move into a high level residential care facility (i.e. a nursing home), after discharge from the hospital following his most recent stroke (Chapter 8). Uncertainty around his health (with multiple strokes in the last ten years) had financial implications and caused difficulty planning for future. Iain was still relatively young – in his mid-50s – and he might potentially live for another few decades, which would require further house modifications and the installation of other care technologies as his condition deteriorated with ageing and potential further stroke recurrence. However, given his already compromised health conditions, he might live only for a short while, and this would mean that, despite the high cost, all of the new house modifications were only going to be used for that short period of time. Expenses on often expensive care technologies only made sense as a long-term

investment if there was some degree of certainty about future trajectory. However, without having any indication of future timelines, spending on care technologies became more like gambling, especially when the costs needed to be paid out of the pocket. Naomi had to weigh up between the potential future financial costs of further home modification, and placing Iain in the residential care facility.

To actually fund what would be needed to keep Iain at home [was difficult due to uncertainty around Iain's health]. If I knew he was only going to live for another three months, I would have found a way to bring him home [to spend the last 3 months together], simply because I thought it would have been nice to do that and I would have taken some extended leave [to spend as much time with him]. But Iain could live for another five years, another ten years, [or] he could live another two weeks. We don't know, there isn't any predictability, so that makes it challenging, because he's [relatively] younger. And having to place him in an aged care facility does cause me some grief – I struggle with it a bit – but, you know, I just can't see I've got any alternatives.

Iain's physical condition had become so unpredictable (he had also broken his hip in the last couple of years) that the actual and potential benefits of care technologies were outweighed by the financial costs of acquiring them. With only Naomi's income, their finances were not a bottomless well; it was not possible to pay for modifications that could potentially become redundant in a short period of time, should Iain not live for much longer or further stroke create the need for even more modifications. Iain's physical body could no longer be accommodated as a constituent element of home, in the context of material limitations. A change to a constituting element of home did not necessarily bring about a wholesale change to the rest of home, for such a change needs to be incorporated in a way that allows for it to blend

in with the rest of constituting elements. In fact, home making as orchestrating efforts are marked by an “uneven mosaic of development, fracture, and continuity” (Hand & Shove, 2004, p. 249). In Naomi’s case, Iain’s changing body was unable to be incorporated, as instalment of care technologies could not keep pace with his changes in capability and need. The care technologies were in turn dependent on their financial situation, which was influenced by the lack of government funding and loss of an economically productive body that was part of home before stroke.

Changes to practices at home

In addition to changes in the nature of home, participants discussed the changes to the use of domestic spaces. Elke described that a section of the house that was previously used for entertainment was now being used for rehabilitation exercises. She had purchased on the Internet a range of rehabilitation equipment for Mick, which were kept and used in the room:

That [room] used be a billiard room. [Now it’s a] rehab room. [When] it’s really hot and you can’t go for a walk, or if I wanted him to be more active – and I don’t want him to sit a lot, or on the couch and watch TV. He has to do other stuff in between. Then he will walk around the billiard table, just to keep moving.

Similarly, Abi provided an account of how she used the passageway to get her husband Cain to do exercise:

I make him walk in the house... So, I would hide, and he’d come looking for me. When he comes this side I’ll go the other side. He would go around many times, and I knew he had enough exercise. And I will come out ‘I’m here!’ Because he doesn’t like to move [and] likes to sit.

The passageway at Abi and Cain's house connected rooms in a circular shape, which allowed for 'around' rather than 'up-and-down' movements. This physical arrangement enabled the hide-and-seek activity described by Abi.

In both cases, existing domestic spaces were repurposed for rehabilitation activities to compensate for the lack of community rehabilitation services. However, these activities did not signal a simple replacement of one identity with another (i.e. from that of wife to that of physiotherapist):

Things obviously change all of sudden, and you have less spare time for you. That's what you do, when you are married. That's your job, basically, to look after your partner if something happens. And if things change, things change. You deal with it then. It might be different, or harder, but that's the way it is. That's what you've signed up for.

Similarly, Abi described her sense of duty towards their children as motivating her care towards Cain. Cain was an important constituting element at home, and maintaining this for children was important to her.

I'm looking after my husband because of my children, because I don't want them to go and see him in a bad condition in the nursing home, [in a] miserable [condition], because that will affect how they feel. And I don't want them to worry.

The care activities for Elke and Abi appeared to be part of their performativity (Butler, 1990) as wife and mother. However, these performances needed to integrate with the spatial, practical and material configurations of home – made in the name of 'home care' – and to be situated in the set of relations amongst constitutive elements of home. This was not done unproblematically, as I discuss in Chapter 8. In the context of informal care at home for people with dementia, Askham et al. (2007)

found that, while aspects of institutionalisation of home were evident, many attempts were made by the carers to maintain a balance between these care activities, and their intimate relationships and home-life.

Dealing with risks

As I discuss above, various changes were made to home to accommodate immediate needs of partners' stroke affected bodies. In the following section, I discuss another way in which home is re-organised: potential consequences of bodily changes, such as risks of accidents, demanded reconfigurations of home. That is, the stroke-affected body caused various elements of uncertainty that could threaten home. In the face of such uncertainty, home had to be transformed so that the forces of chaos were fended off. This involved a range of orchestrating efforts. Below I present two case studies – of Will and Neil.

Will's wife Nadia had a stroke that resulted in hemiplegia and aphasia. Nadia also occasionally had had seizures since the stroke, which prevented her from driving a car.⁵⁴ Her restricted mobility and lack of driver's license meant that she was confined in the home space most of the time, and she relied on Will to take her out of the house. Her movements within the house also required either direct or indirect supervision.⁵⁵ Running a business with a business partner, Will worked irregular hours, and his service could sometimes be required by his clients at short notice on a 24/7 basis. He tried to arrange his work time to accommodate Nadia's and their

⁵⁴ Will told me that, in Victoria, a person has to be proven seizure-free for a period of 6 months after a stroke, amongst other physical, cognitive and sensory tests, in order to have his/her car license reinstated. They were hoping to apply for her license reinstatement some time in the future.

⁵⁵ Direct supervision involved someone being in close proximity, while indirect supervision required someone being physically present within the house and immediately available to provide direct supervision, or remotely supervising and available to provide or coordinate direct supervision.

daughter Sarah's routines and needs, but he was also mindful of not disappointing his clients – and potentially losing them – by being unavailable upon their request. This had significant implications for making home, as Nadia's hemiplegia and seizures could cause falls at any time, and the unpredictable nature of such events created uncertainty. This meant that, while Will often had to be away from home, concerns about Nadia's safety were always at the back of his mind.

The biggest danger is that if Nadia has a fall and I am not [at home], she can't get up because she is not quite strong enough on her right leg to pick herself up if she has a fall. [On a previous occasion when she had a fall] luckily [a home care worker for Sarah — see below] was here. And she called me and I called the ambulance. But if [Nadia were alone in the house] — That's the biggest danger for any stroke survivor who is quite weak or has a deficit on one side. It was just a simple fall in the bathroom where she was just reaching down in the cupboards to get some[thing] – and she just lost her balance and couldn't get up. She needs somebody to sort of be there. Because it did actually happen once before [when no one was around] where she did actually have a fall in the bedroom and banged her face. And she managed to crawl her way to [the living room]. And although she had a banged up side of her face, [the more concerning thing was that] she had ribs bruised.

Home as a site of security and predictability was transgressed by Nadia's fall, and the fear about potential future accidents. Those previous occurrences of fall, for Will, made the risk of future falls very real in the sense that the perceived risk was more than a mere potentiality; instead, a fall had become something that could actualise at any time, and was no longer something on which to take a chance. Will needed a safety net. He mentioned several re-stabilising practices and activities that

he used to alleviate the threat and, therefore, restore the integrity of home. The first was the home care worker, mentioned above. The care worker was provided by a private in-home childcare service to care for Sarah, as part of Nadia's government-funded disability support package.

We are lucky at the moment that we have a nanny service — one of [few] actual services that gets provided. They send a qualified nanny to come round from 8am to 6pm. It started from Monday [through] Thursday because of Nadia's condition, and her ability to care for Sarah on her own was very limited for her... [But more importantly, the risk of Nadia having a fall is] why we normally have to have the service, [to] keep going.

While the service provided care to Sarah rather than to Nadia, the childcare worker nonetheless provided direct or indirect supervision for Nadia. The in-home childcare worker thus provided more than childcare service; however conscious or intentional it might have been for the childcare worker, the care worker provided a vital contribution in maintaining home. The fact that someone responsible was there could fill the gap left by the potential threat of falls. The childcare worker in this way became an important component of home – for the time being. Unfortunately for Will and Nadia, funding for the in-home childcare service was not provided on a long-term basis. Funding for Nadia's own care worker was also hard to come by:

We've lost a lot of the [community care] services now because the time has gone on a bit... [The in-home childcare service provider] reduced their services a bit... It was [initially] four days a week. They reduced it to three [...then] to two days a week... Because normally [the funding] is only for about three or six months. Apparently she is on the waiting list for a package

where they provide a [care worker] service for her [but nothing has happened yet].

Home as a stable, safe territory was fragile. It no longer was a fort that fended off chaos and danger; it required constant orchestrating efforts. With the reduced amount of in-home childcare service, and uncertainty around the provision of an assistant care worker for Nadia through a disability care package (see Appendix 3 for details of various government funded support packages), Will had to devise another strategy to rectify the situation.

We have talked about getting a personal alarm fitted to her wrist. She doesn't want one around her neck. She can press a button, which makes various phone calls to [notify designated individuals like Will himself]. I [would then] call an ambulance, or if I was not too far away, I could go [home]. We haven't enacted on that, but I think that should be something that we'll be looking at.

As far as care technology went, this might have been a good idea. The personal alarm would have brought Will some peace of mind while he was away from home. However it was not to be. Several weeks later, in another interview, Will told me that Nadia refused to wear a personal alarm because it reminded her of 'old' people. To Nadia, it did not belong at her home; it would have invaded her home territory:

She refuses to wear it. If she's home by herself, she won't wear the personal alarm around her neck. She feels that that's for old people.

A personal alarm could not blend together with other constituting elements of home, because the affective dimensions of home needed to be salient not only for Will, but also for Nadia. For her, a personal alarm did not belong at home. Will had to resort to

another strategy. He installed a home surveillance system in order to monitor her while he was away.

I have had to install video surveillance cameras, which [show video streaming] on here [he points to his mobile phone]. So, all I do is just glance on it, and see if she's alright. If she's on the floor, I can call the ambulance.

The surveillance cameras and the mobile phone app therefore brought home a sense of security – not against external invaders, but against potential de-stabilisation from within home. In addition, these devices made home proximate, regardless of how far away he was. Without them, Will would have been constantly worrying about Nadia while he was away from home, which occurred frequently due to the nature of his work. Without them, home might potentially become a prison, locking up Nadia in cases of fall. Once the surveillance system had become a part of home, it had to be defended from de-stabilising forces, including stern criticism from relatives who were concerned about the presence of the surveillance system.

Nadia's godparents [who visit her every Friday] are dead against it, saying it's an invasion of privacy. But, I said, 'well, you know, I didn't have choice, really.'

Having finally found a strategy to ensure some degree of security at home, Will was not about to let it go despite the outrage expressed by Nadia's relatives. Will's accounts highlighted the constant effort involved in selecting and evaluating things that made the home space 'home'.

The case of Neil, below, presents how home was maintained when a component of it was both a stabilising and destabilising force. While Neil's wife Eva was in hospital, the doctors found a hole in her heart – a previously undetected congenital heart defect called patent foramen ovale (PFO) – which caused formations

of blood clots that had resulted in the stroke. Because of the large risks involved in a major heart operation, they decided not to operate on the heart defect. This meant that Eva had to take an anticoagulant (Warfarin) for the rest of her life to prevent blood clots forming around the opening in the heart, potentially nullifying PFO as a risk factor for recurrent stroke.

There is no guarantee about if she would have another [stroke]. It could happen any time, that's what [the doctor] said. But [also] that [with] Warfarin the risk of getting clots in her blood is a lot less. [It is] almost guaranteed that she'd have [another] stroke if she went off Warfarin... [She is on] a very high dosage. So her blood is like water – It's a very thin consistency.

Although Warfarin, an anticoagulant, could lead to profuse bleeding with cuts, the use of it was unavoidable. As was the case with Will and his concern about the risk of Nadia's fall, Eva's risk of another stroke appeared so real that it was menacing. Against the threat of recurrent stroke, Warfarin was literally a lifesaver. It was something that kept Eva alive – a vital component of home – and therefore the medication had become an important component of home. However, the effectiveness of Warfarin – therefore its competency as a component of home – required constant management. This involved a sort of teamwork effort by Eva and her doctors amongst other things:

She gets blood tests once a fortnight, which is quite regular. And they actually ring her [if there is any anomaly in her blood]. It can be 9 o'clock at night, they can ring and say, 'Change [the dosage] to this.' She has little bottles that have different [dosage sizes of Warfarin]. She can choose whether it's 7[mg], 7.5[mg] or 6[mg] – never been down to 6, but around 7½. She's been up a size

[to] 8.5, I think. The blood test she has tells [the doctor] what level she has to be on to get the right [blood] consistency.

Receiving a phone call late at night – something that may commonly be described as a disruption to the home experience – was an important part of maintaining Eva’s health and, therefore, home. In this sense, all the things involved in this practice, such as the regular blood test, consultations with and regular advice from medical professionals, and Eva’s little bottles with different doses of Warfarin, contributed to maintaining home. Therefore, home was not just an assemblage of affective spaces and built environment, but also constituted of practices. This was akin to the example I have already discussed above of relation to the in-home childcare service used by Will and Nadia.

For both Will and Neil, home was not a self-contained container that was a ‘given’; rather, it required constant activities for its emergence and maintenance. Those efforts were carried out by a network of obvious (e.g. the partner, care technologies in the home space) and less obvious (e.g. childcare worker, smartphone app, medical professional who would call late at night) individuals and materials. Some might be resident, or at least physically located for salient periods of time (such as the childcare worker), inside the home space; others were geographically, physically, and notionally separate to and distanced from the home space. In doing so, these orchestrating practices blurred the boundary between what is ‘internal’ and ‘external’ to home.

So, Warfarin and the ‘thin’ blood it produces staved off recurrent stroke, preventing de-stabilisation of home. However, while it was productive of home, thin blood in itself also acted as a de-stabilising force. As with any medication, Warfarin has side effects. During my fieldwork, discussions around the side effects of Warfarin

were common at various stroke support groups, perhaps reflecting how commonly it was prescribed. They included possible interactions with some ordinary foods, such as green leafy vegetables, grapefruit and menthol, and excessive bleeding in cases of injury. Eva was on a relatively high dosage, and excessive bleeding was the primary concern for Neil. Because of poor coagulation, once Eva started bleeding, normal blood clotting to the wound that would prevent further blood flow did not occur. This was problematic, as even seemingly benign and minor bleeding, such as a nosebleed or superficial cuts to the skin, could now become life threatening.

If she is in a bad accident, she could bleed out. If she cuts herself she could bleed out. [If she] has a bloody nose she could bleed out, if she got a bad one... So that's a bit of a worry... It is definitely a risk factor for if she is in an accident or has a bloody nose, or cuts herself. [But] it doesn't change. She is on Warfarin, that's it. It doesn't go away... I am protective [of Eva] only in terms of having an accident or, using a sharp knife, cutting, preparing a meal. So I tend to do [cooking]. I would say I do more cooking than I used to do, preparing meals. I enjoy it anyway.

Since bleeding could be caused by many things, the risk was omnipresent. Everyday objects and practices, such as a kitchen knife and blowing the nose, or brushing against a sharp branch in the garden, were now potential threats. However, because of Warfarin's competence as a stabilising force against the threat of recurrent stroke, it could not be eliminated. Neil and Eva did not have a choice; since the threat of recurrent stroke was much more imposing and immediate than that of the risk of excessive bleeding, they had to live with the effects of Warfarin. Because they could not eliminate Warfarin as a potential de-stabilising component, they had to carefully select other components of home, and the arrangement of them. Eva was not to go

near sharp objects, and Neil took over tasks that were perceived as obviously risky for Eva, such as cooking. Even though this may appear rather exaggerated, a seemingly innocuous practice as cooking was considered risky because of the perceived enormity of the negative consequences. Fortunately, Neil felt comfortable (and perhaps competent at) preparing meals, and this practice could easily fit in as a component of home.

Changes to emotional and affective practices

Another de-stabilising change was emotional changes. Perceived emotional changes in the person who had a stroke created instability at home because they threatened predictability in various everyday practices that were previously taken-for-granted. These included holding conversations of a casual or more serious nature that family members commonly have at home, or having music on while doing household chores – little things, as well as more pronounced things, that made up ‘home’. I provide below some examples of these.

Naomi’s husband Iain suffered his second stroke within a year of the first, relatively minor stroke when he was 48 — this was the second of a total of four strokes as well as multiple TIAs that he had in the last eight years. Naomi reflected that the second stroke was the most significant of all in terms of the degree of deterioration to Iain’s communication abilities, and in his behavioural and mood changes. Naomi explained the situation that led her husband Iain to start taking antidepressants 10 months after the second stroke:

Iain was being very difficult with Tom [their teenage son]. You know, when they get to that age and they start to answer back? Just doing normal stuff [as a teenager]. And Iain would go to an extreme quickly. None of that negotiation skills that you have with kids – it all seemed to have gone and he would get

angry quickly, which was not like he'd been... He was [also] getting angry with me about things that didn't go his way, sort of unreasonably so. He wasn't easy to live with, in comparison to what he'd been like and my expectations of a partner –and I knew that I couldn't have the same expectations – but I knew that being pleasant and living in a home that had a pleasant environment [like it used to be prior to stroke] was much better than living in a home that was angry [following stroke]. He would lose his cool and go [starts screaming in angry voice] 'Ahhh!', like this, very quickly, which was just really hard to deal with.

The perceived emotional changes were seen as disrupting previously taken-for-granted practices. Iain's mood swings tainted his expressions of subjectivities, that is, performances as a father, husband and high school teacher (Naomi described Iain prior to stroke as an excellent teacher who was good with adolescents). Even though Naomi rationalised that these changes were inevitable, it nonetheless upset her. She tried to manage Iain's mood swings through a psychiatric intervention:

I was actually at my wits' end. I basically said to Iain, 'You've either got to go and have counselling or we've got to find some anti-depressants, I can't cope anymore. Now he's on anti-depressants.'

Iain's emotional changes, which brought a sense of unpredictability, was managed by anti-depressant, which made his behaviours, to Naomi and Tom, closer to what they had been accustomed. However, following subsequent stroke recurrence, the changes became too great to be managed, and this had a profound impact on the family life (Chapter 8).

Some of the consequences of stroke were unable to be accommodated easily without a certain degree of sacrifice by the partner. When such a compromise was

made, some of the markers of home had to be given up. Since he had a stroke, Ryan, Emily's husband, could not stand being in a noisy environment; in addition to exacerbating his fatigue, noise severely restricted his capacity to communicate, which was already limited by his aphasia. This meant that they could not have music at home when Ryan was around:

One thing that bugs me is I love my music, but I can't have music on in the background, because the background noise frustrates him, and then it distracts him and he can't think about what he wants to say. So I have to have that off. But I love music in the background whatever I'm doing. So I've had to forego some things [to accommodate]. When I'm out in the craft room and he's not there, I turn my music up full bore.

Home was not stable, nor was it confined in a certain space-time. Home changed and retracted. Emily's home in this instance can be seen as shrinking to the craft room, because music to her was an important component of what it was to be at home. When Ryan was present, music had to go away as a component of home. It was then replaced by other components – most notably, Ryan – to be re-orchestrated as home. What Emily's account also demonstrated was that home was not a singular entity. Rather, it was fluid and multiple, and constantly changing.

Moving home

Home could move; that is, the geographical and physical space that home occupied could change entirely through moving house. At the time that Rebecca's husband, Ned's, had a stroke, they lived near a rural town on a farm, with two teenage children. It was two hours' drive from the closest rehabilitation facilities and other medical services in Hakea, a regional centre. Rebecca returning to work three months post-

stroke, combined with Ned's mobility restrictions, meant that running the farm became overwhelming and burdensome. This was despite their children helping on the farm on weekends and school holidays – an act that Rebecca described as placing “huge pressure on our children.” Finally, they decided to sell the farm and to move to the fringe of Hakea to have better access to the medical facilities, even though this meant leaving their “wonderfully supportive community” behind. What they got instead was a house that incorporated various disability-friendly features designed with help from an occupational therapist. Living in an accessible house was important for Ned's everyday living, but also for having other mobility-restricted people around the house, as they became active members of a stroke support group in Hakea:

We were running a grain farm. [After stroke] he realised he couldn't handle the farm so he had to make the decision to sell it – it was his business, not mine... So we built this house [near Hakea], which is built sort of like a nursing home, so it's got wider passages. We had an occupational therapist help us design it so it's got wheelchair access, wider [doorways] and the passages are wider too so he can fit down them [if he was on a wheel chair]. So if we have people in wheelchairs come here, they can get around with ease.

And with these [smooth, tiled] floors, it's much easier [for Ned] to walk, is that right?

Yeah, you sort of think of those things when you're building a house, whereas you don't look at your house that way until something happens. Our old house had... very narrow passages, narrow showers and a very hard toilet to get into.

What Rebecca's account here illustrates is that the decision to move house was not motivated by a single factor. Instead, it was a mixture of multiple things: the farm, previously their source of livelihood, had now become a burden; the house was

not disability-friendly, although lack of accessibility was invisible prior to stroke; their concerns about farming work overburdened their children; and there was a long distance to medical, rehabilitation and other facilities. These things acted together as de-stabilising forces and turned home into a site of struggle. Rebecca recalled that: “Huge pressure [was] put on [our] family”, due to the large workload at the farm, and frequent long drives to rehabilitation facilities, while attempting to reduce the impact on other domains of life, such as work for Rebecca, and school and sporting activities for the teenage children.

Establishing home at the farm “in a remote isolated rural area” became too difficult. So, they had to relocate in search of a better life, which brought about “a complete change of lifestyle” as Rebecca described it. This move wasn’t as straight forward as it may sound. Even after making the decision to sell the farm, whether their decision and plans were actualised relied on many things. First, and obviously, the sale of the farm required a buyer, who was willing to take the property at the asking price. Initially, this wasn’t an easy process. There were several obstacles to overcome, such as traditions in rural communities and offers made well below the asking price and conditions.

[Once we started looking for a buyer in local areas] suddenly we had neighbours wanting to buy it. But they didn’t want to pay a lot of money for it... You’re supposed to give your neighbours a deal, and I said, “we’re not a charity fund either, we’ve got to live”... One [local] guy really, really wanted it and he kept putting up his [offer] price, but he didn’t want to buy the whole lot [... even though] we put that condition down right from the start that we were selling it as a whole because we didn’t want to be left with a block of land up there – that would be just a pain in the neck.

In the small rural community, there was an expectation that the ownership of the farm was to remain within the community, rather than being sold off to an ‘outsider’. The local people often reminded Rebecca of this ‘unwritten code’:

We weren’t the most popular people in the world because when it went on the market I can remember [people saying to us] “oh, you’re selling out” [...] So there was a little bit of sniping about that [...] It’s just the way country towns work.

Fortunately, the property sale was successful owing to two players: a rural real estate agent/agribusiness broker; and the buyer, who offered Rebecca, Ned and their children the option to remain on the property while they built their new house in the new location. The buyer also provided another important factor in making the move successful; a smooth transition between those two spaces – between the old house to the new house – without having to temporarily move in to another house, which might not be as accommodating of Ned’s needs:

We [initially] had it privately on the market and then we put it through the agent. The [agent] who sold it was very good. He knew the situation [that we were in and that] we didn’t want a lot of stress so he was great [to us]. We managed to get a buyer really quickly actually... And wonderful people who bought it and let us live. So it took a lot of the stress out of that.

However, perhaps more importantly, they did not have to look for a new property to buy, as Rebecca’s parents were willing to give them a patch of their land. This eliminated a lot of stress involved in looking for a new property. Moving to her parents’ property also meant that she could be physically closer to them, particularly her ailing father. But perhaps as importantly, moving to her parents’ property (which was also a farm) provided a sense of continuity. Being ‘country folks’, it was

important for Rebecca and Ned to live in a farming environment, though now without the responsibility and burden of running it.⁵⁶

My parents owned this farm [on the fringe of Hakea] and I'm now an only child so we came back here and dad gave us some land to build [a new house] on, so we had this option to come down [here] – which made it better [than the only option being looking for a new place in the property market]. My parents – my father in particular – was getting old then, so we wanted to come back. It was good to come back for him. We only lived here for five months before he died, so my mother is there [on the other side of the hill on the property] and she runs her cattle, but she needs a backup. She rings up and says 'I've got to get the vet out' and it's really good for Ned because it gives him something to do so he feels important. I don't think he'd survive on a suburban block – and I wouldn't because I like the open spaces.

The decision to sell the farm, and to move to Rebecca's parents' property, emerged out of many things: the physical stroke-affected body of Ned required the material house configurations such as the width of the passage and doorways and the flooring. The move arose out of various social relations including those with parents, children, community, occupational therapist, and those in the property market. It was made possible by expressions of subjectivities that arise out of such relations, which manifested in various practices, strategies, and competence. In other words, moving home involves orchestrating (and unfolding) efforts co-produced by material arrangements, experiences, meanings, and practices, that create a space of comfort and security in a new geographical location.

⁵⁶ This highlights a network of interdependence. I will come back to this notion in Chapter 9.

I now turn my attention to Alix, whose family also moved house after Erwin had a stroke. Alix, Erwin and their children moved house after Erwin's stroke. Living in outer suburban Melbourne, it was not so much that access to medical facilities was one of the primary reasons for their move – in fact, this probably did not feature high on their list, as they moved within their local community. Instead, the financial and practical burdens of living in the house drove their move:

After he had his stroke, it was quite apparent that he was not going to work again. We still had the mortgage... It was on an acre and quarter... the block was steep, and it was a lot [of work to maintain]. It would take me 3 days to cut the grass because there was so much of it. All these things started happening. I've got whatever skills you need, I can do all those things. [But] I don't have the time, I don't have the energy, but now I also don't have the money to pay somebody else to come in and do it for me.

With only one income, the financial pressure from the mortgage became a real issue for Alix. She decided to sell the house, but struggled to find a new house in the same locale, which she sought in order to maintain a sense of continuity and support. Adding further pressure, however, was the temptation of moving to a new housing estate in another suburb where prices were lower.

I decided to sell first and then see if we can find something. But we were struggling to find something, so it was like 'ok, maybe we'll go out to a different area, but then we will lose all our community support, — but if we move out, we could build a purpose built house, and it will be easier, then we will have money left over – but we will be lonely.

Alix wanted several components in her new home configuration: purpose-built, disability-friendly house; smaller mortgage; and community support amongst other

things. However, the lack of funds meant that it was difficult to find a place that met all of her requirements. Meanwhile, Alix, Erwin, and their three children stayed in a small, one bedroom bungalow at her friend's place. Then, they finally found a place that met their needs.

Just after we moved in there we found a house, on a fantastic street, really close to all the sports fields and shops and everything, public transport. So, we have all the kids still in the same community, we all know everybody in the community, we are in a street that's got a footpath, we're near to the bus to the city, we are right near the shops, so everyone can be more independent, because that was the thing – not just get Erwin independent, but also make sure that kids can do things independently, so that I didn't have everybody needing *ME* [her emphasis] to take them everywhere. Instead of having an enormous mortgage, it's just a little one, which is manageable. And we have a flatter and a smaller house.

As with Rebecca, the move relied on a number of elements, particularly the varied types of support that Alix received from a much wider social network – her neighbours, friends, and local charity groups. A friend provided accommodation while Alix looked for a new house. Then, a large number of people helped Alix renovate the old house, so that it could be sold at a higher price:

It's an amazing community out there. Last year when we were [renovating] this house, a neighbour said 'I'll project manage it for you, and we can get this done more cheaply if we organise some working bees.' So we organised three working bees, where we had about 40 friends who came and worked... Everyone painted the house, inside, the walls got painted twice. It was over two days. We had another one where people have demolished [part of the

house], prepared things for the floors and did whatever jobs that they had to do. And while that was going on, we had people rendering the house – kids, adults, they were all throwing concrete on the outside of the house with bricks and stuff like that. So it was really quite a community effort, we got the roof that was donated by the Lions Club, the Rotary Club gave us money for something else. The Blue Light Disco [police-run not-for-profit organisation] gave us the money. So, a lot of good will.

The extensive network of people who helped Alix renovate the house contributed to her ability to financially afford the new house, which became an important component of home. In this sense, they all contributed to creation of home, as well as maintenance of it (as they still live in the same community). The community effort to renovate the house, then, enabled the living arrangement that was close to amenities such as shops and public transport, and children's sports activities.

Home expands and retracts

Home is not confined to a geographical location; one can be away from the place of usual residence, yet some places feel like home. 'Home' extends beyond the physical place of day-to-day living in the face of potential instability. Neil mentioned that their beach house provided refuge, when I asked him about things and strategies that were helpful to him when things got stressful:

We have a holiday house at Summerside, so we were fortunate enough to be able to go down there, sit in the sun, go for walks, away from everything. And that was important... you wouldn't want people coming around all the time asking questions, "Are you all right?" "Are you all right?" "Are you all right?" You become not all right because people are asking those questions... So we

were lucky we had somewhere to retract to or withdraw to, if that's the right word. And that helped.

In this instance, the therapeutic capacity of 'home' was threatened by well-meaning, but overwhelmingly incessant well wishes from family and friends. In the face of this de-stabilisation, Neil and Eva physically relocated temporarily to a holiday house. The therapeutic capacity of home was reinvigorated when the holiday house was entered into and therefore re-stabilised home. It was not that simple, however. The fact that they own a holiday house, for example, owes to the fact that they came from a relatively privileged socio-economic position, as Neil acknowledged.

Participants from rural regions, whose partners were transferred to one of the major hospitals in Melbourne with a stroke unit, needed to stay away from home in order to be close to their partner. However, this led to them experiencing a sense of isolation, which arose not only from disconnection from their social network but also from unfamiliar surroundings. Emily explained:

It's very difficult when you're in a strange area, with everything new, you're not knowing where the shops are, where the bank is, where [mobile telephone] shops are, and just all those silly things that become stressful, and having to find your way around Melbourne... because you don't feel part of anything when you're away. And of course you're in a total stressful situation so it's just difficult.

Being away from home was more than simply not occupying the place of usual residence. Various constituting elements such as local shops and friends and family members provide a sense of continuity and security. In absence of these, the sense of uncertainty was exacerbated. When displaced from familiar environment, one's home may cease to exist. However, this sense of de-stabilisation could also be

followed by a process that provided a sense of reassurance, if a new component was available to come in. For Irene, for example, it was a place nearby to sit down for a coffee with Lucas:

I'd come [to the hospital] and we'd go down into the cafe, because they've got quite a vibrant cafe and food court. We like having our coffee, so I used to take him down there, and we have coffee... That was really good for him, just to get out, because it's like being in a shopping centre or something, and it doesn't feel like a hospital, and it's really vibrant, with people around, so that was really good – it felt like you were out of the hospital environment, just for a few minutes. That was really good... Things like that make a big difference.

A café and vibrant food court brought a sense of normalcy in the sterile, hospital environment, even if it was for a short moment. Another participant expressed a similar notion of creating homely environment away from home. Emily was able to stay at the hospital, which offered a limited number of rooms for people from rural regions.

I was upstairs, and when Ryan was allowed out of the ward, I was able to take him up there, which was out of the ward environment, up to my TV room up there, or I was able to have tea with him up there in the kitchen where I was staying. It was more a homely atmosphere... it was absolutely beautiful. That made me feel like I was out of the hospital environment and it was just a place to relax, and it wasn't far from him if he wanted me or something, and I could come down and see him. If he was tired I could go up there and I could have a break, I could do some of my knitting or I could watch TV or I could read a book, and then I could go back down an hour later and see if he was awake.

Home, in this case, provided refuge from the hospital environment – from the forces of medical emergency, and the surreal experience of hospital stay. The provision of space that could potentially offer a sense of ‘being at home’, even for a short time, was important for participants from rural areas.⁵⁷

Participants’ accounts illustrated that home was not a self-contained, fixed entity that existed naturally or inevitably. Instead, the making of home, and therefore the therapeutic qualities of home, required constant orchestrating efforts that required (re)configuration of various materials, meanings and practices, situated both internal and external to the physical and symbolic bounds of the home space. Some of these orchestrating efforts involved ordinary activities such as cooking and use of care technologies. However, they also interacted with less obvious practices, ideas, and materials that were choreographed to ‘hang together’ to create home as seemingly coherent or integral entity. When destabilising elements entered home, or previously stable constitutive elements became destabilising, they were either incorporated, or rejected. However, this process was not a straightforward act of replacement. The new element interacted with other constitutive elements and as a result of this dynamic process, a new configuration of home emerged. These orchestrating efforts were situated in wider discourses of normality, for stability only made sense in the context of what was considered ‘normal’. In the next chapter, I explore ways through which participants enacted a sense of normalcy.

⁵⁷ However, the accommodation service that Emily described has been terminated. She explained that it was because the hospital had suspected that people “were abusing the system, because it was quite cheap”. I suspect that funding (or lack thereof) was a factor.

Chapter 7

Creating a new normal

I went back to work next year, that was quite good. That, I guess, set me in the right direction. Because, it was back to normality. (Irene)

It's a lot of compromise and the compromise that you do is also about grieving (Megan).

Health care policy and practice inevitably construct certain normativities (Singleton, 2006) — morally appropriate ideals about self-care, and social, employment, and healthcare participation. In this chapter, I show how these normativities, as discursive constructions, are 'done' and not done in the everyday lives of the participants. Participants talked about various ways they attempt to enact a sense of normalcy - their ideas about 'normal' based on what their life used to be, and what they perceive to be a 'common' way of living. Normativities constructed in policy and practice were sometimes congruent with practices of enacting normalcy; at other times they caused frictions.

Doing a healthy lifestyle

Stroke is increasingly constructed in the public health discourse in terms of risk factors. These risk factors are not treated equally, and they enact certain normativities about how people should live, and how they should not live and die (Singleton, 2006). As an example, below I consider the National Stroke Foundation website, entitled *Stroke risk factors*.

strokefoundation.com.au/prevent-stroke/risk-factors/

Text size change small | medium | large | xlarge

Search the site

StrokeLine 1800 787 653

Home What is a Stroke Prevent Stroke After Stroke Get Involved Health Professionals Research About Us

MAKE A DIFFERENCE. MAKE A DONATION. 1300 194 196 Click Here

National Stroke Foundation - Australia > Prevent Stroke > Stroke risk factors

Listen

Stroke risk factors

Stroke risk factors: Risk of stroke and second stroke is influenced by a number of factors. The more stroke risk factors you have, the higher your chances of having a stroke.

They fall into three groups:

Stroke risk factors that you cannot control

- Age – as you get older, your risk of stroke increases
- Gender – stroke is more common in men
- A family history of stroke

Medical stroke risk factors

- Transient Ischaemic Attack (TIA)
- Irregular Pulse (Atrial Fibrillation)
- Diabetes
- Fibrinouscular Dysplasia (FMD)

Lifestyle stroke risk factors that you can control

High blood pressure and stroke
High blood pressure (hypertension) is the most important known risk factor for stroke. High blood pressure can cause damage to blood vessel walls, which may eventually lead to a stroke.

High Cholesterol
High cholesterol (hyperlipidemia/dyslipidemia) – contributes to blood vessel disease, which often leads to stroke.

Cigarette smoking and stroke
Smoking can increase your risk of stroke or further stroke by increasing blood pressure and reducing oxygen in the blood.

Tobacco smoke contains over 4,000 toxic chemicals which are deposited on the lungs or absorbed into the bloodstream. Some of these chemicals damage blood vessel walls, leading to atherosclerosis (narrowing and hardening of the arteries). This increases the chance of blood clots forming in the arteries to the brain and heart. Smoking also increases the stickiness of the blood. This further increases the risk of blood clots forming. Seek advice on how you can quit smoking as soon as possible by calling the QUIT line on 13 78 48.

Obesity or being overweight and stroke
Being overweight or obese can increase the risk of stroke. Too much body fat can contribute to high blood pressure, high cholesterol and can lead to heart disease and Type 2 diabetes. If you are unable to maintain your weight within recommended levels, ask a doctor or nutritionist for help.

Poor diet and lack of exercise
Being inactive, overweight or both can increase your risk of high blood pressure, high blood cholesterol, diabetes, heart disease and stroke.

A balanced diet eating fresh foods where possible is recommended. It is also important to maintain a balance between exercise and food intake, this helps to maintain a healthy body weight.

People who take part in moderate activity are less likely to have a stroke. Try and build up to at least 30 minutes of moderate physical activity most days of the week.

Talk to your doctor about an exercise program as people with high blood pressure should avoid some types of exercises.

Drinking too much alcohol
Alcohol and stroke: Drinking large amounts of alcohol (six or more standard drinks per day) increases your risk of stroke.

Lifestyle tips What is a stroke Types of stroke Medication and surgery

If you think someone is having a stroke call 000 SIGN UP TO OUR NEWSLETTER

<p>About Us</p> <ul style="list-style-type: none"> How we can help Where to find us Carers <p>What is a Stroke</p> <ul style="list-style-type: none"> Signs of Stroke FAST Are you at risk? Prevention Stroke Care Units 	<p>After Stroke</p> <ul style="list-style-type: none"> Leaving hospital after stroke Stroke rehab recovery Re-Stroke Carers and family Get help after stroke <p>How to Help</p> <ul style="list-style-type: none"> Corporate Partnerships DoIt4Stroke Donate to the Stroke Foundation Include a Gift in your Will 	<p>Fight Stroke</p> <ul style="list-style-type: none"> Join the fight against stroke Get involved Share and read fight stroke stories Fight Stroke Advocates View the advertising campaign Campaign with us <p>Health Professionals</p> <ul style="list-style-type: none"> Clinical Guidelines and Audit National Stroke Services Frameworks My Stroke Journey Resource Our Programs Professional Development Alliances Tools and Resources Know your Numbers 	<p>Contact</p> <ul style="list-style-type: none"> Health Check Finder Stroke Library Translated Stroke Resources Stroke in Australia Privacy Policy Terms & Conditions Fight Stroke Stroke for Stroke News and Events Event Calendar Get Involved Australia's Biggest Blood Pressure Check Stroke Solidarity String Photo Wall
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Resource order form Free health check healthinsite Stroke unit locator

ABN 420 081 732 79 - © 2014 National Stroke Foundation - Australia. Digital Agency - Deepend

Figure 7.1: Stroke risk factors. (Reconstructed from multiple screenshots. National Stroke Foundation n.d.)

Stroke risks and conducting the individual body

The webpage starts with a statement: “The more stroke risk factors you have, the higher your chances of having a stroke” (National Stroke Foundation n.d.). This is followed with a list of these risk factors, sorted into three categories:

- “Risk factors that you cannot control” including age, gender, and a family history of stroke;
- “medical stroke risk factors” such as a diagnosis or a history of transient ischaemic attack (TIA), irregular pulse (atrial fibrillation), diabetes, and fibromuscular dysplasia (FMD); and
- “lifestyle stroke risk factors that you can control”, including high blood pressure and high cholesterol levels, cigarette smoking, obesity or being overweight, poor diet and lack of exercise, and drinking too much alcohol (National Stroke Foundation n.d.).

This list of risk factors ‘performs’ (Law, 2011, 2009) certain realities.⁵⁸ Firstly, the opening sentence constructs a reality in which stroke risk factors are something that individuals *possess* and accumulate, thus enacting a centralised agency capable of *collecting* or *disposing* at least some of these risk factors. Furthermore, it makes clear distinctions amongst different risk factors, and these are presented in a quasi-spectrum. There are items that individuals cannot control; those that can be – and ought to be – controlled; and ‘medical’ factors that are in-between — factors, for which, perhaps, full control cannot be granted but should nonetheless be managed. The lifestyle factors are given the greatest attention in *Stroke risk factors*, occupying more than

⁵⁸ Apart from the ones I outline here, the banner on the top of the webpage (see Figure 7.1) appears to depict an Anglo-Australian female healthcare professional taking the blood pressure measurement of a man of ethnic minority background, perhaps (on the basis of his appearance) an indigenous Australian. This also hints at a certain reality of the prevalence of stroke risk factors according to race, gender, and health knowledge and practice. However, this is beyond the scope of the current thesis.

double the space on the screen, compared to other risk factor categories (see Figure 7.1 above).

The lifestyle risk factor items are accompanied with brief explanations and advice under each factor, such as: “Seek advice on how you can quit smoking as soon as possible by calling the QUIT line on 13 78 48” (para 8) and “If you are unable to maintain your weight within recommended levels, ask a doctor or nutritionist for help” (para 9). On the other hand, “Risk factors that you cannot control” are only accompanied with simple, matter-of-fact statements such as: “As you get older, your risk of stroke increases” and “stroke is more common in men” (para 2). Nonetheless, these statements also perform a certain reality, thus reinforcing the idea that stroke is primarily an old people’s (and men’s) disease.

“Medical stroke factors” are provided only with hyperlinks to further clinical information about each of the conditions. At the end of the webpage is a hyperlink entitled *Lifestyle tips*, along with other hyperlinks to medical and clinical information about stroke: *What is a stroke*, *Types of stroke*, and *Medication and surgery*. The *Lifestyle tips* hyperlink takes web visitors to a page entitled *Tips to change your lifestyle* (National Stroke Foundation n.d.), which contains advice under such subheadings as: *Shape up: Keep your weight within a healthy range for your age and gender*; *Eat foods that are good for you*; *Get active*; *Cut down or QUIT*; *Cut down Alcohol*. This page has a further hyperlink at the bottom entitled *Drop the salt!*, another webpage about reducing dietary salt intake.

These messages are quite prescriptive, and address how people should conduct their lives and manage their bodies to reduce the risk of stroke. Notwithstanding some uncontrollable factors (e.g. gender), a ‘healthy life’ and the absence of stroke are portrayed as a product of individual responsibility achievable through the active

monitoring of the self. That is, acting on these ‘guidelines’ is a moral enterprise (Petersen & Lupton, 1996, p. 174). Not observing a healthy lifestyle – and as a result, dying from a stroke or living with resultant disabilities – contradicts the contemporary, neoliberal mentality to be “‘active individuals seeking to ‘enterprise themselves,’ to maximize their quality of life through acts of choice” (Rose, 1996, p. 57).

At the same time, however, stroke is constructed as a generalised, statistical risk, as exemplified in the public awareness campaign entitled *1 in 6*, conducted by The National Stroke Foundation during the National Stroke Week in 2012.



National Stroke Week

Figure 7.2: A ‘1 in 6’ campaign material (an image extracted from National Stroke Foundation, 2012c)

In this representation, “1 in 6 people will suffer a stroke in their lifetime... every 6 seconds someone, somewhere, regardless of age or gender will die from stroke. Stroke can happen to anyone” (from a flyer included in the National Stroke Week information kit: National Stroke Foundation, 2012c). This Stroke Week campaign was accompanied by a TV advertisement entitled *Stroke – The Silent Killer* (National

Stroke Foundation, 2012d). The video, modelled on the filmic style of horror movies (<http://vimeo.com/48931696>), also reinforces the message that one in six Australians “has the makings of [stroke], lurking inside them... For 12,000 of you, stroke won’t just tear everything in your brain, but obliterate it.” (National Stroke Foundation, 2012d) The video describes some of the common stroke sequelae, such as inability “to talk, to comprehend, and...to control your bladder,” before concluding that: “So ends the lesson. And your life.” (National Stroke Foundation, 2012d)

The *Stroke risk factors* webpage that I discussed above (National Stroke Foundation n.d.) also includes an embedded short video called *Know your numbers*. In this video, people utter statements such as “I’m as healthy as the next person”, “not bad for an old bloke”, “fit as fiddle”, “as good as can be expected, I guess,” followed by a voice-over narration telling the viewers that they “could be suffering from high-blood pressure without any warning signs at all” (from the video embedded in National Stroke Foundation n.d.). Viewers are encouraged to visit a local pharmacy for a free blood pressure check; the video shows logos of Omron, a major manufacturer and distributor of home-use digital blood pressure monitors, and the Pharmacy Guild of Australia.

These campaigns differentiate between the *knower* – medical and allied health professionals – and the *ignorant* – lay people who underestimate or are oblivious to stroke risks. The campaigns locate the responsibility for the incidence of stroke in individuals, and shape stroke as ending one’s *meaningful* life. Stroke is shown as somewhat mysterious and uncertain, but important to prevent because it will have serious impacts on people’s lives, and is neither the way in which people should die, nor how they should end their *active* life. These depictions also perform pervasive assumptions in cultural and social discourses. Stroke is *normally* an old person’s

disease, but by the same token, when it occurs in younger individuals, stroke – as a *lifestyle* disease – is often thought of as *caused* by risk factors, such as poor diet, lack of exercise, smoking, and excessive alcohol consumption. That is, stroke in older individuals is constructed as a *normal* part of ageing, while stroke in younger people is anomalous and its explanation leads to a degree of victim blaming.

Stroke that happened out of nowhere

Participants in my study, and their partners, were a younger age than that considered typical for stroke, and because of this they often experienced age and context specific tensions. The onset of stroke in their partner challenged their previously held assumptions about the links between stroke and old age, and this left them with a sense of uncertainty. Their partner often had not lived a sedentary, self-indulgent lifestyle prior to stroke and, as a result of this, the doctors were unable to pinpoint the risk factors that might have contributed to the stroke. Without a clear factor to which to attribute the stroke, it was difficult to identify the risks and so identify the factors that might have prevented it. Even in their presence, the nature of risk factors meant that they could not be identified as the direct cause of the stroke. The search for a cause, while important to participants in order to understand this event, was therefore futile.

Elke's husband Mick was required to undergo and to pass a rigorous annual health examination as a condition of his employment. At the time of his stroke, Elke had not considered him to have any obvious risk factors for stroke apart from a 'minor' heart attack more than 10 years ago, when he was in his early 40s. His blood pressure and cholesterol levels were under control (monitored especially diligently because of the previous minor heart attack) and Elke thought that, in terms of health and fitness,

he was “at 100 percent”. When I asked her if she had ever tried to find out why Mick ended up having a stroke, despite his fitness and monitoring, she stated:

You ask that question at some point, and in the beginning, but you have to try to get over that quickly, because there's no answer. Who gives you the answer to that? And what's the answer? If you ask yourself every day, why me, then you get depressed, because, it just happens. What do you do? You just have to deal with it, and yeah. [A long pause] It's hard. It's difficult, but yeah, I don't know, no one can give you the answer to that. And it doesn't change the fact that you've had a stroke. Some people are in the higher risk group, and some people aren't, unfortunately. And it still happens to them... That's the thing, if you are not affected, you don't really think about it. Or you might think it's more for old people, or big people. But it can happen to anyone.

I am uncertain as to whether my question about the potential cause of Mick's stroke was interpreted as subtly implying victim blaming. Nonetheless, her response sounded defensive, perhaps rehearsed too, having responded to this question in her own mind and to others over time. Perhaps too, she tried to avoid being implicated in Mick's stroke, because it would suggest that she had been unable to ensure that as a couple they had had a healthy lifestyle. In the end, she decided not to keep thinking about the possible cause of stroke, because, for Elke as for other participants, looking for an answer when there was none was pointless.

The circumstances around Fiona's husband Matt were even more mysterious. A clot caused his stroke when he was 49 years old, but the medical professionals could not figure out where the clot had originated. He lived a healthy lifestyle, and although there was a family history of cardiovascular disease, he was not in an obvious risk category:

He had low cholesterol, low blood pressure, he was fit, we were training for the Melbourne marathon when he had the stroke. The Saturday before we'd run 28km. Never been a smoker so he didn't fall into any of the real risk categories for a stroke, and [doctors] did all sorts of tests to find out where it [the clot] had come from but they couldn't determine where it came from. I guess you think, 'Why did it happen?' The only thing that Matt had was a family history – his dad died from a heart attack, which was a blockage in one of the main arteries. I guess family history was the only thing, so that was a bit hard not knowing why and feeling like fit, healthy, young, none of the risk categories, but those things happen.

Fiona, like many other participants, made sense of the stroke as a freak accident. Later in the interview, she felt the need to clarify that she did not think 'why me?' with a sense of self-pity. Rather, she reasoned that it was bad luck that was generally distributed amongst the population: "I just think, 'well why not?' There are so many people that go through this or worse so why should I be exempt from stuff happening?" By attributing the stroke to bad luck, and allowing that this could have happened to anyone, she was normalising the young onset of stroke in Matt. While framing stroke as a random, unfortunate incident helped Fiona, Elke and other participants to make sense of it, this led to practical difficulties in preventing future occurrence.

With no clear 'cause' of the stroke, self-care and management were often the only ways to manage the sense of uncertainty surrounding the possibility of reoccurrence. Anna was told that her husband's only possible link to stroke was his family history; his mother and a couple of his aunts had had a stroke. There was nothing that Anna and Jason could do to change family history of stroke, so maintaining healthy blood pressure and cholesterol level – which were within the

normal range before the stroke, anyway – was the only solution available to them. That is, *doing* a healthy lifestyle allowed them to manage the possible reoccurrence of stroke:

There was no actual cause, so the only thing we could do was make sure that everything like your blood pressure and your diet and cholesterol were all good, so that at least you thought you were doing your bit and that's what we focused on. So we went to see the dietician and things like that.

The advice from the dietician was informative and detailed. However, the complexity of dietary information meant that the application of this knowledge in everyday life was stressful. Now that Anna and Jason were equipped with the nutrition knowledge, supermarket aisles appeared like a maze with traps. Ensuring that all food ingredients were healthy involved a laborious process of checking all food labels, which were often complicated and misleading,⁵⁹ and required making ingredients and meals from scratch. Sodium,⁶⁰ for instance, was so ubiquitous in commercially available food and ingredients that calculating the total daily intake and ensuring that it remained within the recommended daily intake required much planning and fine attention to detail. This was difficult for Anna, especially when she still needed to take Jason to outpatient rehabilitation services:

⁵⁹ For example, many brands are promoted and labelled with a 'salt-reduced' claim when, in fact, it merely means that the product contains less sodium compared to a reference product (usually the 'regular' equivalent of the product). A product with a low salt claim must contain less than 120 mg of sodium per 100g, according to labelling requirements of the Australia New Zealand Food Standards Code (Food Standards Australia New Zealand 2014).

⁶⁰ Salt and sodium are not the same (although sodium is a component of salt), and this can also create confusion. This is because people may think of food high in sodium as 'salty food'. While this is not incorrect, many things that are not salty are high in sodium, such as baking powder. Furthermore, the common unit of measurement for salt and sodium is different. While sodium is usually measured in milligram, people typically use gram or tea/table spoon to measure salt in recipes and in everyday conversation.

[The dietician] gave us a huge list of things in terms of, like, fat content but it's different for different foods, like she'd say in yoghurts you can have this fat content; for this food you can have this fat content; if you're going to eat chocolate just eat this much, etc., etc. ... we got all this advice and checklists on sodium and stuff like that and it would take us a couple of hours at first to go around the supermarket, you know, looking at labels. We were fanatical at the start... it was quite hard at first. I was making all [meals and ingredients] on my own, because you know the stock you get in the [store-bought] box is really high in sodium, so I would make all my own stock and things like that. So it was quite hard at first because you've still got to take him to physio and things like that.

The meticulous attitude towards diet was difficult to maintain, but it also caused a sense of loss in Anna. To Anna, the new, *healthy lifestyle* signalled symbolically (and literally) departure from the *normal life* that they once had. Anna remembered one day when they and their two children went to the beach in St Kilda, a seaside suburb:

I remember we went to St Kilda once, probably about three or four months after discharge, and we all went – all four of us – and normally we would all sit and have fish and chips or something like that. But because he was so fanatical about his diet he insisted that we take sandwiches, and I was just in tears that day because it was so different to our life and I thought life was never going to be the same again.

Anna mentioned the same sense of loss when she was cooking beef stroganoff with low fat cream. Not only did these changes represent a departure from *normalcy*, but they also necessitated adjustments in embodied and everyday practices, including

sense of taste and choice of food. In fact, doing healthy lifestyle was difficult, and created tensions.

As time progressed, with no signs of further stroke, Anna and Jason developed an alternative way to observe a healthy lifestyle. This was still done within the normativity framed in the public health discourse – that of self-management and self-control – however, with some modifications to reduce the impact of readjustments to their practices. Firstly, they consulted the Internet to find a company that specialised in low sodium health food:

Eventually we got onto a company that does low sodium stocks and things like that. There's a company in Tasmania that supplies stock cubes and other low salt things, baking powder and things like that.

Anna now did not need to make stock from scratch; instead, she could purchase stock cubes in order to ensure that they had what they considered to be a healthy lifestyle. This relieved her of the stress and time involved in preparing low sodium, low fat meals herself.

Another change that occurred was with their attitude towards diet. They found that, rather than following rigidly the dietary guidelines all the time, it was possible to consume 'unhealthy' food if this was in moderation and occurred infrequently:

Now, he's a lot more relaxed... over time we learned that it's not about depriving yourself of things, it's about doing them in moderation so if we go for fish and chips, you might have them three or four times a year which is probably okay – you're doing it in moderation. It's when these people are doing it twice a week that's when problems start to occur, but you don't think like that to start with.

This change in attitude did not happen overnight. Anna told me that it took them more than two years before they developed this attitude, and occurred as an outcome of various experiments: “I mean at first we probably didn’t have anything like [fish and chips] at all, but then we’d do it once a year, and then it got more and more”. Therefore, this departure from ‘frantic’ self-management to a more relaxed attitude was expressed in terms of acceptable risk. As long as “bad eating” was infrequent, or in moderation, it still counted as ‘doing’ a healthy lifestyle.

This shift in thinking allowed Anna to negotiate the normativity of living healthy, and normalcy in terms of her life prior to Jason’s stroke and how she understood ‘normal’ life might have been were it not for the stroke. Part of the decision making involved ongoing experiments to see how Jason’s body was responding. Low sodium stock cubes, amongst other things, mediated in this negotiating effort, as did Jason’s body, which had remained ‘stroke-free’ since discharge. What Anna’s account demonstrated was a performance of competence (Moser, 2005). This involved negotiating the notion of self-control framed in the public health discourse, locating participants and their partners as enterprising, calculating, and autonomous subject positions, actively seeking a solution in the market economy. This negotiating effort was not easy for Anna and Jason. However, for some participants, this involved efforts that were even more troublesome, as I explain below.

For participants whose partner’s stroke was attributed to controllable risk factors, the focus was on reducing – and attempting to eliminate – those factors. Controlling these factors in some cases, such as for Abi’s husband Cain, was done through medication as well as lifestyle modifications. Cain was on medication for his cholesterol and blood pressure levels, and Abi prepared food to meet his special

dietary requirements, which they brought with them to stroke support group meetings. In some cases, however, controlling lifestyle factors of the stroke-affected partner created tensions.

The direct cause of Neil's wife Eva's stroke was the formation of blood clots caused by a previously undetected congenital heart defect. Eva was a smoker, and the concern amongst the medical professionals about her smoking was quickly communicated to her when she was still in the hospital:

There were three specialists around the hospital bed and, because she was a smoker, they started to say: '[we're] not saying that smoking caused it, but it may have contributed to it', even though the whole thing – did the smoking make the blood thicker in some way, did it slow it down, you know what I mean, did it contribute [directly to formation of the clot] – they can't [categorically conclude, because] there is no [causal] link that they can tell. But they were indicating to Eva that it could be.

However, Eva interpreted this as an act of patient-blaming. She was aware that smoking was a risk rather than a causal factor, and immediately resisted the blame, and the implications that she had not been a responsible subject. Neil spoke of her reaction when she was told of the link between stroke and smoking:

Now, she has always been aggressive to people who try and tell her that she shouldn't be smoking. She was upset when she first found out — was told [that she had a stroke], but became aggressive when, you know, the lifestyle was indicated as a possible trigger. So she immediately said, pointed to everybody standing around the bed, "well, you might have had a stroke. You might have, everybody might have had a stroke." So she started pushing back — "Don't tell me," you know.

Neil paused very briefly, and added, in defence of Eva: “And a lot of people can have minor strokes without ever knowing it”.

With this remark, Neil distributed stroke vulnerability to the general population, echoing the message in the ‘1-in-6’ public health campaign mentioned above, albeit with a different intention. Unlike the cautionary message that is designed to evoke a sense of fear in the ‘1-in-6’ campaign, by enacting stroke as a common disease and thus normalising it, Neil reduced Eva’s moral culpability. Neil therefore rejected stroke as a consequence entirely of Eva’s *irresponsible* acts. This was further reinforced by his assertion that Eva was able to reduce her alcohol consumption to having only an occasional drink, which Neil said was at a common level before her stroke anyway:

From a lifestyle point of view, with alcohol, she didn’t have [alcohol prior to stroke] to excess anyway – occasionally she would have had a few glasses, like everybody, I’d say. Like, if you go to a dinner party, you know, you’d share two or three bottles round the table. She can’t do that anymore, it affects her the next day – she can hardly get out of bed. So she can only have one, possibly two glasses. That’s a good thing. But I suppose she has to watch that, and people have to be aware that she’s had enough. Don’t ask her any more because she is not going to [be able to take it].

Reducing alcohol consumption, according to Neil, involved at least three factors for Eva. Firstly, Eva faced bodily responses to an alcohol intake that went beyond a modest amount. She therefore needed to be vigilant about her alcohol intake, and others around her also needed to be aware about her limits, so that they would not keep offering her drinks. This was a mediating effort that enabled Eva to adopt a responsible lifestyle; it was an act of balancing bodily limitations and remaining

socially engaged. A degree of responsibility was partially distributed to others around her not to encourage her to keep drinking. This mediating effort on alcohol consumption was much easier than smoking, a habit that Eva continued after stroke, albeit at a reduced amount. Neil tried to convince Eva to quit smoking, but to little avail. Instead of blaming Eva's lack of self-control – and therefore reducing her capacity as a responsible subject – Neil shifted the locus of responsibility to the culturally accepted⁶¹ addictive nature of tobacco:

She has cut back from smoking, but she hasn't stopped. She tries to stop but it's an addiction.

Have you tried to talk her out of smoking at all, or —

Yes. [But her response was] very aggressive. As I said to you, even when she was in hospital, laying on her back, she was throwing it back at the specialist, so — she'd bite your head off, I tell you.

What do you think about her smoking?

Oh, look, I hate it with a vengeance. I've scrunched packets up and thrown them away, only for her to go and buy another packet, you know. And that doesn't work, trying to quit. She's been trying to quit for as long as she smoked. But it's so difficult when you've smoked for — well, she probably started about 14, 15, I'd say, 40 years or so. It's a habit that's very hard to stop.

The fact that Eva continued to smoke frustrated Neil, but he was sympathetic towards Eva because she had *tried*. Neil accepted that it was the addictive nature of

⁶¹ Addiction has become commonly conceptualised in medical, and increasingly neuroscientific, terms. While it was an attempted shift away from framing excessive substance use as an expression of individual culpability, addiction remains an elusive concept in both medical and public discourses. It is laden with various assumptions about agency and volition (Karasaki et al., 2013). For critical examination of addiction, see Fraser & Moore (2011), Fraser et al. (2014) and Keane (2002).

nicotine, rather than Eva's lack of will and discipline, that was preventing her from eliminating what was considered to be a controllable risk factor. In this way, he distributed responsibility to cigarettes (and the tobacco company that promoted and sold cigarettes to Eva when she was a teenager). This did not mean that this acceptance occurred unproblematically. Neil also expressed the normativity framed in the public health and health economic discourses, and felt strongly about the importance of stroke prevention through public awareness about risk factors:

You know, I don't know the costs of everything that Eva has been through, but if you multiply that by the number of stroke people, it's a huge health budget that would have to be set aside for that. So, if you put [more budget?] into preventative [measures], you know, information is powerful. So you need to get that out to the community. That's the important thing.

In Neil's case, the tensions caused by Eva's non-adherence to the normativity constructed by the public health discourse were soothed, albeit somewhat awkwardly, by normalising stroke and constructing smoking as addictive, as discussed above. Other participants, however, displayed a more nuanced appreciation of public health campaigns. It was not that they were unsupportive of the campaigns – in fact, they were appreciative of the messages about stroke risk factors sent out to the community. However, the reality of living with a partner who had a stroke conflicted with the somewhat reductionist public health and social narratives about stroke. For example, Rebecca felt that the message was not only inapplicable to her husband Ned, who was “super fit”, but also felt that it might lead to a sense of guilt in people who have had a stroke and their partners:

[A public health awareness campaign about stroke risk factors], I think, is a wonderful program in that hopefully it prevents strokes, and I think people

need to be aware of their health and get their cholesterol checked and all that. But I'm also a bit cynical about that. I think there's those other people that have strokes through no fault of their own, and they had a good diet and they were extremely fit and they've had these strokes, which was no fault of their own and I think it almost makes them feel guilty that 'perhaps if I'd done this and that', but you know very well that even if they'd done that, it would have made no difference whatsoever... they see that and it makes them feel guilty. So you've got the other side of it. So yeah they're good programs but I mean they wouldn't have helped us at all.

As I have argued earlier in this chapter, the public health discourse often constructs *lay* individuals as lacking in information necessary in preventing stroke occurrence. Due to their lack of awareness about and vigilance in controlling risk factors, they become a statistic – the one in six. This normativity created much tension in Naomi, whose husband Iain had recurring strokes and continuous deterioration.⁶² She told me that, in the first few years until it became clear that Iain's recurring stroke was due to a genetic disease, she felt that she was failing. She was trying her best to monitor Iain's lifestyle while juggling other duties and responsibilities including paid employment, parenting, and caring for her ailing father. When I asked her what contributed to her sense of failure, she became visibly upset:

Oh, that makes me teary. That I couldn't work out why we weren't getting where we should be getting and what was I doing wrong, you know? That wasn't getting us where we needed to go. I realise now that that wasn't the case, but I was trying to juggle too much.

⁶² I provide further discussion about Iain's deteriorating condition, and how it affected the spousal relationship in Chapter 8.

What Naomi reflected were the difficulties involved in staying in line with normativities reflected in and reproduced in policy. Naomi was trying to fulfil her responsibility as the heroic, self-sacrificing carer (Lloyd, 2006), while at the same time performing socially and economically engaged subject. However, this was made difficult by Iain's body: he was not making the recovery that Naomi expected and hoped for, and she was exhausted from managing various competing demands. My argument is that assumptions expressed in policy that carers were unproblematically able to engage in self-management of people who have had a stroke (Chapters 3 and 5), together with the notion that stroke ought to be managed through adherence to a healthy lifestyle, produced Naomi's sense of incapacity. Iain's stroke recurrence, for Naomi, signalled a failure on her part in ensuring that Iain lived a healthy lifestyle to prevent further stroke. Meanwhile, as I discussed in Chapter 5, there was no meaningful support mechanism in place for her in the formal health care system. This sense of incompetence was emotionally distressing for Naomi.

Social engagement

In the *National Carer Strategy* (Commonwealth of Australia, 2011: 32-33), a policy document that sets the long-term carer support framework of the federal government, "health and wellbeing of carers" is listed as one of the target areas. In the document, it is acknowledged that "carers need information and support to ensure they develop strategies to manage their own physical and emotional health. They need to learn how to cope and manage stress" (p. 32), and following this, the government proposes to "give carers greater opportunities to participate in family, social and community life" (p. 33). As with the public health campaigns around stroke risks, this policy document performs certain normativities. Firstly, carers ought to actively seek support to *learn to manage* their social and emotional wellbeing. They are also to be socially engaged

in their social networks, and should seize opportunities to do so as they present. The document also outlines some groups that are deemed vulnerable, such as “older carers, young carers, Indigenous carers, carers in rural, regional and remote areas and carers from culturally and linguistically diverse backgrounds” (p. 11). Here, young carers are defined as those aged 15 to 25 (p. 30). There is no mention of the 25-64 age group in the *National Carer Strategy*, although this is mentioned in the follow-up document *National Carer Strategy: Implementation plan* (Department of Families, Housing, Community Services and Indigenous Affairs, 2012). In this latter document, even so, the 25-64 age group is mentioned only three times in relation to target measures around labour force, education and training participation (p. 30). These policy documents not only shape who should receive extra support, but also in what domain of their lives they should be supported. Arguably, labour force and training participation are the primary needs of this particular age group. In the following section, I discuss various contexts in which such assumptions affected participants’ experiences.

Support groups

I recruited some participants from stroke support groups and, as active members, they found attending the group beneficial. Although many stroke support groups were established to provide peer support to people who had had a stroke, many spouses were also members and attended the groups. This was partially out of necessity, as they transported members who had had a stroke to the venue (mostly a church hall or another community facility, such as a room in the local library or community health centre). Rather than going home or elsewhere and coming back in a couple of hours when the meeting was over, they often stayed and joined in the group activities. They also provided various types of assistance to the person with whom they came to the

group, such as getting a hot drink or sweets for her or him, cutting up food⁶³ such as steak on outings, in cases where she or he had hemiplegia, or acting as an interpreter if he or she had aphasia. They also provided assistance to the group as a whole; they served refreshments and did the dishes afterwards, organised raffles at meetings to raise money for group activities, were involved in running the group and activities, and provided instrumental assistance to other stroke-affected members, such as helping them getting on and off a bus on social outings.⁶⁴ In this sense, attending the support groups for spouses was part of caregiving. In fact, participants told me that they initially started attending the support group because they thought it might be beneficial in managing their partner's social-emotional wellbeing. They were concerned about emotional difficulties that their partner was going through, and wanted to create a social outlet to ameliorate them. As Anna's comment below indicates, it was not something they attended out of their own needs, at least at the beginning:

I wouldn't have seen [attending a support group] as something for me that sort of thing [but it was for her husband Jason]. I mean I don't really like talking to strangers and I didn't see myself in a big group situation as being of any benefit to me. But it was.

Initially, partners were not very enthusiastic about attending a stroke support group. For example, Jason was "tearful" after attending a meeting for the first time, because they saw "people that were a lot worse off than him... He was still probably thinking

⁶³ Support group activities included regular social outings to a hotel (pub), while some groups held their regular meetings at a hotel.

⁶⁴ They also contributed financially through their annual membership and gold coin donations for refreshments at the meetings. Although these were requirements for attending a support group, they would be considered 'stroke related' out-of-pocket costs because they would not have been paying those recurring costs if it were not for their spouse's stroke.

‘I could have another stroke at any time, and if I do, I could end up like this person’.” Rebecca also told me of her husband Ned’s initial reluctance to attend their support group. However, having been concerned about his depression that developed when he was alone, she decided for him that they were going to go back to another meeting – a decision that both appreciated now:

We went for the first time and Ned said, “I’m not going back”, because it was noisy and the group had people that had lost their inhibitions and they’d just say what they thought [irrespective of the comments’ appropriateness]. I mean, I’m pretty thick skinned but some were just very loud. So I made him go back and we’ve got into a terrific group of people there.

The initial reluctance in meeting and seeing other people with disabilities also arose out of resistance towards assuming a disabled identity. As I discussed in Chapter 4, stroke occurred unexpectedly for relatively younger people. This meant that various stroke sequelae and bodily changes occurred forcibly and suddenly in their biography, and created tensions in their social selves. Tracey’s husband Ted exemplified this: he initially thought attending the group was irrelevant to his sense of self – as an independent and autonomous subject. Tracey persisted and, over time, Ted has come to enjoy attending the group:

I think we’ve been going two years now. Ted didn’t want to have anything to do with [the support group] for a long time. He didn’t want to socialise with other disabled people, because he wanted to just mix with able bodied. He didn’t want to be labelled. But I kept saying to him ‘it might be good to sort of learn from their experiences, and find out how they cope with things’, but it took a long time before he started thinking that ‘well, okay, perhaps we should do’, and yeah, he enjoys going there.

What initially started as an activity purely for their partner's sake soon became a source of emotional support for participants. The experiential knowledge of other group members was invaluable; it created a sense of belonging that stemmed from a collective identity as people who were living with effects of their partners' stroke. At a stroke support group, they did not feel 'invisible'. As Fiona explained:

I think the group has been fantastic. It's been wonderful for Matt, he loves it, but it's great for me just to come along and sit with the other carers and just chat and to know that there are other people who've been through the same thing and who, I know, understand completely. Whereas friends are wonderful, there's nothing like having someone who's experienced what you've experienced to really understand and identify with things. Not that we talk about stroke all the time at all, but just to know that there are people there who do understand and, if something happens and you do need to talk about it, there would be people there that I'd feel very comfortable talking to, because I know that their experience is very similar to mine, I think that's important.

Similarly, attending a stroke support group was an important part of Emily's life. In fact, she felt that she was getting so much benefit out of attending the group that she decided to take on an active coordinating role within it:

[Attending the group is] really important [to me], I do it more for my sake than Ryan's. ... Sometimes people don't have to do much to support you, just to understand where you're at and to chat to you, you know... I took on [a position in the organising committee] because I'm getting a lot out of it. Knowing there's other people there. Even just the social contacts and talking with people, meeting new friends, it's really important. And if I can make new

friends, then Ryan will also make new friends in the same environment, and it's good for him socially to gain his confidence.

Emily's account shows that, while attending a support group was beneficial to her, ultimately, the value lay in the fact that both participant-carer and partner could participate in the same social activities, which also had a rehabilitative value for Ryan. In this sense, being involved in care activities, being socially engaged, and performing partner were intertwined. However, not everyone felt that attending a stroke support group was beneficial. Alix, whose husband Erwin was 45 when he had a stroke, felt out of place at her local stroke support group, due to their relatively young age compared to other group members:

In the beginning I was taking him to all those activities, like the stroke group. But I was thinking, 'I don't want to go to this, a bunch of old people, it sounds like an elderly citizens' club, like the one that my grandparents go to'.

Erwin was enthusiastic about attending the group, so Alix felt compelled to take him to the group, despite her discomfort. She also found that people at the group were helpful. However, being the only person in her age group created tensions in her sense of self and this became unbearable. She did not feel she belonged:

I took him there all the time, and you know, I found it supportive and they were very emphatic, especially the other women, who are all much older than me. Because [they] just said, 'look, it's terrible what happened. Because, you know, for us we are old. You kind of expect it a little bit, but you guys are still young'. And then, just after a while I thought, you know, 'it's not me, it's not my life. I'm not – I don't need to go there. I don't need to go there and sit with these old people'. In fact, I hate the fact that I have a disabled person at home.

I actually don't want to spend three hours with a whole bunch of disabled people, as horrible as that sounds.

Most stroke support groups were held during the day on a weekday. Therefore, it was also difficult for Alix to attend because of her paid employment. Erwin's significant physical and cognitive stroke sequelae meant that getting him ready to go out, and providing supervision to do so, took a long time. Persevering with attending a support group was difficult, especially when she did not find it beneficial for her. Naomi, who was also in paid employment and whose husband Iain's stroke sequelae were severe, also talked about the lack of support services for younger partners:

I mean, they set up all these things so that you can have – you know, for carers and stuff, but they don't necessarily fit people that are younger as well, I don't think. I guess it's getting to know the bits and pieces that are out there and it just takes a hell of a lot of effort. And when you've already got a lot of other things on your plate it's not easy. Other needs are there [such as paid employment and parenting].

Alix explained that finding an avenue of social support suitable for younger people was important also for their school aged children. This was because, at a group for younger members, there might be other children of a similar age. They might find it more helpful to meet and play with other children, rather than sitting bored amongst mostly older adults. This also meant that they could attend the group together as a family, rather than organising a childcare service and leaving them at home. She eventually found another stroke support group organised specifically for younger people. She was initially excited. However, her excitement was short-lived:

Well, I didn't like that either. The reason was because all these people came in, and then I felt like I had the most disabled husband, because there're all these

young people and I thought "I actually can't even tell who had a stroke". You know what I mean. So they actually had recovered [although, I understand they are] still suffering the consequences, of course.

Yvette made a similar observation. Her ex-husband Chris had cognitive difficulties, and she felt that stroke support groups were more suitable for people with fewer and less serious stroke sequelae. On occasion, she attended a stroke support group on her own, without Chris, primarily to ask practical questions, such as rehabilitation services available for Chris, rather than to seek social and emotional support from other members. Having seen more severely affected people at the hospital, she wondered where all those people had gone:

When you go to the stroke support group, most of the survivors are the ones that can now cope. So what happened to the ones that can't cope? See, it's unknown. So again there's a gap there. I find that with the physical side I think there's more help. They can tell you what you can do and things like that. But I think with the mental side, there's not much there, maybe because people who are mentally affected, or their memory's affected and all that, maybe they are so bad that they just end up in a [nursing] home. So it's out of sight out of mind sort of thing. I don't know.

What Alix's and Yvette's accounts illustrate is a paradox. For Yvette's ex-husband Chris, difficulties in initiating and sustaining conversation, due to his poor memory, problems with vocabulary, and struggles with executive function, created *incapacity* in the social situations at a stroke support group, which, again, provided a normalising avenue for active members. Since Yvette felt it was not beneficial to Chris, she had not become a regular member of a support group. In Alix's case, the efforts to normalise Erwin's situation by having him socially engaged in a support

group contributed to a departure from normalcy – practices of spousal relationship and family life were routinised prior to stroke. Mutual support, of the kind that enabled Emily, Fiona, and others to establish support networks that also incorporated their partner's needs, did not seem to offer the kind of support that Alix needed, as it reminded her of the age *inappropriateness* of her situation. She was unable to do a *normal family*.

Employment and re-negotiating normalcy

Participants talked about the ways that paid employment enabled them to regain or retain a sense of normalcy. Emily was working about 30 hours a week before Ryan had a stroke. When Ryan was discharged home, he was still not physically and functionally well enough to be left at home alone. He needed someone to provide direct care and supervision for everyday activities such as getting around the house, eating, and making a cup of tea. Emily was also spending a lot of time with Ryan, going through exercises that the speech therapist had given to him. In addition, she had to take him to rehabilitation sessions in Hakea, a regional centre two hours' drive from their town Adelie. The rehabilitation session timetable was subject to sudden changes, which made it difficult for her to commit to regular hours at work. This meant that, although her employer was sympathetic, her position at work was not tenable:

Ryan needed just somebody with him, so I couldn't leave him for six hours during the day on his own. [Work] needed somebody to be there every day, and so I said to my boss, 'look, I could come in for a couple of hours, but then some days, [I might not be able to come in].' The thing is that we had rehab twice a week in Hakea, so that was two days out a week. And [rehabilitation session] changed different days sometimes... so I said 'look, it's going to be

fairer on you, for me to resign'... I had to resign from that job, well, because of the stroke.

Ryan's employer was more accommodating – perhaps to a rare degree. After Ryan had recovered enough to have his driver's license reinstated, he was invited to return to work on a flexible basis, even if only for a couple of hours a day. However, Ryan was suffering from fatigue, which was unpredictable. Considering the long (45 minutes) drive to and from work, going to work was too dangerous, especially on the way back home when he was tired. Ryan's inability to return to work had implications other than loss of income; it also affected him emotionally, as I discuss below. This also meant that Ryan was at home all day, every day, and required constant supervision.

Even after Ryan made enough physical and functional recovery so that he no longer needed direct care on activities of daily living, Emily still could not leave him alone at home. This was due to a number of related issues. Because of the numbness and lack of feeling on one side of his body, Ryan was prone to injuring himself and needed supervision when he was doing handyman work in the shed, which was an important outlet for his self-expression and compensated for him no longer having a paid job. He once cut – and lost – the tip of his thumb on the saw bench, without even realising the injury until Emily saw him with a bloody hand. Concerns about potential injury and inability to do the handyman work as he once had, due to reduced dexterity, “set him a step back [in terms of his mental and emotional wellbeing].” Emily needed to spend as much time with him as possible to encourage him to stay active, and to ensure that he was safe in doing so. This was especially important, since his communication difficulties led him to socially withdraw:

He's a real handyman, but he wouldn't have attacked [any project] when he first had his stroke because he'd lost all confidence. It took a lot of gentle pushing on my half, and persuasion to get him to do things. I had to be out in the shed with him, or basically following him and get him to help me do things, because he'd lost confidence... And he didn't like to go out with people because he was conscious that he couldn't speak, because he couldn't speak.

Furthermore, as Ryan made progress with his speech therapy and, therefore, with his ability to express himself, it became apparent to Emily that stroke had affected his mental health – one of the 'invisible' sequelae of stroke that I discussed in Chapter 5:

The emotional and mental stuff didn't really appear until probably six to nine months after the stroke... I was really worried at one stage, he was really quite down and, well I thought he was depressed.

Ryan's emotional instability greatly concerned Emily. She took him to several counselling sessions with a social worker, who concluded that "it was a normal grieving process over the loss of the life as it was" and told them that "you've got to learn to live with your new life". He was taught some coping strategies, however his mood did not improve. Emily grew sceptical of the social worker's exclusively cognitive approach, and decided to seek medical advice. They initially had difficulties making appointments with a regular doctor due to their rural location. As she explained, "it was hard to get him to see the same doctor, and we often just have the ones that come in for six months or 12 months, so he'd seen a few different doctors."

It was only after their family doctor, who had previously moved to Hakea for work, relocated back to Adelie, that they were able to see a doctor on a regular basis.

Concerned about Ryan's mental health and a lack of improvement from the counselling sessions with the social worker, Emily consulted with the doctor.

I was talking to the doctor, and I said, "the social worker reckons he's not depressed, I am really not sure – I beg to differ. Sure, he's got to get used to his new life, but it's more than – he can't cope with it at the moment."

The doctor assessed and diagnosed him with depression. The doctor's boyfriend at the time happened to be a psychiatrist, and was visiting her every week from Hakea. Ryan started weekly sessions with the psychiatrist, who put him on medication and provided psychotherapy. He gradually got better "with medication and strategies [from psychotherapy] and a lot of positive input from me – anytime he does something really good I really praise him."

Another important aspect of improvement in Ryan's emotional stability was his new paid work at a local bowling alley, with which he was matched at a disability employment service. He started working two days a week doing maintenance and general handyman work. This greatly improved his emotional wellbeing.

He's also been working part-time for six months as well. Since he started that work, his emotional state is 180 degree turnaround – really boosted his emotional state hugely. You know the man ego thing, he's got to go out to work, because he's now contributing to society again, and to the family, so he feels he's doing his manly duty by going to work. It's just those, trying to get back into 'normal life', whatever that is.

Emily was also grateful for the new employers' understanding about Ryan's fatigue.

They're absolutely a lovely couple. And they're very conscious of his mood swings and him being tired. A couple of times he's just been really, really tired, so I've rung up and they'd go 'oh, that's fine, tell him not to bother

coming'. We needed somebody who was really understanding of that too, so they're absolutely excellent.

The close location of work, which eliminated the risk of driving fatigue, the type of work, and the understanding of his employers, made this an ideal arrangement. Emily also secured casual work as a personal care assistant. The daughter of someone she knew in Adelie required a personal care assistant due to an Acquired Brain Injury (ABI) from a car accident. She initially nominated Emily's daughter, who had just completed a certificate in personal care, for the job. However, Emily's daughter could not take on all the shifts, so Emily decided to take the rest of the shifts. Although when I interviewed Emily this family had moved from Adelie, she had taken on other clients through an in-home care agency. She was still reluctant to leave Ryan alone at home for an extended time due to his emotional wellbeing, and the casual job arrangement suited her because "I am able to say yes or no to jobs, if they were too long [distance away]." The psychiatrist who happened to regularly visit Adelie for personal reasons, medication, coping strategies, Emily's emotion work, their new paid work in the local areas, and understanding and flexible employers enabled both Emily and Ryan to feel a sense of new normalcy, as Emily explained:

So we're at a much better place now. So, it's taken us 2.5 years to get to a sort of a 'new normal' state of living. We've got a whole new way of life, both of us have got new jobs, both part-time instead of fulltime, kids have all left home, but just getting into a new normal pattern. So that's sort of where we're at the moment.

Emily now felt that she had a sense of control. She was able to plan and manage her social, economic and employment lives. This is in line with the objectives of disability and carer policies, such as the ones I referenced above, which encourage

social and economic engagement. However, this doing of normativities was not an automatic or smooth process. Emily had to actively ensure that Ryan was receiving an appropriate mental health care, and support from the community network in finding suitable employment arrangement was important. She also mentioned that she had to advocate on Ryan's behalf to retain his articulated truck license.

VicRoads [road authority] were going to cancel his truck license [despite the driving assessment determining him fit to drive in short distances]. ... We had to fight VicRoads to be able to get that back. So it was a lot of fighting on my part. I mean Ryan may never drive a truck, but if he'd have lost that, that's something he would lose because of the stroke, you know, that loss in some of his independence again. So even though if he doesn't drive a truck, he's still got his truck license, so it's still mentally important to him.

Emily and Ryan's children also contributed to this process of enacting new 'normal', by arranging settings in which Ryan could perform his role as father. Their daughter was getting married, and they were concerned that Ryan's emotional wellbeing and self-esteem might be affected, given that he was unable to give the father of the bride speech at the reception. So, their daughter instead asked him to participate in their wedding preparation in a way that he was proficient – wood crafting.

Kids understand [although] I think they still miss dad doing things... [Their daughter] wrote a lovely email saying 'daddy, I love you xxxx, I want a wishing well for my wedding, and they're really expensive to buy, and you're such a very clever daddy – is it possible that you can make one? Let me know if it's too hard and we can buy one, but you're a lovely daddy.' And so that gives Ryan something useful that he can do towards the wedding, and it makes

him feel like he's contributing and doing something still. So the kids try to get him to do things that he is capable of.

Emily explained that their daughter gave Ryan plenty of notice so that he could pace himself to avoid overexertion. "And it looked absolutely beautiful", she announced proudly, before she showed me a photo of it. This task enabled a sense of dignity in Ryan – and Emily – and to perform family, albeit in a different mode compared to the way it was prior to stroke.

So, dignity and confidence were active and ongoing achievements for Emily and Ryan. Another example was at their church, which was an important domain of spiritual and social support in their lives. Due to his communication difficulties, it was difficult for Ryan and other people to engage in conversation. This was an isolating experience especially in the small rural community where everyday small talk was an important part of its social fabric:

People up in Adelie knew Ryan had had a stroke, and because of his very limited language, he wasn't able to talk to people, so people felt a bit awkward talking to him. They were scared that it would upset him or offend him, or that it would tire him out too much... they didn't know how to communicate. But it's important for Ryan to be able to resume normal relationships and stuff like that.

After realising that his confidence suffered from not being able to interact with his friends at the church, she decided to 'educate' people on how to effectively communicate with Ryan, and the importance of patience in doing so. She explained some communication strategies to people, such as talking slowly in short sentences, focusing on one topic at a time, not changing topics quickly, and asking him yes/no

questions more often. This changed people's attitudes, and enabled Ryan to resume friendships, and to feel dignified:

And after that, things really improved, and those that really wanted to talk to him understood how they could talk to him, and how to communicate to him, and not to treat him like a mental dumb-wit or something like that... He used to go out and walk home as soon as the church [service] finished – he wouldn't stay for a chat. Whereas now, he's getting more and more confidence [to approach people for a chat]... it made a huge difference and that boosted Ryan's confidence.

Many people at the church were willing to change their communicative habits to engage with Ryan. This was an important part of the 'new normal'.

Paid employment, amongst other things, allowed Emily to enact a sense of normalcy. However, for some participants, this sense of normalcy was partial and situational. As I discussed above, the reality of living with physically- and cognitively-affected Erwin created tensions in Alix. She explained that she was now living in a "double life": the home life and work life. In the domain of home, she was constantly reminded of changes to her life that have been introduced by Erwin's stroke. She gave an example of a family night at their daughter's netball club.

On Sunday, they had a [award night] at my oldest daughter's club. And then they had dads' netball game. Erwin wasn't there, he was somewhere else. There were all these dads, all the same age, fit — well, some of them, I wouldn't say fit [Alix chuckles] — playing all this kind of stuff. And you just think, 'well, I don't have, my kids don't have a dad like that.'... My real life [at home] is a bit surreal, it's not real, being 45 and having a severely disabled husband... It's not normal. It's not something that should happen.

In the domain of home life, she felt disconnected from the ‘normal’ life – a kind of life that she imagined her life was going to be based on the biographical, social, and cultural contexts. She mentioned that she thought she was the only young person living with a spouse with disabilities in her suburb. While this claim was factually disputable, it nonetheless illustrates her sense of isolation from normativities of socially engaged, active and autonomous subjects. However, at work, she could feel normal; she could enact the notion of citizenship, closely associated with the productive body – economically producing and socially engaged subjects (Bacchi, 2009):

I love going to work, because I'm not trapped! I'm free! You know, going to work, I can be completely normal, I can do my intellectual things, I can have discussions with people, I see my friends, I can go and see other people at lunchtime.

What Alix illustrated here was that, at work, she could enact a sense of control, and that she was able to perform her identity as young, intellectual, and autonomous person. This sense of normalcy was partial and situated. Furthermore, she was only able to work part-time, due to the eligibility criteria for the Carer’s Payment restricting carers’ employment participation at maximum 25 hours per week (the ‘25 hours’ rule). Furthermore, the provision of respite services was also limited both in terms of amount and appropriateness, as I discuss below. So, while being at work enabled Alix to feel normal, it did not mean that she was completely free from concerns about home life.

Tensions in being socially engaged

For some participants, enacting a sense of normalcy in social relationships was problematic for a number of reasons. In the *National Carer Strategy* (Commonwealth of Australia, 2011), mutual support groups and respite services are listed as the government's solutions to improving carers' social engagement (p.33). As my discussions above about the stroke support groups indicate, while the mutual support groups were utilised and appreciated by many, there were people whose needs were not necessarily met. This was the same with respite services. This was exemplified by a discussion I encountered at a stroke support group. The husband of a person who had had a stroke, who was slightly older than my recruitment criteria, explained to other stroke support group members that he could manage everything with his care for his wife and things around the house. One thing that he did need help with was ironing – he was always behind with ironing the laundry. However, the respite service that he contacted would not provide this service, because it was not what their service was set up for.

Similarly, Alix has had difficulties with respite services. While she regularly used them, organising appropriate services was made more stressful due to their young children [3, 6, and 8 years old]:

We have had people [who were meant to] come and do respite, but the problem is, because I've got three kids in the house, I can't have just anybody there, who either doesn't get along with the kids, can't manage them or anything. I just can't get a random new person all of the sudden looking after him, and the children. So, it's very hard when we get new and different people to come into the house to do respite... For me, respite is getting away from everybody, coming home, everything is nice and tidy, and there're no dramas.

[But my experience was, after I got home] kids were freaked out and not listen [to instructions] and all those kind of stuff. So, it means someone who can manage the kids, cook, clean up, and take a bit of an initiative to do all that kind of stuff.

While Alix tried to request regular respite care workers, they were not always available. This created a sense of uncertainty while she was away from home on respite – not of Erwin’s welfare, but of the children’s behaviours when she got home.

Will also mentioned the limitations of respite care that were predominately designed for particular lifestyles. Because of the nature of his business, he often worked outside the typical business hours and sometimes on a short notice. This meant that he was not able to utilise the respite services the way that others might. His particular concern was with dropping off and picking up their daughter Sarah at the childcare centre when he was not available to do so due to work. As with ironing, this was not something that the respite services could provide:

It’s very difficult to try and shuffle things around, try to find someone to take my place, especially at that time of the day or the evening... I've made enquiries about trying to find people who would be good enough to possibly pick up Sarah and take her to the [childcare], or even bring her home, but you don't get that service... it's really only designed for those who are normal '9-to-5' job people.

This had potential financial implications. Will sometimes had to forfeit work in order to prioritise Sarah’s transport to childcare (despite it being only 500 m away from home). If he was stuck at work around 6pm, the centre started charging penalty rates per minute, which could be costly.

For Naomi, her difficulties with remaining socially engaged were not due only to a lack of access to appropriate respite services. She explained that following his stroke, especially the second one, Iain's ability to engage in conversations was compromised due to cognitive difficulties. It was difficult for him to read the direction of a conversation, and he would interrupt it by breaking into it with a completely different topic. Or, he would not realise that the topic of a conversation had already moved onto another one, and make a seemingly disconnected statements. This meant that making free flowing, spontaneous conversations in social situations were difficult. She explained how this impacted on her social life:

I think I experienced what a lot of people do with having a partner [with] an illness and stuff like that – that some people drop off [because] they can't handle it... Like, we used to have people over for dinner. It is much more difficult [now] because the conversation was more challenging. [For him] following the conversation and actually making appropriate responses when you were in a group was very difficult.

Hosting a dinner on the weekend – an activity that Naomi used to enjoy – also became a daunting task after an exhausting week. This was especially so, when the enjoyment of having people over was tainted by difficulties with maintaining entertaining conversations, as Naomi's account above indicated. This meant that dinner parties were no longer worth the effort organising it:

It's hard to maintain friendships because by the time the weekend comes, it was exhausting... The impact of actually organising myself to have people over for dinner was just impossible, almost. I just don't do it much now, because I don't have the energy, quite frankly. By the time the end of the week came – and I did food shopping, organising bills, organising appointments [for

Iain's medical services], organising things with our (teenage) son, you know, all those other things that you're doing as well. And, I guess, probably me came last.

Normativities constructed in policy conflicted with one another; carers were encouraged to be socially and economically engaged, yet they were at the same time expected to be dedicated, self-sacrificing, heroes (Chapter 3). As Naomi's account illustrated, negotiating these normativities was difficult.

Normalcy after stroke operated differently across various life domains. For some people, it was enacted through their efforts to align themselves with the normativities constructed in healthcare and carer policies. However, these normativities and their idea of normal, situated in biographical, social, and cultural contexts, did not always operate smoothly together. Moreover, some cases, it conflicted with their capacity to perform subjectivities, especially in the context of limited formal support structures. This meant that enactment of normalcy relied largely on individual efforts and compromises, in a process that was partial and contextual. The centrally defined goals, such as the ones in the *National Carer Strategy Implementation Plan* (Department of Families, Housing, Community Services and Indigenous Affairs, 2012), were not able to capture this nuanced, fluid, and unfolding operation. In Chapter 8, I further explore the unfolding nature of living with a stroke-affected partner.

Chapter 8

The loss of mutuality

I mean she has just lost so much of her function, and that's the distressing part. You know, I miss the wife I [had], pre-stroke: very bright, very talented, very independent, very organised. Yeah. And that's something that's been taken away from her. And that's probably the most frustrating part for Nadia. And then it's up to me to try and sort of pitch in (Will).

Stroke changed the nature of spousal relationships both immediately and in the years that followed its onset. In Chapter 4, I discussed the impact of unexpected stroke on participants' sense of self and their taken-for-granted relationships with their partners, while the partners were still in hospital. In subsequent chapters, I explored the ideational, social and practical consequences of stroke in terms of how it affected their partners' re-introduction to everyday life at home, and I challenged the unproblematically assumed role of the spouses and 'home' in the recovery of stroke-affected individuals. In this chapter, I turn to the multiple ways in which stroke impacted their relationships.

Rearrangement of relationship balance

Because stroke affected and limited the body, various roles, expectations, tasks and responsibilities between spouses necessarily changed. In addition to new tasks required as part of caregiving, most everyday tasks became the responsibility of the caregiving spouse. These varied depending on stroke sequelae and arrangements

established prior to stroke. Some tasks may seem trivial, but their presence was firmly felt, as Anna explained:

I mean just little things, just things that he would have done himself like going and buying a newspaper, even things like that I was doing. I mean it's not a big thing, but it's just another thing that he wouldn't do, or he didn't have the confidence to do.

Initially, Jason wasn't mobile enough to physically get himself to the shops. Gradually, he got better – his walking improved, and he successfully completed a 'fitness to drive' assessment for his driver's license. But even then, the severity of his hemiparesis meant there were still risks of falls due to gait unsteadiness, or risk of car accident once he regained the driver's license. So, Anna undertook all activities that required travelling outside home to avoid exposing Jason to incidents that could potentially cause physical injuries and/or bruise his confidence. Anna and Jason lived in a rural town, and prior to Jason's stroke, her driving was mostly limited to short distances:

I suppose one of the big things [that changed after stroke] was driving. Because – even though I [can] drive – [before the stroke] normally I just get in the passenger seat and Jason drives, especially when we go driving to Melbourne. We just wouldn't even consider it – he would drive. But I was driving everywhere [after Jason's stroke], and I'm not that keen on driving into the city, things like that, but I had to do all that so that was one of the big things.

Others too took up driving, depending on the extent of recovery and residual disabilities for their spouse. Neil's wife Eva had her driving license re-issued one year after her stroke following assessment of her driving ability. Her residual disabilities

were described as relatively “mild” and, to a casual observer, she might not appear to have had any problem driving on her own. Nonetheless, Neil did most of the driving, especially at night when Eva had particular difficulty, and over long distances:

I am tending to drive 95% of the time now. And at night, because at night she gets confused. She says... she gets a bit confused, lights coming towards her and the wind is blowing, and it's not good. So I have to drive at night, especially long distances.

The practical difficulties associated with the reduced capacity of the stroke-affected partners to drive were especially evident during the first year post-discharge, when they were still attending outpatient rehabilitation. Ben explained that Amy was not able to drive for 18 months post stroke. Since he needed to be at his workplace when the rehabilitation sessions were booked, he needed to coordinate her transport to and from rehabilitation. Although he acknowledged that he had “a lot of support from Amy’s family and friends, which made things a lot easier”, it was still stressful for him:

Because initially she didn’t have any independence to start off with for the first year at least [in terms of her mobility], and it probably took her 18 months to get back to driving. So we had to always organise someone to take her to her appointments, take her to her speech and her physiotherapy and all that stuff. It was quite hard juggling getting [transportation for] Amy’s therapy organised and being able to put a bit of time and effort into work as well. I guess there was a lot of stress organising.

Anna’s account, and those of a few other female participants, suggests how gender influenced such activities. When describing that some aspects of her life had returned to how they used to be six years after stroke, she stated: “I’m now back to

the passenger seat.” Newly assumed responsibilities involving new sets of skills were often those that were particularly gendered. In Chapter 4, I explained how Will had to learn to perform ‘maternal’ tasks after his wife’s stroke, shortly following the birth of their daughter. Other typically gendered activities included financial management and ‘handyman’ work. Even though women had been responsible for day to day financial management before their husband’s stroke, such as paying utility bills and managing the grocery budget, they now often had to assume more complex and larger scale aspects of household financial management. Fiona explained:

Matt used to do all our financial stuff — I used to pay the bills but he did all the big picture investment, whatever else and he understood that really well and enjoyed it, but I have no interest whatsoever, so that’s been a pretty steep learning curve for me, picking up all of that and trying to make sense of it.

Like Fiona, Rebecca was not involved in household finance management prior to Ned’s stroke, though she “kept an eye on things”:

That was his field and he did the finances very well – not that they’re huge these days. Well he did our finances before he had the stroke and I had to take over ... but I hate doing that sort of thing even though I always knew what was going on”.

Cheal (2002) argues that economic inequality within marriages has become a thing of the past in Australia, as the ideology of companionate marriage, characterised by democratic and egalitarian relationship, and female workforce participation, have become prevalent. He continues that the gendered division of labour between ‘money management’ – typically a wife’s responsibility over day-to-day management of money for everyday household expenses – and ‘financial control’ – husband’s power over money allocation and decision- making regarding major purchases – has largely

been replaced by income pooling and shared management (Cheal, 2002). However, these changes are complex in gendered arrangements in households (Broomhill & Sharp, 2005) and finances (Waseem, 2004; Worthington, 2006). While gendered power inequality in household economics may not be explicit, traditional gender roles are still performed, often expressed as personal preferences, largely reflecting the social and cultural patterning of gender.

Other tasks, such as ‘handyman’ jobs, were more obviously and explicitly gendered responsibilities. At a stroke support group discussion, the wife of a person who had had a stroke – slightly older than my recruitment criteria – suggested that, although she used to be a ‘girly girl’ before her husband’s stroke, she had had to ‘toughen up’ to do all the handyman jobs around the house. And in an interview at a later date, Tracey reflected: “I don’t think I’m as soft as I used to be. I was the soft touch – I’ve had to toughen up”. I mentioned to her the other woman’s comment. She enthusiastically responded:

Yeah, definitely. Definitely. I have to fix the fences when the dogs escape. I come down and am fixing the fences late at night. He had a swimming pool that was being dug the week before he had his stroke, so I have to do all that maintenance now. I don’t swim. The pool was for Ted, he was going to be swimming and look after the pool. And he still isn’t in there now.

Although Tracey tried to take on as many responsibilities as she could to fill a void, there were limits to what she could manage. Because she was petite, she could not physically lift and use “Ted’s” whipper snippers (lawn trimmers) and lawn mower to maintain the acre block on which they lived. This necessitated them to hire people for various maintenance jobs, adding to their financial difficulties. Furthermore, now that she was forced to actively participate in settings that were traditionally

considered masculine, she was exposed to power differentiation and appropriation, which manifested in sexism and financial exploitation.

When the lawn mower broke I had to get it in the car and take it, and they said ‘typical woman – it’s just run out of fuel’, but it hadn’t, it was more than that, but that’s how I get [treated]... I have to [maintain] all the cars. I don’t know anything about cars, and Ted did all that before. Now I have to do it, and when the cars need servicing, I hate the way the guys talk down to me as if I’m just a woman who doesn’t know anything, and I find that I get ripped off all the time. That’s probably why I sound sceptical.

Before his stroke, Ted managed household dealings in the public spheres. Now Tracey had this role. Even when people were not overtly sexist, in interactions with trades people and healthcare, welfare and other service workers, she felt that she was not being listened to or taken seriously. She quickly learned that being a “soft touch” did not necessarily work to her advantage. She had to learn to be assertive and negotiate – to perform masculinity.

[Before stroke] if we had any problems, Ted would do the talking. I would be like the wife who looks after the children – that was my role, looking after the children and house... he did all the negotiation of things. [When Ted had a stroke] I suddenly had to step forward and I had to talk for Ted, I had to make decisions on behalf of Ted.

Additionally, due to his speech difficulties, even when Ted is physically present, Tracey still needed to ‘do the talking’: “(Ted) starts off okay, but then it goes into a mumble, and people can’t understand what he says, so I’m a translator too.” Thus, in a sharp turn from their previous relationship and ways of negotiating with others, Tracey now had to represent Ted and to be in charge in public spheres; this

made Ted feel alienated. Tracey described him as an ‘old-fashioned gentleman’ — a chivalrous, confident and strong-minded man with distinguished prowess. However, his reliance on Tracey in conversations and on physical tasks, because of practical limitations, prevented him from performing masculinity.

[When Tracey is subjected a sexist comment as quoted above] it makes Ted cross, because he’s there with me but he can’t do anything about it. And if we go to Bunnings [a hardware store chain], he doesn’t like coming with me because if we’re buying something big, like doors [for home repair], they automatically look at Ted and say ‘here you go, mate’, and he has to say ‘I’ve had a stroke, I can’t do it’, and he hates it. And I have to say ‘that’s alright, give it to me, I’ll take it’.

Stroke management upset the distribution of responsibilities previously marked by clear gender roles, and the rearrangements disrupted assumed binary categories of gender. An internally consistent sense of gender identity was threatened, as conducting tasks considered masculine contradicted, for Tracey, gender binaries and discursive practices. She struggled to accept ‘undecidability’ (Derrida, 1997) – ambiguity that does not conform to a rigid and hierarchical gender. However, in the absence of an alternative arrangement, she had little choice but to become ‘everything’:

You told me that, before Ted was the man of the household and you were the wife of the house. Now it’s —

I’m everything now.

And how do you feel about that?

Sad. I don't want to be everything. I find I get so tired, and it makes Ted sad [because] he's watching me doing everything, and he can't do it. But if I don't do it then there's no one else who's going to do it. You just have to step up, don't you?

Managing the unruly mind and doing the 'thinking'

Cognitive sequelae caused fundamental rearrangements of responsibilities in the spousal relationship, and this was particularly impactful practically and phenomenologically. The nature of both direct and indirect supervision became especially salient, when their partner's capacity to conduct self-management tasks was compromised. Participants had to constantly remind their partner, or to interpret their bodily signs, or to think on their behalf.

Abi explained that, despite Cain's ability to conduct most daily activities on his own, he still needed indirect supervision for much of the day. Due to the difficulties he had with short-term memory and problem solving, he required constant reminders on self-management tasks, some of which were essential in managing his medical conditions including diabetes and hypertension:

Cain can't be left by himself. He can't [self-manage]... Because of [mental] confusion, you have to remind him sometimes to go to the toilet. Or to drink water, like now [in the support group meeting], someone has to remind him to drink water. So sometimes the brain just wonders around and I have to say: "Do you have to have a cup of tea?" You have to remind him things.

Because Cain was at times unable to interpret and make decisions on the bodily signs to, for example, urinate, or drink to avoid dehydration (caused by a high blood sugar level), Abi acted as a 'timekeeper' to prompt him on a regular interval to conduct

these activities. This enabled Cain's capacity to manage his body, and to avoid potential embarrassment, discomfort and, in cases of diabetes management, potentially life threatening situations.

Emily spoke of similar work with Ryan. For her, it involved management of Ryan's fatigue. He had difficulties managing his fatigue by planning breaks, and being overexerted negatively affected his emotional wellbeing. So, she had to actively interpret Ryan's bodily signs of fatigue during everyday activities to prevent his overexertion:

Originally he didn't know when he was getting tired and he would get over-tired which didn't help his mental state either or his speech, and he didn't see the cues [of fatigue]... So I have to read the body language, because he will say he's fine... I was always having to be one step ahead, and I'll say to him, 'oh are you getting tired darling?' 'No I'm alright'. I said 'you're just looking like you're getting tired',

He became better at interpreting his own bodily signs of fatigue after Emily, with some help from his psychologist, taught him "to understand what the cues are when he's getting tired and needs a break". Even so, she still constantly managed his breaks. She would prompt him by suggesting him to have a cup of tea, or to play solitaire on the computer, which gave him "just a mental break from what he was doing". Also, the meaning of personal greetings has changed; a simple 'how are you' was now used to assess Ryan's level of fatigue and emotional state, rather than as a mere phatic expression⁶⁵:

⁶⁵ The term 'phatic communion' was first introduced by Malinowski in the 1920s (Malinowski 1994). Phatic expressions include greeting and parting utterances such as 'how are you', 'fine, thank you', and 'see you later' that do not convey information on their own, but rather act as a ritualised gesture to establish a setting of sociality. However, they are not mere, purposeless expressions. Studies in the ethnomethodological tradition, especially

The first thing I will be assessing when I get home [is his fatigue and emotional state]. Because I can read his body language, I'll say 'how are you going, darling', and if he goes 'yeah...' he's not quite right... I'll go 'yeah you're saying you are, but you're not'. You know how you can read into somebody, the tone of their voice...

Although this indirect supervision did not involve constant monitoring, it was time and energy-consuming, and affected both everyday activities and other aspects of her life. Emily gave an example of their daughter's upcoming wedding. She was worried about the noise level at the wedding reception, which would exhaust Ryan. She would therefore have to constantly remind him to go outside to have a break. This meant that she had to closely monitor both the proceedings and Ryan's movements, so he did not miss out on speeches or other key moments:

Even on the wedding day, I'll be watching him from one corner of my eye, as well as what's going on. So that's tiring too. Because he's only concentrating on what's going on around him, and he doesn't realise how tiring it is, I've got to be aware on the day that he gets to [have regular breaks]... And you don't take everything in because you're half focussed on him and only half focussed on the other things that are going on. So I get mentally tired and drained at the end of the day.

Other partners too had to constantly observe, remind, and direct their spouses. Naomi explained that the nature of these supervision activities was that of doing the 'thinking' on her husband's behalf. Iain had difficulties with executive function and short-term memory, sometimes leading to unpredictable and reckless behaviours:

conversational analysis, have established a body of research on how phatic expressions are used to define social settings, and to negotiate such definitions (see, for example, Coupland et al., 1992).

You do the thinking and that does get tiring. Because you're constantly trying to – because Iain has an impulse button as well – I had to be outthinking him as times... You'd have to say, 'What are you planning there?', and be thinking about what he was planning and thinking [and say], 'No, that's not a good idea.' [For example,] he'd go to climb the stairs. [When I see him do that I have to say] 'No, Iain, you can't climb the stairs anymore [due to his mobility].' That sort of thing.

Naomi sometimes encountered resistance from Iain. She had to make a decision about cessation of Iain's driving and taking over medication administration. She did not wish to deny him of the capacity to make his own decisions and to manage his own conducts – personhood and agency – yet not intervening would have had serious implications:

It's really a difficult thing because you want to respect people's independence to some level. It's the same with driving. When they start to become a danger to someone else or a danger to – [themselves]. I didn't believe that he was taking the drugs appropriately and it could really impact on his health; [he could] have another stroke or – worse. It was time to take over, but it's difficult. When do you make that call? That's a challenge. But, by the same token, you know, both of them [driving and medication] would have serious impacts. Driving could have a serious impact on himself, but it could also have an impact on other people. So it's a bit tricky, but I had to make a decision, 'No, you can't do it anymore. It's just not safe. You're not safe anymore'.

The dilemma was made even problematic, as Iain often made sensible decisions, but it was unpredictable. This meant that Naomi had to always plan things in anticipation that he would make errors in his judgement:

Sometimes, he could problem-solve and get something right and you'd think, 'Gee, you made a good decision there', but you can't trust him to make the right decision all the time. You'd have to think probably 75 per cent of them might be wrong and 25 would be right.

Some of errors of Iain were unpredictable. Naomi recalled the time Iain had drunk their pet cat's water, in a cup in the sink:

I have no idea why he drank the cat's water. He's got a fridge full of drinks and he knows where the glasses are. And there's water in the tap, so why would you drink the cat's water? Because that's about, 'Oh, it's there, I'll drink it,' you know? I don't know, he couldn't be bothered doing anything else. His insight's poor that way. He does things that people don't expect, at times.

When Naomi was not with Iain, she was unable to do 'thinking' for him, but she could not rely on other people, such as respite care and healthcare workers, to conduct this work for him. The cat water incident occurred either while a respite care worker was at home, or immediately after he or she left. Despite Naomi warning care workers about Iain's impulsive behaviours, it was not taken seriously until something happened.

Shifts in relationships

Changes to various aspects of spousal relationships were at times so great that relationships were irreversibly fractured. Even though there were brief moments interspersed through their caregiving experiences that reminded them of the prior

intimate relationship that they had, these were often insufficient to compensate for participants' subjective feelings of strain.

An endless marathon

Alix told me that she was still coming to terms with her sense of loss revolved around changes to certain aspects of Erwin's cognitive functioning and personality. These changes led, in her eyes, to a loss of his personhood:

Part of your personality is things that you like, and that you don't like, but also [another] part of your personality is your intelligence, how you communicate, and how you get along with people. It's like he's had a personality transplant, basically, because he's not the person that I knew before. He was extremely shy before but because of all his brain damage to his frontal lobe, he is just disinhibited.

Erwin's disinhibition and loss of self-reflective skills as a result of stroke were manifested in what Alix considered to be immature behaviours. She gave an example:

Someone sent him a rude joke email, and he was going to send it to his OT. He was like 'oh, she will think it's nice'. [I had to tell him,] 'But you can't send that to your OT, that's inappropriate from a client'. He'd go 'oh, you don't think [it's a good idea]?', I'm going, 'No. You've got a professional relationship and you don't send stuff like that'. So he stopped doing that. But then there'd be something else.

Another aspect of changes in Erwin's cognitive functioning was his problem solving skills, although this might not be obvious to others in casual conversations. Perhaps to compensate for the decreased ability to engage in turn-taking

conversations that require a degree of problem solving in constructing responses, Erwin became an enthusiastic collector and teller of jokes:

He was completely obsessed with jokes. He would study those jokes on the Internet. But because of the cognitive processing problems, he would take a long time [to tell a joke], because he has to think about what he has to say. So, when there's a pause, you don't know, 'is this the end of the joke, or is it still going? Is he telling me a joke, or is he telling me something that really happened?', but then he would just go on, and you'd go 'oh [he is telling me a joke]'.

To Alix, the confusion caused by the slow tempo of Erwin's joke telling was one thing, but the constant exposure to distasteful and unintelligent jokes was another:

In the beginning, I thought, 'oh yeah [he's doing it again]'. But, I'm not into those jokes – it's a kind of things that old people do. There're some personalities that like telling those kind of jokes, that like listening to those kinds of jokes. I'm not one of those personalities.... In the end, because I was just getting angry, I was just saying, 'look, I don't like these jokes. Not interested'. So, he doesn't tell them to me anymore... I just hate [them] — it's not me.

Erwin also developed an obsession over football statistics and player details in order to engage in conversation with people. Again, this was not something that Alix could share:

I don't give a shit about football, really. And he will wear his scarf everywhere. We'd go out, and I say, 'do you have to wear that scarf?', 'Oh, yeah, people love it! They always ask me questions, and talk to me because of it.' [Alix in a weary voice] '— Oh, yeah, whatever'.

To Alix, it was not just that Erwin was unable to hold an interesting and intellectual conversation with her, but also that he lacked autonomous, logical reasoning. This was extremely frustrating:

[For example] I sent him to the supermarket to get basil. Basil is a very specific herb. And then he text me back and say 'can I get spinach instead'. And then I went, 'no'. So, maybe an appropriate thing to say would have been 'can we get basil in the tube, or do you want me to get dried basil?' But spinach is not a substitute for basil. Yes, it's green, yes, it's got small leaves. But it's not the same. You just think, "oh, god..."

The changes to his personality and cognitive functions turned Erwin into 'someone else'. Furthermore, the sequelae of stroke were seen as causing premature ageing (Singer, 1974):

He will age earlier [than other people of a similar chronological age] you know, he's already like an old man now, the way he shuffles about, all those kind of stuff. And just through inactivity and all that kind of stuff. Like last year he had his gallbladder attack and had to get his gallbladder out. You know, I would say that's also an old person's thing.

Alix mentioned brief moments when Erwin acted in ways that were consistent with how he was before stroke, for instance, when they were talking about things that happened or that they did together before stroke. These were ephemeral moments, though, and the changes to Erwin were so significant that Alix felt that she was married to a different person. Her relationship with Erwin was fractured in many ways:

It's ultimately devastating for your relationship, it's not a relationship anymore.... It's not an equal relationship, it's not equal intellectually, it's not

the same, personality wise. If I met him today, who he is now, would I be attracted to him? Would I want to have coffee with him, or spend lots of time with him? No. I wouldn't. So. That's the cold, hard, brutal, honest [fact].

Since the present was such a struggle, it was difficult to find a sense of hope in the future; the link that connected the present and the future was broken. Alix felt trapped; the present seemed to endlessly unfold without any sense of positive changes. But she also could see no alternatives:

You know, [in 'normal' relationships] once all that romance is gone, you just think, 'well, you shit me because you do this and that, or", you know, how it is, that's why people break up. So, I feel trapped [Alix pauses and starts crying]. I feel trapped. Because, what I see in people in my age group, where their kids are growing up, they are all going to school, and stuff like that, now. And people are breaking up with their husbands. You know, "oh, he does this, he does that." And I'm thinking like, "well, look what I'm stuck with. You know. I just can't dump him, because I'm not happy with his personality or his behaviours anymore. Where is he going to go? He's got nowhere to go.

Unlike others of her age, who she felt could exercise agency and separate if they so wished, Alix felt she had no control over the situation. The moral implications of dissolving the marital relationship were too significant for her, evoking a sense of guilt and challenging her ideas of being a responsible parent, ensuring that her children had a 'stable' family. This created tensions with her ideas about women being empowered, agentive subjects:

The older generation, it's that kind of thing, 'you [women] just put up and shut up', and you know, because of feminism, we have more choices, it's 'hang on, I'm not happy in this situation, not happy with the way you are treating me, so

this isn't going to continue!', you know, so you have that, which is how everybody lives by now. But I'm kind of in this situation where, if I do that, [people treat and assume as if] I'm on the beach [all the time]. I'm the cow that's left him to go off and have a better life, and 'poor him'. But [also] you know, just trying to balance his needs, kid's needs, because they still value him as a father, you know.

Alix was well aware of what other people might think should she decide to leave the marriage. She too used to view separation after stroke through these moralised lenses. She recollected a time when Erwin was still in semi-acute care. A friend, who worked as a medical professional, remarked how well she was doing, considering the severity of Erwin's stroke: "Most people would've left by now — it happens." Alix responded: "What do you mean? How can you possibly leave your husband, when they need you the most!? Jeez, I can't believe that." Six months later, she met a man at a support group, whose age, severity and stroke sequelae were similar to those of Erwin. His parents were there to support him, as since his divorce he had no one else to bring him to the group. As at the semi-acute hospital, Alix was shocked and morally affronted that his wife has left him:

His mum was going, [Alix pretends to put on an exhausted tone] 'Oh, you know, his wife left him because she was too embarrassed to push him in the wheel chair, took the two little kids', and stuff like that. I was like [Alix in a terrified voice] 'Oh, that's horrible.'

Alix considered stroke as a challenge that partners faced together, and that this shared challenge would consolidate their relationship. This was certainly the dominant cultural narrative available. However, her enthusiasm had waned as the

reality of living with a severely disabled spouse set in. Time was cruel to her; as the time passed, it exposed chronicity and complexity of Erwin's stroke sequelae:

I remember saying after about a year, to one of the workers at [a disability organisation], 'I feel worse now than I ever have.' She goes, 'yeah, that's a common story.' Because after about a year, you realise 'eek, this is it. This is forever. This is not an illness that you get over, or a car accident, or whatever, that [can be resolved after a certain time].' And because during that first year you are so focused on the physical [conditions], you are not paying attention to the cognitive, you know, all that emotional or intellectual stuff. [Cognitive changes are less obvious during that time] because they sleep a lot as well, because they are tired.

Three years after stroke, Alix empathises with those who felt they had no choice but to leave following stroke. Instead of a challenge that would strengthen their marriage, caregiving – and Erwin – were now experienced as a 'burden':

I can understand them [partners who leave] now. I didn't understand them then, I couldn't imagine, 'wow, why would you do that!?' And it was like, you know, 'the relationship was re-born again', and you are sort of 'fight this together!' and 'you are such a fighter, doing so well!' And then later, you think, 'hang on, this is shit'. You know, 'this is fucked'. And to the point, where you just think, 'maybe he should've died. Maybe we would've been better. I could've moved on, I could've met someone else, kids could've had someone else'. You know, but anyway, this is how it is, so it's like this now.

Naomi too described her experience as "a marathon that seemed to have no end." Iain had his first of multiple strokes at the age of 48. While the first stroke was relatively minor compared to later strokes, Naomi was concerned because of his

family history of stroke. His father had had strokes from his late 40s until he died at 54, and his father's mother had also died at 66 of strokes. Furthermore, Iain was born with aortic stenosis, a narrowing of the aortic valve, which was medically attended to when he was 14, and a valve was replaced when he was 28. A year after the first, mild stroke, he had a “massive – a much more massive frontal lobe stroke,” caused by a small clot flicking off the heart valve. Despite the initial, optimistic prognosis, Iain was showing significant declines in his cognitive and emotional capacities:

The specialist told me [after the second stroke] that Iain would be back at work in six weeks, but he was back in nine months and he still wasn't functioning well... His behaviour was frontal lobe affected, which meant that he had poor insight, a temper - which he really didn't have much before, he was a pretty laid back sort of guy – and lost eye contact with people.

After the second stroke, too, they learnt that Iain had been born with a rare hereditary stroke disorder known as CADASIL (Cerebral Autosomal-Dominant Arteriopathy with Subcortical Infarcts and Leukoencephalopathy).⁶⁶ Its main clinical manifestations include recurrent stroke, cognitive deficits including apathy and declines in executive functions and attention, migraines, and mood disorders. These manifestations appear typically in mid-adult life, and thereafter the person generally deteriorates (Chabriat & Bousser, 2007; Chuah et al., 2001; Opherk et al., 2004). The neurologist at the time of the second stroke mentioned CADASIL to Naomi, before he

⁶⁶ CADASIL was ‘discovered’ as a genetic cerebrovascular disorder relatively recently, in 1993 (Tournier-Lasserre et al., 1993), and the exact prevalence of CADASIL is still unknown. A lack of recognition of the disease means that, in many cases, it is misdiagnosed as multiple sclerosis, Alzheimer's disease, or other neurodegenerative diseases (Ampuero et al., 2009; Choi 2010). After explaining to me that CADASIL was a rare disease, Naomi clarified: “It’s not as rare as people think, according to our neurologists, but it's only started being diagnosed fairly recently in Australia. Iain’s father [probably] had it and Iain’s father's mother had it... We didn't know it existed in those days. We just now know how it worked, looking back on history.”

dismissed the idea of the genetic disorder as the cause of Iain's strokes. But the possibility of CADASIL firmly planted a sense of uncertainty and doubt in Naomi and Iain's minds:

The doctor said, 'I don't think it's CADASIL,' but I don't think he was 100 per cent convinced. And when Iain and I walked away he still had enough insight then to say, 'I'm not so sure,' and I agreed with him, too. Once I knew what CADASIL was, I thought, 'hmm' – I probably already had a pretty good idea that it was – I was hoping differently but underneath it all, my gut feeling was that that was what we were in for. There was certainly a bit of me that said, 'I'm not sure I believe you [the doctor], I'm not sure you're right'.

Her 'gut feeling' about "what [they were] in for" – recurrent stroke and long-term deterioration – turned out to be correct. Eighteen months after the first stroke, Iain had his third stroke, which forced him to stop working. Naomi sought a second opinion, and a skin biopsy test confirmed that Iain had CADASIL. After "a bit of a hiatus, a period not that long" in which Iain "got back to a bit of himself [with] at least [some] improvements in behaviour and stuff", he began to deteriorate further. There were further strokes over the following years, and other health complications – endocarditis (heart infection), epileptic seizures, musculoskeletal problems leading to several hip operations, and adverse reactions to anaesthesia. With his condition deteriorating after each stroke, other health issues and frequent hospitalisation, it was not a matter of whether Iain was going to have another stroke, but when, and to what extent his next stroke would further reduce his capacities.⁶⁷ For much of the last decade, Naomi experienced a continuing sense of loss:

⁶⁷ The dogging sense of uncertainty also extended beyond that of stroke reoccurrence in Iain. CADASIL, being a genetic disorder, could have been passed down to their son, Brett. Naomi offered: "You know, I can't pretend I'm not worried about the impact of having to deal with it,

It's not been an easy journey by any means, and it's ongoing. And how to describe it? I think living with long-term grief, which is what this is, to some extent.

With gradual loss of short-term memory, executive functions and concentration, and decreasing mobility, Iain was losing his personhood – “the essence of the person” as Naomi described. However, like Alix and Erwin, there were moments when Naomi saw the Iain of the past:

There're bits of him that are still there. In fact, the other day we were talking about something – because I still talk about what I've read in the newspaper so he'll remember bits of it – and he just said to me, ‘You've still got that lovely smile’. It must've been something we were laughing about. And he'll just say nice things like that at times. So he's still got that ability to do that at times, which is nice. And he tells me he loves me, and things like that. So that's nice, I appreciate that.

However, these moments were buried under her hectic life. Although she insisted on “just facing whatever you've got to deal with” rather than dwelling on the past, she resented the caregiving duties that affected her capacity to be effective in her other relationships — as a mother, daughter, friend, productive worker, and her own self:

I felt torn between supporting dad [when he was fatally ill a few years ago] and supporting Iain and at times felt that I was not doing as much for either as I would've liked to have done. I don't want to focus too much on regrets, it's unwise for anybody. But there's probably underneath it there's some truth in

if our son does turn out to have it as well into the future – it is really challenging for me, I think. I push that thought down a fair bit, I don't deal with that one much because I really don't feel I can go there too often, it's too painful.”

that. Just trying to juggle it all. At times underneath it all I could feel a bit resentful. I hope I didn't show it, but thinking, 'boy, this has really impacted on our lives.' And I'm not just talking about my life, I'm talking about my ability to support my dad, my ability to have friendships, my ability to do – you know, like when your child gets to a certain age you get a bit more freedom. The ability to make some choices and have freedom, the ability for us to travel. I couldn't think of any way it didn't impact really

Holding a “senior enough management” position at work, juggling all the demands was difficult. In order to fulfil responsibilities, she sacrificed her own time. Despite feeling exhausted, she still had to maintain her ‘sociable impression management’ (Goffman, 1959) in social circles, at work, and home:

At times the pull from work, because I've got a very busy job, and the pull from needs at home... Pretty hard to keep going, try and maintain a degree of pleasantness underneath it all when you were thinking, 'I'm really finding this difficult'. Yes, very hard, actually. Particularly the last three years, I've just spent most of my life exhausted. The majority of my sick leave in the last 10 years has gone on carer's leave to a significant point, simply because that's what I've need it for, but it probably hasn't afforded me any [respite] – and a lot of my long services leave has gone on carer's too, just simply to keep all the juggling.

Naomi resolved that she would manage her ‘juggling’ as well as she could. When I commented on how hard it must have been for her, she explained that there were a “myriad of reasons,” included compassion, affective and contractual natures of marital relationship, and parenting, for continuing to provide care:

I made a commitment, I suppose, when we were married. Like, who else is going to do it? Why wouldn't you do it? I wouldn't like to be walking in his shoes, I think it'd be very difficult, and I would like someone to treat me like that if I was in the situation. So there's probably a myriad of reasons. You love him. I mean, he's not the same person and I've had to deal with those issues, but by the same token I wouldn't —. You know, I want to be an example to my child as well, about what I think you should do. Lots of reasons. I don't think it's ever one completely. My belief is that Iain would have done the same if it had been the other way round. But that doesn't make you do it, I think you do it because you have compassion for the other person. I think that's probably as strong as anything ... Not that I'm a big religious person — in fact, I'm an atheist and have been for a very long time but I just — but I guess it might be a religious 'do unto others as you would have them do unto you', that probably resonates.

Naomi mentioned too her own upbringing, when she was encouraged to be resilient despite her mother's death at a young age.

However, Iain's deterioration forced Naomi to make a decision that she had been dreading: it became clear that the home environment was no longer safe for Iain. He preferred to stay in bed, and his incontinence had increased; this meant that he needed to be frequently helped out of bed and taken to the toilet. However, he was too large and heavy for Naomi to manage this. He was also increasingly impulsive, and these behaviours were becoming hazardous. In the end, Naomi had no choice but to place him at a residential care facility:

We had to tell him when he was in rehab that it didn't look like we were going to be able to bring him home at this point in time because his needs were too

great and I couldn't manage him physically. And that was difficult. And I said [to the social worker], I wanted to be the one to tell him, I didn't want anyone else telling him. So I took a day off work and came in. And he was very upset. When I explained it all the social worker was sitting there. She let me do the talking but she did chime in a couple of times. When we were going over reasons why, Iain understood, because he's got a reasonableness part of him, but that doesn't mean your emotional part matches that.

Finding a suitable residential facility, however, proved difficult:

Because Iain is younger – most of the aged care facilities are not appropriate for someone that was 55 – and he's not needing [24/7] care or all that sort of thing, and we don't have a spare \$400,000 sitting in the bank anywhere. We have to wait for a government-assisted place in terms of where he's going to go. And even the ones that cost \$400,000 to get in have to have a government assisted – there're a certain number of places available – but it just takes time to get in. And the transitional care social worker is really working hard to try and find the right place, because what we'd really prefer to do is actually find him a permanent place so that I don't have to move him in six months or a year, that he'll actually settle in and find some happiness.

The wait was made harder because Iain struggled to comprehend the situation. Naomi reasoned that denial was his way of coping emotionally, but this was difficult for Naomi:

He is having trouble reconciling what's happening. It's really difficult. Like, even after I explained, he said to me the other day, 'when's the doctor going to let me go home?' and I hate having to go over the stuff that 'you can't come home at the moment'.

At the moment. She had to use these words. It was too painful to repeatedly go through the process of explaining the decision to him:

He's been there I don't know how many weeks now, but quite a few. Every so often he'll say to me [the question] – and I kind of haven't said too much when he's said it because I got to the point, 'well, until we've got a place, and then I'll go over it again with him, why do I keep re-upsetting him by telling him again?' So I kind of just said to him, 'look, I don't think you can come home at the moment'. I didn't say to him why, we just went on to other things [to talk about]. Do you keep slapping someone in the face with it or do you just – you know, I kind of feel until we've got somewhere to go we're better to just leave it. So it's been a hard one.

Contrary to a common and moralised perception that placing a disabled partner was equivalent to 'abandoning' the person, Naomi fully understood this was not the case:

Sometimes, you know, walking away and leaving Iain at the place, thinking, 'It's not going to get any easier, it's just getting harder,' you know. And I've got to find him a place, and hoping he settles, and that they care for him appropriately. It's challenging. So, from that point of view, I still probably don't feel that the weight's off my shoulders. It's just a different weight. Maybe I have a little bit more free time, but not a lot.

The long journey of struggles was yet to finish. Naomi was preparing herself for more to come. While other participants often mentioned various signs of recovery, which provided them with a sense of hope, Iain was steadily deteriorating. I asked Naomi what 'hope' meant to her:

Hope for what? I'm hoping that Iain will settle and he'll find some happiness in whatever time's left. Yes, there is that. My other shadow self says... I hope that whenever it happens for Iain it's quick and fast and that he doesn't keep losing more [personhood and dignity]. And in some ways one of my hopes hasn't come true. I did actually hope that he wouldn't really know where he was [due to a devastating loss to cognition] when we actually had to [make the decision to] place him in care. So I feel that more physical disability without more mental disability has been particularly cruel, and that's been difficult for me. It wasn't what I hoped. So in some ways I was hoping that Iain's next stroke – and I knew he would have one – would actually wipe out understanding of what was happening for him. Because it's been a very hard journey for him, exceptionally hard. I would not like to be in his shoes.

* * * * *

Alix's and Naomi's accounts of their relationships with their partners highlight the tensions for young couples where one has had severe stroke.. Care policies have traditionally been silent on these tensions, due largely to their construction of care as either a labour of love or a burden. Even recent policy frameworks that acknowledge the multidimensional and dynamic nature of care tend not to recognise the nuanced challenges that individuals face. For example, a Victorian care policy document (Victorian Department of Human Services, 2006b), drawing upon survey findings, acknowledges “the importance of family members having the opportunity to choose, moderate or reject the caring role.” (p. 12) However, by emphasising the importance of ‘choice’, the document fails to recognise the complexity of individuals’ lives, and instead constructs the partners of those severely

affected by stroke as able to unproblematically solve various practical and ethical dilemmas.

Skewed mutuality

Participants whose partner's limitations were more severe in terms of cognition and communication than physical tended to talk more about the changes in their relationships. Fiona's relationship with Matt prior to his stroke was characterised by collaboration, mutuality, and open communication. Both partners made financial contributions through paid employment, and shared everyday mundane tasks such as domestic chores and parenting. They were able to discuss and make decisions about the household and parenting together, as 'autonomous' and 'equal' individuals. Stroke, and Matt's consequent aphasia and cognitive difficulties, took this away from her:

I guess one of the things that I miss the most, even though Matt's much better, is just being able to sit down and talk about stuff with him, maybe stuff with the kids, all sorts of things. Whilst I still try to do that, it's obviously not the same because he doesn't have the ability to communicate effectively, well, effectively [may not be the right word] but communicate in the same way as he used to.

Fiona seemed to be carefully considering her words, caught between the need to express her sense of loss and her desire to avoid constructing Matt as 'disabled' and 'lacking'. Nonetheless, she continued, providing parenting as an example:

Particularly with, if I say to him, 'What do you think about [something with their teenage children]?', 'how do you think we should handle this?' He really doesn't have the ability to, what's the word, to talk about it like we used to, I guess, so I feel this in lots of ways all the stuff with the kids... [And I have to

take care of] Everyday things and ultimately I have to make the decisions on everything, even though I still talk to Matt about it, ultimately the responsibility is for me now to make decisions on everything, really. Look, Matt's improving and he has opinions now and obviously I take note of that, but the bottom line is still, it's my responsibility.

Matt's incapacity to communicate as he once did affected family dynamics. Their teenage children no longer approached him for advice and guidance about everyday matters, or about social and emotional issues typically associated with adolescent development, due to perceived and practical difficulties in engaging with him:

Whereas before Matt's stroke, [their teenage children] would come to him to talk about some things and come to me to talk about other things, but now they come to me to talk about everything so there's a bit there and I feel with guiding them and all of that it's pretty much my role now whereas before it was very much a joint thing, that sort of thing has been significant.

Fiona needed to take over parenting duties and decision-making, without the emotional and affective support from Matt that they had when they were "doing parenting, together." Although he was physically present, Matt was 'absent' from the parenting partnership. This was difficult for Fiona:

It affects everything. Obviously Matt's speech is improving which is great but I still miss having just a conversation like you and I are having now – the backwards and forwards is limited with Matt still, even though he's improving, it's limited. His concentration wouldn't last for a long conversation like this, so I miss that and I just miss being able to talk to him about anything. Because

we did, we had a relationship, which we talked about everything, that's the biggest loss for me.

The fundamental part—

Of our marriage and our relationship, definitely, I can't really think of anything specific but it's just that every day [things]. It's hard because we do have everyday conversations now, because his speech is improving and the more he talks the more he communicates with different people and us the more he's going to improve and I know he's still got improvement there but it's not the same.

Communication difficulties extended beyond those of an instrumental nature. Fiona explained that, since his stroke, Matt was “not quite as intuitive [emotionally] as he used to be.” She provided an example just before their daughter's overseas trip. Describing her daughter as “a real homebody,” she noticed that their daughter was very anxious about the trip. Matt seemed oblivious to her nervousness, and Fiona had to provide him with explicit instructions on how to support her:

I said to Matt, ‘Now, what could you do if you saw her having a tear or whatever, what do you think you could do?’ He thought about it and he said, ‘Say – what's wrong?’ I said, ‘Is there anything that you could actually do?’ and he thought about it and eventually I said, ‘Yeah, you could put your arm around her.’ The next day she was sitting on the couch next to him, she wasn't crying or anything, but I noticed he put his arm around her. Whereas before [stroke] that would've been something that he would've done naturally, he sort of needed the prompt. And then afterwards he looked me and he said, ‘Was that alright?’

Matt could now physically participate in an interaction, but although his participation in a conversation was encouraged as a ‘naturalistic’ rehabilitation activity, his verbal contributions were limited. Situations that required communication of meanings beyond superficial and/or instrumental matters, especially affective and nuanced interactions, reminded Fiona of Matt’s incapacity, and highlighted the difference from Matt of the past.

Accommodating the communicative difficulties in conversations posed practical difficulties for the partners of people living with aphasia. The taken-for-granted, smooth turn-taking in conversations was difficult to achieve, and this meant that even a simple conversation could become drawn-out. Even though participants understood that including their aphasia-affected partner in a conversation was beneficial to them emotionally, the slow, intermittent pace of the conversation frustrated them. As Emily told me:

So, even though I don’t have to physically look after Ryan anymore – I mean, he can shower himself, dress himself, feed himself, he can get his own cuppa and things like that – but it takes a lot of time with the communication, so I have to actually sit down with him... I’d be sitting at night time, waiting for him to tell me a word, and I’m thinking ‘I want to go to sleep, I’m tired’. Then you go to bed and he’s trying to tell you something, and thinking ‘oh, just shut up I want to go to sleep, I’m tired’, but you can’t tell him that, because then he would feel inadequate because he couldn’t tell you what he was wanting to say.

Emily was frustrated by Ryan’s communicative incapacity, although she clarified, “I’m not frustrated with him, it’s not his fault.” Ryan was not intentionally causing Emily’s frustration; rather, it was the stroke, the brain damage, and the consequential aphasia and cognitive difficulties. Emily could make this separation to,

perhaps, preserve Ryan's personhood, but the distinction was awkward and problematic:

[I'm frustrated], usually because I'm tired, or I want to go and do something else. So I get frustrated because I can't do things I used to do when I used to do them, and I have to actually stop and listen, and you have to sit there and wait and wait and wait sometimes, and it's really hard to — I try not to show that I'm frustrated, I say "okay dear, just [take your time]..." even though inside I'm thinking "oh for goodness sake, spit it out, will you".

Emily's attempts to engage with and include Ryan in conversations disrupted the rhythm of her everyday life. Daily routines previously done concurrently with conversing with Ryan – like "working out in the shed together, or I'd be helping him, or he'd be helping me inside do something, getting dinner out, or making a cuppa" – needed to be postponed while she paid her full attention to and patiently waited for what Matt wanted to say. She insisted that she needed to be patient to allow a lot more time for Ryan to express himself because it was, as his speech therapist advised her, an important part of his rehabilitation. So, she would wait for him to think of the word and then express it, even though most of the time she could interpret from cues what he was going to say. Maintaining her patience was not easy, however, when she was under life's daily pressures:

The speech therapist said, it's more important that you wait even five minutes for him to think of the word and get it out, than you saying it ... So sometimes I'm thinking, "oh I've got to let him get this word out", but I know exactly what he's trying to say, and it could be 10-15 minutes later [that he completes his sentence], and I think "oh I could have got it out in 30 seconds". And it's

hard sometimes, because I'm thinking, "oh I've got this to do, I've got that to do, and I've got..."

The directions from the speech pathologist, normative assumptions, and expectations about the role of spouses in ongoing rehabilitation at home, created other tensions for Emily. When Emily was conversing with Ryan, time flowed more slowly. But under the pressures of the everyday life, she did not always have patience or time. She provided an example of a time when she was using a home computer with Ryan sitting next to her. She made a spelling mistake and Ryan tried to communicate this. The difference in cognitive and communicative tempo frustrated her, leading her to snap at him:

By the time he said 'no, no, no', I'd deleted [the word] and gone on to the next thing. And then he'll go 'but, but, but', and I'll go, 'what are you on about?' Because I'm already six steps ahead of him, but he's trying to tell me how to do my stuff too, and I said 'darling, I know what I'm doing, butt out of it; you go crook at me when I'm telling you how to do stuff on the computer and I butt into you, so stop butting into me.'

This reaction from her "sent him into a downer". Since Ryan's emotional instability was one of Emily's concerns, Emily had to be careful about how to express her frustration. She was careful too about what kind of information to share with him — she explicitly asked me to send any research findings to her email account on her mobile phone, rather than their joint email account, out of concern that any portrayal of him as a 'burden' would upset him:

I can't always talk to Ryan about some things because I know it will depress him, or it will frustrate him, or he'll feel bad that he can't fulfil that particular

need, or he can't help doing what he does, and that will send him into a depressive low again. So I've got to be very careful what I say.

In the context of the open communication that they had enjoyed prior to stroke, this 'censorship' caused a sense of guilt:

I feel terrible because I've never hidden anything from Ryan in our relationship, and I don't deliberately hide things from him, but sometimes I just don't tell him things because I know he's not in the frame of mind to hear it yet. I will tell him later, and it could be a few weeks later, and I feel terrible, because when I say to him 'oh a couple of weeks ago...' And I feel terrible, it's like a burden, I've had that on my shoulder not being able to tell him because he's not in the frame, he's not capable mentally and emotionally to absorb it yet.

Emily tried to rationalise this act as "just part and parcel of it" to reduce guilty conscience. It was nonetheless difficult for her to bear — difficult enough to secretly wish his stroke sequelae were more of a physical, rather than cognitive and emotional, nature:

Sometimes I wish he was more physically disabled than mentally and emotionally, because I feel that would be easier to cope with... I think the mental and the emotional is harder because you can't see it, and other people can't see it either, so they don't realise what you are going through.

In addition, Emily now had to make certain household decisions alone:

One thing I really miss – because anything that we used to do, like organising holiday, where we would go, how much we're going to give to the kids for their wedding present, all this kind of stuff, we used to talk together about it.

But it's over Ryan's head now, so I'm having to make all those big decisions on my own. And I miss that, there's that missing link in our relationship.

This contradicted with her idea about what a household structure should be like:

I feel, as a Christian relationship, we believe the man's the head of the house, like God's the head of the house, and then it's the man, and he's in charge. So I used to say things, 'we'll do this or this', and if he said, 'no, we are going to do A not B', I'd say 'okay', and I respected him for that. But now, he doesn't know, and I just don't like to do things without his consent, and it's just – it's tough, I really miss that. And being able to have the deep and meaningful conversations. I really miss that

Emily mourned the loss of Ryan as she knew him before his stroke. However, she talked of the regeneration of their relationship. She recounted an occasion when she explained to Ryan that he needed to trust her decision making, because he was no longer able to carefully consider options. By doing this, she was hoping to establish a sense of trust – trust that she used to place in Ryan: "I feel it's important to still grow our relationship, we're still a partnership." However, she continued:

But he can't do his side of the partner. And I really miss that, because I feel like I'm running up a hill. Up a fairly steep hill sometimes, because I feel like I'm pushing the barrel all the time, because he can't help me. And it's not his fault, it's the stroke that's done it, but it's tough.

Although there were differences in how they understood the nature of 'working' spousal relationships, both Fiona and Emily experienced a sense of loss over *how* to perform a companionate and expressive relationship.

Now I return to Tracey; I have already described that the physical and communicative nature of stroke sequelae of her husband Ted prevented Tracey from

performing her previously taken-for-granted spousal roles. However, there were moments when she felt like the relationship dynamics resembled those prior to stroke, reflecting the dynamic nature of life. She gave an example of Ted making an effort to look his best when going out, even if it meant that he had to endure some discomfort:

He is very proud. He likes to go out and feel that he looks good. He still wants to wear trousers, that he struggles to do up on his own, which means he can't go to the toilet when we're out, but he wants to look good. So he'd rather hold on for the toilet than wear track pants when we go out. And he'll squeeze his feet into his nice boots, which takes ages to get on, because he wants to look good.

Ted dressing up in nice clothes, to Tracey, meant that he was doing his part in spousal relationship. Rather than presenting himself as a dependent 'care recipient' situated in 'care relationship', he was locating himself in the spousal relationship. His making an effort on his appearance signalled that he cared about Tracey as an intimate partner:

Yeah, because I like dressing up. I like looking good. If you're making the effort to dress up, and you've got someone who's just got trackie [tracksuit] pants on [that would be a let down]. He wants to also dress up and look good and feel good. That's a powerful feeling then, isn't it, if you think you look alright, then it helps you feel good, doesn't it?

Definitely. And do you think that's a part of Ted that has never changed?

Yeah. He's always liked to wear nice clothes that make him feel good. Yeah. And he's always very complimentary to me, you know, saying how he's always proud to go out with me and... so I think that's good that he wants to still make himself look good. Because he doesn't go out much either, so when we do go out he likes to make the effort.

However, this performance of intimate partnership was not easily or unproblematically enacted, as it was situated in material and bodily contexts. When they dine out, Tracey is reminded of Ted's bodily constraints, vulnerability and dependency, and of 'disabling' social arrangements:

If we go out with Ted, he can't pull his chair in because [the legs of the chair get caught] on carpet, so he has to sit down [first] and I put the table to him. Sometimes the tables are heavy, and no one offers any help – they just look at you and think 'what's she doing?' Lots of places we go to, he can't even get into the table because the tables are so close he can't walk around them. He'll ask for his food to be cut up by the chef sometimes, otherwise when the food comes I have to cut it all up for him, and he gets very self-conscious when he's eating because he tends to spill things. His left hand's still not really that good, and at home he has an apron on, but when he goes out he sort of tucks his serviette in, but he doesn't really like doing that. And then he always spills it down his top so he doesn't like wearing white, because otherwise he'd be walking out with all stains on his chest.

Concerns about stroke reoccurrence

The fear of reoccurrence was common, shifting from background to foreground depending on the state that their partner was in, with a 'tangible' impact on the relationship of partners. For participants whose partners had made a 'good' recovery and/or displayed relatively minor sequelae, this fear receded, especially if the partner had had no obvious risk factors prior to their stroke. Irene's husband Lucas had a stroke following an uncharacteristic migraine. The doctors could not figure out the cause of clotting that resulted in stroke, and described it as a random accident. This, and the fact that Lucas continued to adhere to what was considered a healthy lifestyle

– a few years on, he had recovered to an extent that allowed him to participate in competitive sport – meant that Irene rarely worried about possible reoccurrence:

Doctors pretty much said that was a freak thing, and there's not much of a chance it happening again – you know, there's as much chance of happening it again as the last time sort of thing.

Do you still think about the risk of another stroke?

I suppose you initially do, but because we sort of kept getting told that it's a freak thing and it probably won't happen again, so, well, I didn't [by the time Lucas was in the rehabilitation hospital, and] I don't think about that much [now], actually... because he lives a really healthy lifestyle anyway, there's not anything else that he really needs to change. So, not really.

That the medical knowledge system could not identify a precise cause of clotting, paradoxically, gave Irene a sense of assurance; she found it comforting to know that the chance of stroke occurring again was the same as anyone else, thus bringing the perceived level of risk down to the 'norm' of the general population. It was also reassuring to know that the stroke was not caused by Lucas' poor 'lifestyle choices' – it was not his fault. The mysterious origin of stroke and absence of risk factors prior to stroke shifted the perceived aetiology of stroke from controllable factors implicated in individual responsibility, to uncontrollable risks, obscure enough to be neglected in carrying on with life.

Time was important. Fear fades as time extended from the first and only stroke. Fiona's husband Matt was also fit – he was training for a marathon – and did not fall into any risk categories apart from a family history of cardiovascular disease. As with Lucas, medical professionals were unable to find out where and how the clot had formed, so they concluded: "it's a mystery, it's one of those things." When I

asked her whether this affected her thinking about the chance of reoccurrence, she said:

Actually I was thinking about that the other day — I don't think about that much anymore, I suppose because it's two years on and generally they say it's in the first few months particularly and then the first twelve months and then the likelihood of re-stroke gets less and less. I guess once we've passed each of those hurdles I don't even really think about it now.

However, increased visibility, albeit temporarily, of stroke symptoms, and/or a sudden presentation of signs of potential stroke reoccurrence, rekindled the fear. In Irene's case, it was Lucas having a headache. Despite stating that she no longer thought about stroke reoccurrence, a headache brought back fear: "If Lucas had a headache, I'll pretty much jump onto straight away and go 'what sort of headache?' that sort of thing, because that was the only early symptom [when he had his stroke]."

For Megan, a reminder of stroke, and fear of recurrence, was fairly commonplace. Simon's stroke affected the phrenic nerve, and it caused him to have continuous hiccups for the first 16 days of his acute care. Several years after the stroke, he still had occasional bouts of hiccups, a bodily warning sign of his fatigue and a vivid reminder of his stroke: "He still continues to hiccup now and usually when he gets tired, he hiccups. Every time that happens, you are re-reminded of the fact that he's had a stroke and that we have to be mindful that he's rested and can't take things for granted." Simon was not significantly affected in terms of his cognitive and communicative capacities, and had made a remarkable physical recovery to the extent that "people [who] meet him don't realise he's had a stroke". On the surface, everything might seem as though back to where things were before

the stroke, as many people in her social networks assumed. However, the fear of reoccurrence was very real:

Even to this day – he goes to work every day and he travels a lot with his work – I never once take for granted that he’s going to come home, because you never know what’s going to happen. The chances of him having another stroke are minimal, but he’s had a stroke, so he obviously has a predisposition to having them [again] – it is never far from your mind once it’s happened.

The fear of reoccurrence cast a shadow over many facets of Megan’s life, including with regard to family planning and mothering: they were initially uncertain if they could ever start a family. By the time the interview took place, Simon had resumed his full-time employment, and they had a young daughter Lucy, two years old at the time of the interview. Even so, the lingering sense of uncertainty prompted Megan to depart from her assumed ‘blueprint’ for her life:

I think for me, and especially having a child, [stroke] has really affected the way our lives have panned out since then. We bought this house with Simon’s mum and his stepdad ... so that if we wanted to have children then we could do that and cope [with daily challenges of raising young children] because I didn’t know whether I would have to go back to work again, and that thought is always there — if Simon has another stroke, I’m going to have to be the breadwinner.

Even though reoccurrence was unlikely, this was menacing enough for Megan and Simon to re-evaluate their life plans. Strategies were put in place as a safety net against the possibility of Simon having another stroke, which could diminish his capacity to perform the role of main income earner and parent. As well as providing this safety net, living with her in-laws provided instrumental and emotional support

that Megan would have otherwise expected from Simon were it not for his stroke, which reduced his tolerance for fatigue. To avoid stroke reoccurrence, Simon needed to get enough rest and sleep; this prevented him from sharing parenting tasks. This meant that Megan was carrying out most parenting responsibilities for their daughter, who was, as with any toddler, constantly active, wandering around the room and/or seeking her mother's attention for the duration of the interview. As she was preparing food for Lucy, Megan reflected:

What happens when you have a child and the child's very demanding, you get very tired, all the stuff that new parents talk about and I can't lean on Simon for that because he needs to sleep. If he doesn't sleep, so many of his stroke symptoms exacerbate. His hiccups return, his eyesight starts deteriorating, his balance starts going, he gets very sick very quickly, so him getting enough sleep is a very important thing for me to keep in mind.

Megan's primary role in household and parenting duties was inconsistent with their arrangements pre-stroke. Before the stroke, both Megan and Simon had worked and shared household duties, such as cleaning and cooking; they saw themselves as equal, autonomous partners:

You think that you're a team, that you're going to be doing things as a couple. That was the case for us, anyway, that's the way we had always talked about – that we had a very equal partnership with our relationship.... He was very much about we're both adults, we're both individuals, so that support has always been very equally balanced and I guess when he had the stroke I sort of had to take over that role a bit more.

The stroke changed their relationship. Although Simon was still involved in parenting and other household duties, striking an 'equal balance' to which Megan was accustomed was difficult, and this affected their relationship:

When I married Simon and when I had that image of what I would be as a life – taking care of him and taking care of my child – it didn't extend to wiping both my husband and my child's bottom in the first five years of marriage, that kind of thing, which is a bit crass to say.

The sense of suddenly 'mothering' her husband signalled a departure from the previously taken-for-granted spousal relationship. Now Simon was either the recipient of support, or had to have his share of household and parenting responsibilities covered by Megan. Megan also had to actively monitor his health and the level of fatigue to ensure he would not have another stroke. Simon resisted performing a sick and dependent, 'victim' role, and actively tried to resume some daily activities, such as vacuum cleaning. He resisted being 'mothered'.

While Megan appreciated him trying to perform the role of 'partner', she was also bothered by his attempts to 'move on', partly because of her concern that he not take on too much. Simon's sense of independence was therefore dependent on Megan's direct and indirect care work. Simon wanted to resume as many daily activities as possible to feel a sense of control over his body and destiny, and to put the stroke-tainted memories of the past behind him. She felt that he was emotionally and cognitively 'getting over it' while she was still dealing with and grieving over consequences of his stroke. She wanted to be reflective of what had happened, and to face this with Simon. However, to Simon, that would constitute 'dwelling on' the stroke:

He's pretty resistant to letting that [being dependent] happen... He's been very mindful that he doesn't want to become a victim of what happened and I guess that was another thing that really affected me because he didn't want to talk about it and I don't think he wanted me to talk about it... I would think, is important, but he doesn't want to revisit that part of his life at all now.

This enactment of Simon's 'independence' continued even after Simon returned to his work, and became the sole income earner. For Megan, care work was as significant as a formal, paid employment. When I asked her if she had resumed her work, she responded that she was not working at the moment. She then continued:

I feel like it's hard for me to go back to work because I'm still caring for him and the [level of] support that I have at home and with Lucy – she is very demanding – and I feel that between the two I feel very much like I'm working full-time, just looking after that family unit... My tolerance for stress is very low.

So although now Simon had become the 'breadwinner' and Megan was to perform a more traditional housewife role, so allowing Simon time and energy to perform an 'active' self, not only in paid employment but also in social activities. This gave Simon a sense of *independence* – a sense of control and spontaneity – that he found invaluable in 'moving on' from the past tainted by stroke. But Megan stated that Simon had lost a sense of spontaneity after the arrival of their daughter Lucy, and that this was similar to that after his stroke. And she grieved for him:

I think Simon actually found it harder having a kid than having a stroke in one sense because [even after] he had the stroke, he still had independence and that was really important to him, whereas I felt like I lost my independence way before that when I had to start looking after him, so having a child is

really no different to looking after a husband who's had a stroke. But he really grieved — the first few months, he was really depressed because he was like 'there are the small things I can't do' [because of the demand from infant care]. I think I've lost more independence and I guess that's the thing. I grieve for him. I grieve that he feels like he can't do certain things, like he used to enjoy doing sports.

Despite Simon's grief over loss of independence and Megan's feeling that he was trying too hard to 'move on', to Megan, this aspect of his attitude – desire for autonomy, dignity, and his forward-looking nature – was the cornerstone of their relationship. Although her grief and loss featured heavily in her narrative, she insisted that Simon's attitude after stroke had reinforced her commitment to him. After telling me about his eagerness to help her with household tasks such as cleaning, she continued:

He was always trying to help. He's really balanced me out in my life as well. I was a lot more unstable emotionally before I met him. And, so, he's been a very good influence in my life and I hope the other way around, but I guess that emotional part of that relationship has been – it's [stroke] really cemented us. I think, the moment that the stroke happened was not the moment that I define as the most important of that time. It's the time when I was sitting in intensive care and Simon's cracking jokes about having a stroke, I was like 'how can you do this?'... He was just so buoyant and it was that particular moment that I knew that I'd married the right person as opposed to [just] the man that I love, I married the right person because he wanted – I wanted to be a better person around him, even when he was in a hospital bed, having had a stroke. Because, if someone has that depth of character, you think to yourself I

need to dig deep because if he can do this when he's like that, I should be able to do this when everything's fine.

Although Megan faced hardships and uncertainty that accompanied living with impacts of Simon's stroke, to her, his response to stroke – his resilience – reaffirmed the affective basis of the spousal relationship.

Stroke as revitalising relationship

Stroke fractured many spousal relationships, although sometimes fracture allowed for regeneration. In many cases, participants spoke of their partner as 'different' person to whom they married. Abi felt her husband Cain was a 'new man' after his strokes, especially the second one that significantly affected his cognitive functions. However, unlike other participants, Abi told me that her "world somehow changed for better" after Cain's stroke. Marriage prior to stroke had not been happy, and she and her children had had to endure Cain's abusive behaviours for years:

Before the stroke he was very bad... not thinking about the family... I was mentally so abused, psychologically [exhausted]... He was a very abusive man, and he was very controlling.

Because the family environment was so tense prior to stroke, when Cain had a series of stroke and was severely affected by them, even their own children suggested to Abi to leave him. She was not prepared to do so:

They [children] hated him. They hated him so much that they wanted him out [of their life]. And when he had the stroke, they said to me, "mum, you can't keep him, get rid of him [because] now you've got a chance to get rid of him". I said, "I can't do that. He doesn't have anyone [in Australia, as he has

migrated from South Africa]. How can I bring myself to do something like that?’

She was initially tempted to leave him:

Because I was in the midst of the abuse he did before, emotionally I was still angry with him. So, when I started looking after him after the first stroke, I felt that I was not prepared. There was no reason for me to look after him. Because that time my kids were [also] so angry with him, and I was so angry with him, when he does something [that were triggered by his functional or cognitive deficits] I was so angry with him. It was *SO* messed up [her emphasis].

Abi initially took on caring because of her understanding that a wife ought to look after her husband. Her decision to stay, however, seems to have been strongly motivated by a mix of her personal beliefs, Christian faith, love for the children, a sense of parental obligation, and a means to personal development:

As a human being, we've got no control over our situation — we can be normal healthy, and the next minute you can become very significantly disabled. And — I don't know if it's because of my religious belief — but you learn that everything happens for reasons. And, I have this problem, because God knows I can cope with it. So I know I can cope with it.

Caring for Cain was a means to teach and impart her values to her children. She believed that despite his past abuse and the current hardships involved in care, this set an example for their children.

I had to talk to her [one of her children who suggested her to abandon Cain], and said, ‘you don't throw out the problem, you will learn through this, this is a learning experience.’ I can't [place him to the nursing home]. I can't bring myself to do that ... I don't think it's for me, as a parent, to set that example to

my children... Because even myself, one day I could have a situation like Cain, and they will get rid of me!

Abi also explained her motivation to care in terms of karma; her deeds would have consequences in the future, either directly or indirectly through her children:

I believe in karma too. I have a son, and I don't want my son to pay for my doing. Because my husband, whether he was bad or not, whatever he was doing, he is a son of somebody, and he is a brother of somebody. Whatever he is. So, I believe if I had done something bad to him, or abandon him, or not take care of him, my son will pay the price for him. And that's how I'm going to pay the price, through my son... And I don't want my son to be treated like that one day by the wife.

Abi emphasised that she 'voluntarily' took on the caregiving role out of her love for their children and her sense of duty as a mother:

At times he was making me upset, there were times when he was thinking that he had the right, it's a must [for] me, as a wife, to look after him. I said, "no, it's not a must, I can divorce you any time, and not even the government can force me to look after you. No, I have my right as a human being to have my life". So, when I decided that I'm doing it, I'm doing it for the love of my kids. Because I don't want my kids to stress. So, it's a commitment I made for my kids, in my head... Yes, it is a parent thing, protecting a child.

The six years of caring involved duties that might have appeared quite burdensome to casual observers, but Abi's faith and sense of fulfilling the parental obligations made her content; the 'new' world was better than that which she had had before. It was much more peaceful:

So, we now have peace in the house [after his stroke...] He doesn't abuse anyone, he doesn't shout to anyone. So, he's a new man. We can talk with him, we can laugh with him — before we couldn't do that. To be honest, I can't complain (laughing)... even my daughter said, 'I prefer this situation than before.'

Rather than experiencing life after Cain's stroke as 'biographical reinforcement' (Carricaburu & Pierret, 1995), where her caregiving duties were an extension of her struggle in an abusive marriage, Abi described stroke as a pivotal point in obtaining a sense of control. Cain had previously controlled household decision making. Although much of her time now was spent on caregiving duties, she had control over her life, parenting, and paid work arrangements:

[As well as being in a controlled relationship], I was still working hard at home. Now, I'm more relaxed, I don't work as much, just because I choose not to work, but I'm happy not to work much... And control, so I got back my controlling my life better now. I decided if I want to go out, if I want to have friends over, if — whatever I want. So I have more freedom than before — whereby he was controlling my life and kids' life in an abusive way.

Stroke as a gift

In many ways, the narrative Adam and Belinda shared with me was anomalous. They met after they had both had strokes, when Belinda was living in a retirement village in a rural town, and Adam was living in an outer suburb of Melbourne. Belinda's marriage was dissolved three years after her stroke, and Adam had never been married. They met through a dinner organised jointly by their respective stroke support groups and, once music started, Adam asked Belinda to dance. They spent the

following day together, and when they parted ways, Adam had Belinda's phone number in his pocket.

Their life changed dramatically. Soon after they met, Adam started commuting on weekends to the town at where Belinda lived. They would spend the weekend together, and Belinda would drive Adam back home. This continued for a few months, until Adam suggested she move in with him. The distance between them was an issue, but it was also that the retirement village was not the most appropriate form of accommodation for Belinda. The room she had there was tiny, and in her early 40s, she was the youngest person there. Adam explained that Belinda getting behind the wheel for a drive was "her outlet, how she compensated" for her life there. Soon after she moved in, they became engaged, and married.

I was still holding a preconceived idea about carers and care recipients at the time of the interview, and I asked them to nominate the 'carer' in the relationship. They both nominated Adam. However, when I asked to clarify this, the response was less clear. Belinda did all the driving, and she was very mobile; Adam's caregiving was limited when they travelled to places without an accessible and safe shower room. "She's very low maintenance", Adam offered with laughter. But Belinda had aphasia, and Adam, for most part, did the 'interpreter' work.⁶⁸

What made this interview unique was their explicit resistance to having their identities and their relationship defined by stroke or informal care. When I asked about the meaning of providing care to each other, Adam insisted:

⁶⁸ I did not have any arrangement for the interview to accommodate Belinda's communication difficulties. In fact, as they both nominated Adam as 'carer' in our communication leading up to the interview, I was not expecting that Belinda would be so eager to participate in the interview. My preconceived ideas and attitude enacted Belinda's 'disability', and at the same time prevented her meaningful participation in the interview.

I don't see us as carer and recipient. I see us as husband and wife. I don't know, that I'm doing anything different with Belinda, if we got together and hadn't had strokes. I don't know if the stroke had made any difference to the giving and connection between us at all. She is my wife, I react to her, and I respond to her as my wife [Belinda is saying 'Yes', to each of his statements]. The stroke is irreverent.

So, to you, stroke is just a part of—

Belinda: Loving —

Adam: And supporting each other.

In fact, they both described stroke as 'gift'; it enabled them to feel a sense of control over their lives. As Adam described:

For me, to be down about my stroke would be to reject the gift, because my life is so much better, so much happier, so much lighter, so much fuller, than ever was before.

Adam described his life before stroke as "bland," characterised by stress from work, "copious amounts" of alcohol and cigarette, and no social life. The second stroke that he had in 1989 was life changing. He stopped smoking, cut down on alcohol, improved his diet, and started walking instead of driving. He had lost his job, but this was compensated by superannuation – "nothing flash, but it pays the mortgage and puts food on the table". He travelled overseas on a number of occasions and started performing in a choir,⁶⁹ which became his passion. He was also able to use his time and energy to pursue spirituality, which has come to be an integral part of his

⁶⁹ The choir group of which Adam was a member, was different to the choir group for people with aphasia that I attended during my fieldwork.

life. He appreciated these things that have been introduced to his life since stroke. So too, Belinda was grateful that they met because they both had had a stroke:

Adam: I really don't need much else. I really don't need to get caught up in meeting deadlines, I don't need to get caught up in being pressured to perform. I have a very good life. Not perfect, but it's pretty good, much better than used to be. I've got the freedom and time to indulge in my spirituality... I couldn't have done [travelling and performing with the choir] if I was working. If I hadn't had the stroke, I wouldn't even get to the choir practice in the first place. I got all these outcomes, which just wouldn't have happened if it wasn't for stroke. So, what else can I say? It is the best thing that happened to me. I wouldn't have met Belinda.

Belinda: Me too. Best thing. Um, stroke, I met Adam.

Abi, Adam, and Belinda described the lives after stroke as better, and in doing so, they actively resisted the cultural narratives of stroke as a tragedy and of caregiving as burdensome. This emerged out of various subjectivities situated in the contexts of cultural, religious, and philosophical beliefs, their biography, gender, and their own body and that of their spouse, which were understood as more manageable than before the stroke.

The stroke-affected body introduced uncertainty into participants' lives, and this led to various rearrangements of responsibilities in the spousal relationship. Participants faced myriad of ethical dilemmas as their partner's capacity to perform partnership was compromised. However, the decisions made in response were not absolutes; they were nuanced and often fluid, and constructed within cultural and biographical contexts. Various tasks assumed by participants post-stroke – most obviously 'thinking' on behalf of the stroke-affected partner, but also other seemingly

mundane activities – skewed the distribution of responsibilities. In the cultural context in which personhood is closely tied to the notion of rationality, self-awareness and governance, and moral autonomy, having to assume everyday decision-making based on the stroke-affected partner's welfare affected the very nature of the spousal relationship.

However, this 'dependence' was not always or wholly negative. It could also have regenerative effects both individually and as a couple (Frank, 1991). Even so, in many cases, this was not what enticed participants to assume care, and was experienced more of a 'by-product'. As Naomi summed up:

It's been a journey that we would have preferred not to have. And I'm not going to say that it's [all negative] – yes, maybe it's helped me grow as a person and yes, it's probably taught me some different things about life and stuff like that, but I wouldn't say it's enriched my life. It's been something I've just had to deal with and try and find the way forward and try and find some enjoyment in life along the way, for everybody. Because you only get the day, that day...because nobody has any guarantee of how long you've got. So certainly, I'm not a saint.

In this sense, the notions of 'strategy' or 'coping' do not quite capture participants' experiences; rather, impact of care on the spousal relationship was experienced as a complex, diverse and unfolding process emerging out of physical, philosophical, social and cultural relations (Fox, 2005). In the final chapter, I will discuss how these various relations could be considered in a wider societal context.

Chapter 9

Ordering a caring society

In this study, I sought to explore the experiences of spouses of relatively young people who had had a stroke. Each of previous substantive chapters focused on a particular dimension of participants' experiences. In this chapter, I locate my research findings in the context of contemporary Australian policies. This will be followed by concluding remarks including contributions and limitations of the study.

Fractured lives

Stroke is a disease commonly associated with an old age. Partners of people whose stories I have told in this thesis defied this assumption; they were relatively young – at a 'productive age' – and did not, as a collective, perceive themselves and their partner as the stereotypical 'old, sedentary, and/or unhealthy' people. This meant that the onset of stroke was neither expected nor accepted as a 'part of an on-going life' (Faircloth et al. 2004). This unexpectedness of stroke onset in their partner challenged participants' assumed coherence in life. In the acute settings, surreal feelings characterised their experiences; all of a sudden, they were in an unfamiliar sections of the hospital, hoping for their partner's survival, desperately searching for signs of his/her recovery, and feeling daunted by uncertain prognosis.

The sense of uncertainty continued long after the onset of stroke and eventual discharge home. This involved concerns not only about the physical conditions of their stroke-affected partner, but also around their financial future, maintaining social relationships, wellbeing of their children, and feasibility of fulfilling what they assumed to be 'normal' life. While the sense of uncertainty sometimes shifted to the

back of their mind, there were many things that brought it back to the foreground; fatigue, communication and/or cognitive difficulties, unsteadiness and other stroke sequelae not only served as symbolic reminders about stroke, but also necessitated practical rearrangements in many aspects of their lives.

These rearrangements were expansive and included providing practical, emotional and rehabilitative support, as well as assuming responsibilities that their spouse was no longer able to fulfil. These changes ensued by stroke impacted upon various domains of participants' lives including spousal, familial, economic, employment, and social relations. Gender mediated both changes brought about by stroke and how spouses experienced them. As I discussed throughout this thesis, and especially in Chapter 3, the explicit and implicit assumptions around caregiving as a women's role permeated policy, clinical and social services, and were reflected in people's accounts. The assumption that carers do not need comprehensive training to take on what could be considered semi-professional jobs as carers suggests that they – women – were assumed to 'naturally' possess competence in providing care.

These assumptions created tensions for participants; although women often accepted the gendered nature of caring for their husband as a given, they also had to negotiate various consequences of this. Apart from the great practical difficulties they faced in conducting caregiving tasks, many wives discussed how they had to assume more assertive and active roles in public activities, such as advocating for formal support for their husband and conducting tasks often considered men's jobs. These, however, often contradicted with their gendered identity embedded in the spousal relationship with their husband. For example, Megan described herself as 'mothering' rather than 'wife-ing' her husband, and Tracey expressed sadness over not being able to perform the kind of wife she thought she was before stroke (Chapter 8).

Men also had to negotiate various new responsibilities following their wife's stroke. However, the cultural assumption that the man was the sole household provider, especially in cases where dual income was not possible, had a firm hold on people's was culturally pervasive. While men seemed to unproblematically accept that they were to return to paid employment as soon as their wife's condition stabilised, this ensued great practical difficulties. The kind of work, and the role and position they occupied at their workplace, appeared to be less affected than was the case for women. This coincides with my observation that there were hardly any younger men accompanying their stroke-affected partner at support groups. Many female participants also participated in paid employment after their husband's stroke, both out of necessity and as a means to minimise the impact of stroke on their selfhood. However, most of them did not immediately return to work, as male participants did, and, once back at work, they often worked in part-time or casual employment.

Experiences of care were mediated by different contexts, including gender and age, and were characterised by profoundly disrupted biographies. Bury's (1982) concept of 'biographical disruption' acted as a sensitising concept in development of this study, directing my attention to *why* caring for a partner at a relatively young age might be experienced as 'burden'. Traces of this concept are evident in participants' accounts of the various impacts of stroke on their lives and their sense of self. However, despite its conceptual utility in some aspects of participants' lives, it did not capture the full picture. For example, the concept assumes that there is an assumed 'normal' that is seemingly context dependent, and people follow a singular, linear progression towards it (or fail to do so). My participants' accounts illustrated that impact of stroke was multi-faceted; their various domains of life including spousal,

familial, employment, and social relationships were affected. The act of caring for their partner was one of many interwoven, yet sometimes conflicting, aspects of their lives. Within and amongst these domains of biographies, there were moments of ‘repair’ (Locock, et al., 2009), ‘reinforcement’ (Carricaburu & Pierret, 1995) and, indeed, ‘disruption’ (Bury, 1982), ‘flow’ (Faircloth et al., 2014) and ‘continuity’ (Pound et al., 1998). That is, the linearity of the concept of biographical disruption was challenged. Furthermore, the concept assumes that ‘disruption’ is solely caused by an onset of illness. This obscures various wider social forces, including limitations and insufficiency in support provided by the state. In fact, this assumption is reminiscent of the way policy constructs care relationships.

While policy and healthcare practice assume that the spouses of people who had a stroke will suddenly become ‘carers’, and that they exist only within the ‘care relationship’ – a self-contained unit, my participants’ accounts illuminated that the everyday lives of ‘carers’ are much more complex. In the remainder of this chapter, I will present concluding remarks and implications of the findings in relation to the contemporary Australian welfare policy.

Ordering a caring society

[A] myth that is firmly upheld is that disabled people are dependent and non-disabled people are independent. No one is actually independent. This is a myth perpetuated by disableism and driven by capitalism – we are all actually interdependent... The world has been built to accommodate certain needs and call the people who need those things independent, while other needs are considered exceptional. Each of us relies on others every day. We all rely on one another for support, resources, and to meet our needs. We are all

interdependent. This interdependence is not weakness; rather, it is a part of our humanity (Withers, 2012, p. 109).

I have so far highlighted how the lives of partners have been affected by various and profound changes following their partner's stroke; these changes occurred as a consequence of both providing care and assuming responsibilities that their spouses were no longer able to fulfil. Rather than locating these experiences in the narrative of 'caregiving as burden', a dominant representation in the literature (Chapter 1), I attempted to provide a more nuanced picture; while these care relationships were characterised by various forms of dependence, these were complex and embedded in multi-faceted networks of social, economic and moral relations. I now shift my attention to the forms of dependence amongst relationships, most notably those between the family and the welfare state. In this last section of the thesis, I consider wider implications of these findings in the context of neoliberal Australian policies, followed by concluding remarks about contributions and limitations of the study.

As I illustrated in Chapter 3, although policy acknowledged importance of informal care, this recognition was limited to the idea that carers provided the government with a means of reducing its health care costs. This masked the government's responsibility for providing long-term rehabilitation, disability, and carer support for people who have had a stroke and their carers. I opened this section of the chapter with a quote from *Disability Politics and Theory* by A.J. Withers (2012). While the passage concerns assumptions of dependence embedded in ableism, I borrow it to draw our attention to the inter-dependent nature of the society, and the skewness in the dominant conceptualisation of dependence, evident in current welfare policies as I will explain below.

In times like these...

This study took place in the aftermath of the global financial crisis (GFC). Although the impact of this was less severe on Australia than many other countries, the Australian economy, its financial market, and balance sheets – from individual households to the federal government – were not immune. Budget deficits, dubbed ‘blowout’ by various media outlets, were a focal point of the 2013 federal election, and ‘fiscal responsibility’ and ‘rational economic thinking’ were the gospel of the pre-election campaign on both sides of politics.

Meanwhile, health has become a large part of the economy. Australia as a nation spent \$147.4 billion in 2012–13, equivalent to 9.6% of the national GDP — compared to 6.8% in 1986–87 (Australian Institute of Health and Welfare, 2014b). This trend was projected to continue – some may say, with a vengeance – due to demographic ageing, which is supposed to become a ‘burden’ on national prosperity. Given that almost 70% of the national health expenditure was contributed by Australian federal and state/territory governments (Australian Institute of Health and Welfare, 2014a), it has increasingly become a source of budgetary pressure on governments already struggling with falling revenues. Health spending took up 19% of federal and state/territory governments’ combined expenditures on top of another 22% for welfare (Daley et al., 2013), and this has come to be seen as an area of potential budget savings. The current federal Liberal-National Coalition government was considering a \$5 ‘co-payment’ — a term that fits neatly with the scheme of ‘mutual obligation’ that has come to dominate welfare policies⁷⁰ — for Medicare

⁷⁰ Initially limited to unemployed young people in 1990s, the scope of mutual obligation policy has since expanded, and is expanding, to cover older adults, single parents, people with disabilities and entire Indigenous communities (Catholic Social Services Australia, 2007). More recently, an interim report prepared for *Review of Australia’s Welfare System*

bulk-billing GP services, which is currently free of charge. In November 2014, the federal government fully privatised Medibank Private, a previously government owned private health insurance provider;⁷¹ its status had already been changed from not-for-profit to for-profit in 2009 by the previous Labor government.

At the same time, the Victorian Liberal Government was in the process of privatising or closing government-run residential care facilities (Adoranti & David, 2014). Although these were considered to be ‘aged care’ facilities, many younger people with severe disabilities – people like Naomi’s husband Iain and Yvette’s ex-husband Chris – were also placed in them due to lack of more appropriate options. This move – the sale or closure of 1,000 public aged care facility places (out of 4,076 high care and 1,980 low care beds which were operational as of March 2014, according to Victorian Department of Health, 2014) – was expected to save the state government \$75 million from its health budget over two years, while the sale of the facilities would also add another several million dollars to the state government revenue (Hagan, 2013).

Apart from being able to use the cost savings and proceedings of sales to plug the budget hole, the idea of healthcare privatisation was made appealing by the prevailing belief, especially by the government in power, that the private sector is better equipped and more efficient at running the healthcare system. In the examples of Medibank Private and Victorian aged care facilities mentioned above, these moves

(Department of Social Services, 2014) frames welfare and employment policy for carers in terms of ‘mutual obligation’.

⁷¹ Medibank Private was initially established in 1976, a year after the establishment of a publicly funded universal health care scheme, then called Medibank and now known as Medicare. It has operated as a Government Business Enterprise with the Commonwealth being its sole shareholder. For further details about the complex historical and political contexts of the birth of Medibank Private, see Buckmaster & Davidson (2006). A research report by the Private Health Insurance Administration (2013), a Commonwealth statutory authority, also provides background information about the private health insurance market in Australia.

were justified on the grounds that “a privately-owned fund would be able to be more efficient” (the then federal Minister for Finance and Administration Nick Minchin on Medibank Private, cited in Buckmaster & Davidson, 2006, p. 2), and privatisation “is a very successful model... very often the private and community sector can run it as well or often better” (the Victorian Health Minister David Davis on privatisation of public aged care facilities, quoted in "Sale of aged care beds to private sector raises Opposition concerns," 2013, para8).

This belief is a myth – or only conditionally and partially plausible. For instance, Duckett (2005) demonstrates in an Australian study the negative impact of the expanding private sector on patient waiting times. On the other hand, while in a different social, cultural, and political economic context, the Danish healthcare system remains almost entirely public, yet maintains comparatively higher efficiency, in terms of both service provision and costs (Mooney, 2002). Furthermore, what constitutes as ‘running well’ depends on the definition and measurements. For example, ‘slow-stream’ rehabilitation was considered less profitable and, therefore, many privately run rehabilitation facilities tended to accept fast-stream patients over slow-stream patients in an effort to profit maximisation – and as accountability towards shareholders, in cases of publicly listed companies.⁷² It is this kind of rationalisation – where quantitatively calculable efficiency, often in financial terms, prevails at the expenses of potential qualitative experiences of suffering – that may

⁷² This was one of the concerns expressed by the Australian Competition and Consumer Commission (ACCC) in a proposed acquisition of the Brunswick Private Hospital in Melbourne by Healthscope Limited, a company publicly listed in the Australian Securities Exchange (ASX). The ACCC was concerned that once acquired by Healthscope, the Brunswick Private Hospital, which had a reputation for accepting slow-stream patients, may have less incentive to accept slow-stream rehabilitation patients, who yield less profits for the ASX listed company (Australian Competition and Consumer Commission, 2014).

lead to “irrationality of rationality” (Ritzer, 2007: 54-58). As Naomi’s experience demonstrated:

When Iain broke his hip just before Christmas, they pinned it and then he went into rehab for some period of time after that, and there’s whole stories about [how] private rehab wouldn’t take him... He was in [a private hospital for the surgery] and they said wouldn't take him [at their rehabilitation wing. So Naomi had to find somewhere else for post-operative rehabilitation]. Then three days before Christmas, they said they'd take him. Then the day before Christmas they told him they couldn't keep him, because he was too much work. And I said, ‘Well, where am I going to go at this point, the day before Christmas?’

In fact, the compatibility between health care and the free market ideals has long been questioned (Arrow, 1963; see also Mol, 2008); people who use health care services do not have as much ‘choice’ as portrayed in the neoliberal rhetoric. Technological, systemic, and funding constraints mean that people are often not presented with a wide range of alternatives to choose from, and available choices are also shaped by their financial, social or cultural capitals. Furthermore, few have access to expert knowledge in health care to evaluate available choices. Available choices are even more limited, when people are under moral obligation to provide care to significant others, such being the case with the participants of this study.

Nonetheless, successive governments of both sides of politics have encouraged the expansion of the private health sector through private health insurance rebate as a carrot, and the Medicare Levy Surcharge as a stick, for mid- and high-income earners who did not purchase private health insurance. Meanwhile, public health campaigns discussed health – or rather, seemingly, a *lack thereof* – in terms of

disease ‘burden’. They targeted ‘preventable’ lifestyle diseases that were threatening the national wellbeing – and the productivity level. As I discussed in Chapter 7, they often construct normativities regarding how lives ought be lived. The message was thus: Individuals ought to take care of themselves because it is good for them and/or we, the society, cannot afford to look after them and maintain ‘healthy’ economic development.

The community sector, which historically has always played an important role in social and health service provision in Australia, was also struggling in the waves of economic rationalism. At a fundraising event for a small not-for-profit organisation that I attended, the host eloquently expressed that there was ever increasing pressure on community organisations to remain “not-for-profit, but not-for-loss” by replicating and incorporating many features and strategies of for-profit enterprises.⁷³ In this political economic climate, ‘carers’ have become ever more important.

The complexity of family care

The explosion of policy attention on carers in Australia in the last decades has been the continuation of the ongoing process that initiated three decades ago. This ‘discovery’ of carers in Australian political landscape in the 1980s and onwards has been based on demographic, cultural and structural transformations, including women’s increased participation as paid labour in the formal workforce, coinciding with demographic ageing, the feminist movement, and its focus on gendered

⁷³ The small non-profit organisation was a social enterprise running catering business to provide hospitality training to young people with disabilities. This organisation was born of the closure of a nearby university/technology college campus due to funding cuts. Its hospitality course had attracted a sizable number of students with disabilities, and when the campus closed down, two teachers decided to set up the social enterprise in order to continue providing training and work opportunities for young people with disabilities in the local area. This also reinforces my point below regarding existence and maintenance of support network relying initiatives of handful of individuals.

inequities in care responsibilities. More recently, however, it was an understanding that carers are cost-effective resources, with “the valuable social and economic contribution” to society (Commonwealth of Australia, 2010, p. 9), that has propelled the importance of carers as a political agenda. Carers have attracted attention, precisely because they were cheap economic resources against the backdrop of the perceived ticking time bomb of demographic ageing.

My argument is that the way that carers have been constructed in current policy and practice frameworks failed to capture the complexity involved in spousal care. Carers centrally constructed in them remained largely static. I use the word *static* in two senses. Firstly, these frameworks assumed that the spouses of people who had a stroke would suddenly become static ‘carers’, existing only within a ‘care relationship’. Even the policy frameworks that acknowledged the dynamic nature *within* care relationships, for example, in the Victorian policy framework *Recognising and supporting care relationships*, a care relationship was portrayed as a self-contained unit: “care by definition involves the interconnection between the person who gives care and the person who receives care” (Victorian Department of Human Services, 2006b, p. 10).

Yet, as I have shown throughout this thesis, caring did not occur within a vacuum that is the “care relationship” – it took place in a network of people, groups, institutions and things. Care relationships intersected with various relations of financial support, parenting, employment, filial responsibility, and personal ethics, as the participants’ accounts demonstrated. As Anna explained, not only from her own experience of the time around her husband Jason’s stroke, but also from her observation of other people who she met through a stroke support group:

Everybody assumes that people are going to be focused 100% on recovery. Well, for some people they've got that many other things, financial or children, because younger people might have quite young children. So they have all these other things that they're thinking about, but often there's a total unawareness out there that that will be an issue. The medical people are thinking, "What can we do to aid this person's recovery?" But [the carer] is thinking that their mortgage is due in a week on Friday – how on earth are we going to pay it? Paying the rent? Paying the car loan, etc. What do I do? Who do I go and see to get help in this area? And the hospitals are not geared up for that.

Spouses of people who have had a stroke had to rely on various people and things, as I have discussed throughout my thesis. In acute settings, they had to rely on the specialists and medical technology to save their partner's life. They also had to rely on their friends and relatives in fulfilling their other responsibilities. Rebecca had help from other parents taking their children to local sports events, and Alix's neighbour coordinated their house renovation so that the house could be sold in an attempt at preventing her household's financial breakdown. The food roster run by Irene's friends provided meals on the table for the first three months after Lucas' stroke and, together with friends' help with their young children's school drop off and pick up, this help allowed Irene to make the gruelling hospital visits from their rural hometown to Melbourne. Will's business partner and employees covered his work responsibilities to provide continuity so that the business could retain customers, and Emily's friends at the church provided her with important spiritual support when Ryan's prognosis was still unclear.

Beyond the initial period after stroke, Elke's mother-in-law shared some caregiving activities so that she could go back to paid employment and, after Elke herself became ill, to give her brief breaks so that she could focus on her own health. Meanwhile, Megan's co-residing in-laws provided instrumental and emotional support that enabled her to become a mother. This was despite the fact that co-residence with in-laws, a departure from the 'normal' nuclear household structure, would not have been her choice, had it not been for Simon's stroke. The medication and the work of various medical professionals, who were willing to work around the clock to maintain Eva's blood pressure level, enabled Neil to feel a sense of certainty at home.

Furthermore, various forms and degrees of home modification and care equipment mediated the social, physical, and emotional impacts of their stroke-affected partner's reintegration into the everyday life at home, even though the financial support for this was limited. Similarly, despite some relatives' opposition, a security surveillance system allowed Will to monitor his wife Nadia's safety while he was away from home. Low-sodium stock cubes delivered from a health speciality store in Tasmania allowed Anna to prepare meals that met dietary guidelines given by her husband Jason's dietician. This allowed them to observe a *healthy lifestyle* without spending a large amount of time going through food labels at the supermarket and preparing stock from the scratch, and reduced the impact, practically, phenomenologically and financially, of altered culinary practice following stroke. Emily's casual employment, and Ryan's sympathetic and understanding employer, enabled them to participate in the formal economy, and consequently, allowed for a coherent and routinised 'new normal' — though vastly different from their life prior to Ryan's stroke.

Mutual obligation and dependency

To an extent, this support led people to feel *dependent*. In some cases, it was experienced with a sense of isolation. Alix, for example, reflected that her family unit, with Erwin now severely disabled, was ‘too hard’ for her circle of friends to accommodate in social activities. Some participants attempted to actively resist being labelled as a burden by drawing upon the cultural ideal of self-reliance. As Rebecca said, “we’re not burdening the world with it, we’ve got to get on with it.” This was ‘doing’ dignity; this allowed them to preserve their sense of self-respect and respect by others in the context of cultural expectations (Griffin-Heslin, 2005; Jacobson, 2009). However, ‘getting on with it’ was also a necessity, for available formal support structures were limited. The welfare payments were “measly” (Will) and a lack of ongoing rehabilitation options meant partners of people who had had a stroke were often required to find and meet the costs and means of ongoing rehabilitation activities on their own. The service system was not capable of offering meaningful choices for partners of severely disabled people, who were much younger than typical residents at aged care facilities. Most residential care facilities also did not offer meaningful ongoing rehabilitation, from which they would still benefit. In these cases partners felt stuck in the care relationship.

The carers as constructed by policy and practice were also static in the sense that they were left with little room for change. Instead, they tended to reproduce relations of power. This was because various policy and practice interventions have tended to operate on an individualistic model and did not address systemic and structural inadequacies. Of a relatively small amount of support services available to carers, most fell into the category of psycho-educational interventions, such as counselling and information provision about coping strategies and available resources.

One of the issues was that spouses often do not have meaningful access to them, as I discussed in Chapter 5. When they were delivered effectively and meaningfully, they could indeed be valuable and useful. Still, the underlying assumption remained individualistic; the solution to ‘caregiving burden’ was to ‘train’ carers to operate more effectively within the constraints of the existing, inadequate structure (Hooyman & Gonyea, 1999). The result of this was that care relationships as self-contained units were supported to prolong their existence, as long as it made fiscal sense in conventional economics.

Meanwhile, carers were also encouraged to seek their own wellbeing, means to personal fulfilment, and to become “an entrepreneur of itself” (Rose, 1998, p. 158) through social, economic, employment, education and training participation. The normativities around socially and economically engaged citizenship performed in healthcare and carer policy and practice were not, in themselves, problematic. Many participants identified with elements of such normativities. Alix was able to feel ‘normal’ when she was at paid work, because this enabled her to perform a young and engaged subjectivity, positioned in professional relations and characterised by mutuality and intellectuality – the elements now largely missing from her spousal relationship with Erwin.

However, despite the rhetoric of ‘carer recognition’ and ‘*mutual* obligation’, the state on one hand encouraged carers to engage socially and economically, while on the other, it withdrew from the responsibility to provide much needed structured care and support, such as continued, ongoing, meaningful rehabilitation that could foster the stroke-affected partner’s capacity. Furthermore, income support payments for carers were framed more as ‘gift’ or ‘good will’ than ‘entitlement’ and this led to the belief that the increasing expenditure on carers should be addressed in relation to

carers' "reliance" on income support (Department of Social Services, 2014, p. 36), or to their potentially claiming the benefits inappropriately to avoid "hav[ing] to look for a job in order to claim Newstart Allowance" (National Commission of Audit, 2014, p. 309).⁷⁴ In emphasising carers' reliance on the welfare payments and their obligations as individuals and families (see an interim report on the government's welfare reform for further details: Department of Social Services, 2014), the obligations of the state became obscured. This was despite that *the state was dependant* on carers.

Changing body, altered personhood

I have already noted that care relationships were embedded in various networks of people and things. One of the most obvious and important elements was the relations around the stroke-affected person's body. Managing a spouse's body with various physical, emotional, cognitive stroke sequelae after an unexpected onset was never easy. Difficulties with this management were also intensified by cultural narratives around the nature of personhood which, to borrow Manderson's words (2011, p. 24), had 'fingerprints' of Cartesian mind-body dualism all over. The impact of mind-body dualism was multi-faceted. Firstly, western medicine, with its paradigmatic stance based on this dualism, focused almost exclusively on the physical body of patients and its function, and cognitive and emotional aspects of stroke sequelae were often neglected in rehabilitation both immediately after stroke and in the long-term. Once the patients were functional enough, they were discharged home, an assumed domain of the mind.

Yet, these 'hidden' sequelae were often perceived by spouses as more problematic than physical sequelae. They spoke of cognitive deficits, such as decline

⁷⁴ The Newstart Allowance is the main unemployment benefit for working age adults. This benefit requires the recipients to be actively searching for work in order to receive the payment.

in executive function, as altering their partner's personhood, and this greatly affected their spousal and other relationships. Their friends, relatives and wider social networks including medical professionals, also made assumptions about the stroke-affected partners' capacities, based on their bodily appearances. Many of those in their social networks assumed that once the stroke-affected person physically presented well enough, things were back to 'normal'. This led spouses to feel that the degree of, and the hardship involved in, their care and emotional work was undervalued – rendering them and their care work invisible. The idea that cognitive changes were more impactful on the personhood of their partner was, of course, also a product of the dualism. That is, the changes to cognitive facilities were seen as fundamental to the personality and the 'essence' of the person.

However, cognitive deficits also caused practical difficulties in everyday life, which also perpetuated the poignancy of the altered personhood. The cognitively-affected partners' incapacity to make considered decision meant that much of household and parenting decision-making rested on their spouses' shoulders. Impulsiveness meant that the cognitively-affected persons were prone to accidents, and required a degree of supervision. Getting ready to go out, for instance, to a medical appointment or a social activity, took much longer and required supervision for persons whose sequential thinking and the sense of time were affected. This was made worse in case of added mobility problems. As I discussed in Chapter 8, partners of cognitively affected persons had to manage "the brain that sometimes just wonders around" (Abi).

Furthermore, in the cultural context in which verbal expression was considered an important aspect of personhood (Dennett, 1988), communication difficulties had a profound impact on the nature of spousal and wider relationships.

Participants had to often act as an ‘interpreter’ in social situations, and other people’s impatience – and avoidance – towards the partner who were struggling to find the right words frustrated both partners. Communication difficulties, however, also interrupted the rhythm of everyday life for participants. The slow pace of the conversations made them boring and tiresome, and the absence of nuanced and in-depth communication led to various rearrangement of, and skewness in, spousal and familial responsibilities.

Ordering incapacity

These ‘deficits’ in and of themselves did not produce ‘lack’; rather, the incapacity was produced by “an order of normal” (Moser, 2005, p. 676). That is, the capacity or incapacity of the person who had a stroke and their partner (i.e. participants) to perform partnership and mutuality depended on various material, economic, ideational, and ideological relations that often favoured certain bodies and subjectivities. Bodies, for example, that required active and on-going rehabilitation; that were unable to benefit from day-care respite services due to irregular work hours (e.g. Will); that were too young for ‘standard’ residential care services; or that spent ‘too much time’ (i.e. more than 25 hours) in paid employment despite having to be a ‘dedicated carer’, disappeared through the cracks (Moser, 2005). Meanwhile, other bodies were considered ‘responsible’ and ‘self-governing’ despite – or because of – certain forms of dependence. For example, the government did not have any intention of reviewing superannuation tax concessions that costed the budget \$35 billion in 2013-14 (Ingles & Denniss, 2014). This policy predominantly benefited those, whose income was high enough to deposit extra money into the superannuation account that was not accessible until the retirement age (Ingles, 2009). This was indeed a form of

welfare policy (Carers Australia, 2014), yet this mode of ‘welfare dependence’ was celebrated as ‘responsible’ financial management and thus rewarded.

The government’s interest in ensuring that carers were engaged in both caregiving and the formal economy was evident in the ‘25 hours rule’ that I mentioned above. This was driven by the government’s attempt to maintain and reproduce productive bodies for the present and into the future. According to Deleuze and Guéry (2014), by treating productive bodies as ‘body-machine’, these policies were also firmly rooted in Cartesian dualism. In this framework, disabled bodies of working age were ‘broken down’ bodies that were supposedly burdensome to the national prosperity. Carers were, then, tasked both to neutralise the ‘loss’ incurred to the society by ‘dependent’ people with chronic conditions, and to contribute economically in the formal economy so that their family unit could remain ‘independent’. This leads to the static nature of carers, as I discussed above.

Opening alternatives

How can we break away from these binary relations of mind and body, dependence and independence, productive and unproductive, and normal and abnormal? This may be possible by thinking in terms of ‘what a body can do’ (Buchanan, 1997; Deleuze & Guattari, 1987, p. 256; Fox, 2005). This approach of the body, and of individuals, diverts our attention away from what a body *is*. Rather than considering how a body is ‘dependent’, for example, this approach points our attention to what a body is capable of – not in terms of its functionality, but of how it can affect and be affected by other bodies. Such affective relations are not limited within spousal relationships. By taking into account physical, emotional, social, economic, philosophical, cultural, and material relations that partners form and reform, it may be possible to conceptualise the outcome as a diverse and constantly unfolding process of ‘becoming’ (Colebrook,

2002). This approach may open up new possibilities for articulating multiple ways of living with stroke-affected bodies in the spousal relationship and in wider networks of relations. Such space may be characterised by cultural ideals of interdependence (Fine & Glendinning, 2005; Fine, 2007a), ways of living chronic conditions other than through normalisation (Moser, 2005), and meaningful distribution of responsibility, rather than the skewed notion of ‘mutual obligation’.

As I stated in Chapter 2, the claims I make in this thesis are modest. I do not intend to make any generalisation about the carers as a whole; the findings presented here are partial and situated in their contexts. For example, due to the recruitment procedure, there was an absence of partners who were not in a legal marriage, and an underrepresentation of those who were not receiving any form of peer support. However, given the type of the study – qualitative ethnography – generalisation was not sought. Rather, I aimed to produce rich accounts of participants’ experiences in a way that was credible, resonant, sensitive, and useful (Beck, 1993; Bochner, 2000; Charmaz, 2007; Corbin & Strauss, 2008; Finlay, 2006). This thesis offers an in-depth insight into the realities of people, who managed and negotiated various biographical changes in the lives after their partner’s stroke. While situated in particular temporal and geo-political contexts, the findings would be of relevance to many other industrialised countries facing similar issues, such as a high incidence of cardiovascular disease, the withdrawal of the welfare state, and the ‘pivot’ generation of women (Mooney, et al., 2002). Through this thesis, I am calling for a fundamental re-think in the way in which disability, carer, and wider welfare policies are ‘done’ (Bacchi, 2009; Moser, 2005; Singleton, 2006).

At the time of writing this thesis, Australia was undergoing a period of various disability-related reforms, the most notable of which was the National Disability

Insurance Scheme (NDIS). The NDIS is a program that could broadly be categorised as a cash-for-care scheme (for studies on potential implications of cash-for-care schemes for people with disabilities and carers in the international context, see: Da Roit & Le Bihan, 2010; Moran et al., 2012; Glendinning et al., 2015; Rodrigues et al., 2014; Winkelmann et al., 2014). The NDIS entered the first stage of a national rollout in 2013, however only a small part of Victoria was currently participating. Given that the partial implementation of the NDIS did not directly affect the lives of participants, I have refrained in this thesis from discussing about the potential implications of the scheme. However, an update of this study may be worthwhile after the full implementation of the NDIS (projected to be in 2018-2019, although there were reports of a possible delay).

Furthermore, there were many domains of informal stroke care that could have been fruitful for further investigation, such as: interactions between care and ethnicity, socioeconomic status or migration status; experiences of working age parents who cared for their stroke-affected children;⁷⁵ or young adults who cared for their parents; or of former partners who had no choice but to leave their stroke-affected partner. However, these are domains of care worthy of separate projects of their own.

Also, it is not my intention to provide prescriptive accounts of how things ought to be, or of ways to reduce care ‘burden’. Instead, by telling these particular stories, my wish here is to provide a fertile ground, hopefully rich with possibilities for further discussions about alternative modes of ordering a caring society – where meaningful interdependency is recognised, facilitated, and nurtured. This is important, I believe, because – to quote Withers (2012) again – it is a part of our humanity.

⁷⁵ There was a support group for children who have had a stroke – some of whom had a stroke as a baby – and I have met some parents through attending this group. However, I was unable to further explore their experiences due to the constraints of the PhD project.

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Appendices

Appendix 1: Recruitment Materials

Recruitment Flyer

Experience of spousal caregiving

Is your spouse/partner a person who has had a stroke and is aged between 25-55?

If so, I would like to hear your experience.

What am I trying to find out?

- How does stroke affect younger couples?
- What are the needs of spouses/partners?
- What kind of support is already available for them?
- Do men and women have different needs when caring for their partner?

What do you need to do if you want to participate?

You will be invited to talk about your experience of caring for your spouse/partner in up to three informal discussions with me (Mutsumi) over an 18-month period.

How long will it take?

Each discussion will take approximately 60 minutes and is strictly confidential and anonymous.

Who is running the research?

Mutsumi Karasaki (PhD researcher), Dr Narelle Warren and Professor Lenore Manderson (research supervisors) from Monash University.

Your story is important and valuable.

For further information, please contact Mutsumi Karasaki on 0410 388 024 or Mutsumi.Karasaki@monash.edu.



Media release

(This media release was circulated through local newspapers and newsletters published by relevant community organisations)

Who Cares for the Carers? Experiences of Spouses of Working-Age Stroke Survivors Sought

Researchers at Monash University are looking into ways to reduce the impacts of stroke on spouses of younger stroke survivors

Stroke affects not only the individuals it afflicts, but also the people who care for them, especially spouses and partners. Caring for a spouse who has suffered a stroke can have significant impact on the carer's personal relationships, employment and financial situation, as well as their sense of self, especially if they are relatively young.

There is currently very little research however on how younger couples face the challenges associated with stroke. Monash University researchers are trying to find out what spousal carers of younger, working-age stroke survivors experience, and how best to address their support needs.

Medical and clinical aspects of stroke have received extensive attention, but little is known about its social impacts on family and friends. And although stroke is often considered as a 'disease of old age', it is not uncommon among younger people – about 18% of stroke survivors are under the age of 55 years. Family carers, most often spouses, play important roles in the recovery.

"Carers of younger stroke survivors are often isolated and their contributions are not always acknowledged," said Mr. Mutsumi Karasaki, a PhD candidate whose father suffered a stroke at a relatively young age. "Seeing what my parents went through together since his stroke – both ups and downs – inspired me to talk to people in similar situations, listen to their stories, and write a thesis about them, which hopefully will be useful to other carers and stroke survivors, medical and health professionals, and policy makers."

This research, conducted by Monash University, attempts to look at the ways in which spousal caregiving is influenced by age, gender, social and cultural factors, and how this might change over time, as the carers deal with the long-lasting impacts

of stroke. The findings will be used to support the development of better strategies to improve the physical, social and emotional wellbeing of spousal carers of working-age people following a stroke.

Participants are currently being recruited to participate in a series of in-depth interviews. The researchers are inviting men and women whose spouses or partners are aged 25-55 and have suffered a stroke. Each participant will be invited to participate in up to three one-hour interviews over 18-months and may also be asked to allow a researcher to observe their everyday caring activities. Participants will be given a small gift in appreciation of their time.

For more information please contact Mutsumi Karasaki on [REDACTED]
[REDACTED]

Appendix 2: Interview Guide

This interview guide was prepared for the purpose of the ethics application and candidature progress report prior to commencement of participant observation and recruitment of interview participants. It was not used as a list of structured questions during the interviews; rather, it was only used in preparation for the first few interviews to remind myself of key domains that I wanted to explore in the interviews.

- Can you tell me about things that happened around the time when ___ had stroke? (The onset and cause of stroke)
- Can you tell me about your life as _____'s partner/wife/husband?
Follow up with: How about before stroke? (Participants' perception of their life prior to and after the stroke event)
- Can you tell me about _____'s rehabilitation and how you assist him/her in the rehabilitation process? (Rehabilitation)
- What are the things you do to make sure _____ stays healthy? (Prevention of stroke reoccurrence)
- What do you think people expect of you as _____'s partner/wife/husband?
(Social and personal expectations on them)
- What are some of the things you find difficult in caregiving? (Hardships)
- How do you see the future for you and _____? (The future)
- Can you tell me about people whom you find helpful?
Followed up by: Are there times when their support is not very helpful?
(Informal support network)
- What kind of formal support system do you use? What do you think about them? (Formal support system)
- How do you think _____'s stroke impacted you financially? How about in terms of paid employment? (Financial and employment situations)
- How do you see the relationship you have with _____?
Followed up with: How about with other people who are important in your life?

(Participants' understanding about the nature of their relationships with the care recipients and the others)

Appendix 3: Stroke and disability support system

In Australia, the federal government funds and administers social security income support for people with a disability, and their carers through Centrelink, a program of the federal Department of Human Services (hereafter federal DHS). The federal Department of Social Services (federal DSS) develops social policies relating to disability, and their carers, and the Department of Health (federal DH) is involved in respite service funding and coordination. The state and territory governments are on the other hand primarily responsible for most of funding and delivery for services broadly categorised as community and disability care. In the state of Victoria, where the present study is situated, the Department of Human Services (DHS) is responsible for disability support while Department of Health (DH) provides services in the areas of aged care and mental health. These government departments became separate departments only in 2009, and therefore many policy initiatives overlap across the two departments.

As with the Australian health system in general, stroke care and carer support services are provided by public (government) and private (non-government: for- and not-for-profit) service providers within complex and bureaucratic funding and regulatory arrangements (Bundoora Stroke Carers Support Group n.d.). Funding for services is provided by all levels of government (federal, state/territory, and local governments), statutory insurers (in Victoria, TAC, or Transport Accident Commission, and WorkSafe Victoria), private health insurers, not-for-profit organisations and individuals in the form of out of pocket expenses. Figure 1 below illustrates funding and service delivery responsibilities.

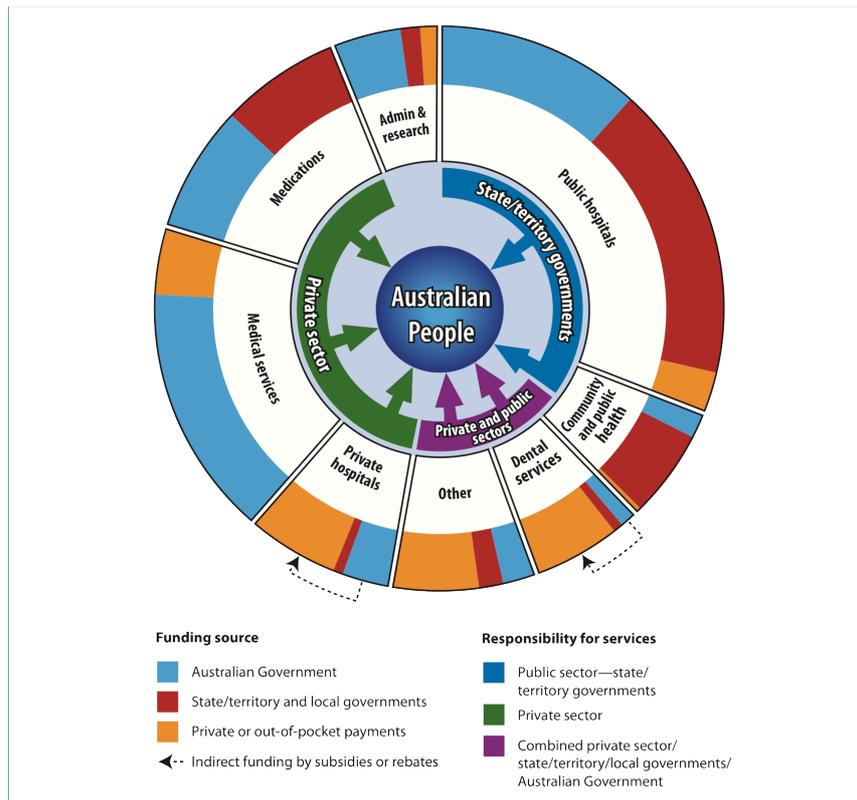


Figure 1. Health services - funding and responsibility (Australian Institute of health and Welfare, 2012, p. 17)

The federal government is responsible for funding and administering the Medicare Benefits Scheme (MBS) and the Pharmaceutical Benefits Scheme (PBS). Under the MBS, many general and specialist health services, and some allied health services, are offered for free or at a subsidised cost, and the MBS also covers free treatment at public hospitals and an income-tested rebate for those who purchase private health insurance. The PBS subsidises payments for a wide range of prescription medicines and, under the scheme, out-of-pocket expenses for listed medicines are capped at \$36.10 (with differences across medications). The federal government also co-funds public hospital services with state/territory governments under the National Health Reform Agreement (Council of Australian Governments

2011) through a funding agreement that is increasingly geared towards an activity based funding model rather than the more conventional block funding model.

These initiatives are augmented by social welfare arrangements provided through Centrelink, a federal Department of Human Services program, such as Carer Payment, Carer Allowance, Carer Supplement, and Disability Support Pension. The following information was retrieved from the federal Department of Human Services website (Australian Department of Human Services, 2013) and was current as in December 2014.

The Disability Support Pension program provides financial support to individuals with a physical, intellectual or psychiatric condition that prevents them from working 15 hours or more per week. As with the Carer Payment, Disability Support Pension is means tested, and the rate is set at \$776.70 per fortnight for a single person, or \$585.50 for a member of a couple. There are also special health-care arrangements and welfare payments for members and veterans of the Australian Defense Force and their families, which is provided through the federal Department of Veterans' Affairs.

With contributions from the federal government, the state/territory governments provide funding for, and administer, a range of health services in their jurisdiction including public hospitals, public health programs, community health services, health and medical research and training, Aboriginal and Torres Strait Islander health services, mental health services, and, in Victoria, the Home and Community Care (HACC) program (Australian Bureau of Statistics, 2012). Many of these services are delivered by not-for-profit and community health organisations through various funding agreements. Many not-for-profit disability and carer organisations are also funded by community grants, community donations, self-

funding or a mixture of these as well as or instead of the state government or local government funding.

Under the National Disability Agreement (Council of Australian Governments, 2012), the federal government is responsible for employment services for people with disability. It also administers the Commonwealth Respite and Carelink Centre, which provides information and referral service for individuals seeking locally available community disability, aged care and respite support services. State and territory governments in turn administer accommodation support, community support and community access services for people with disability, and respite care services. In Victoria, the Department of Health is responsible for health, aged care, and mental health services, while the Department of Human Services oversees disability services.

Local governments provide various community-based and home care services, such as personal and home care, respite and day care, home maintenance, Meals On Wheels (meal delivery service), and community transport schemes; the actual services vary across local governments. These programs are mainly funded by federal and/or state governments, though local governments are usually required to tender against other service providers for those funding schemes. Private health service providers also play a significant role, delivering general and specialist medical and rehabilitation services and other allied health services, private hospitals and residential care services (Productivity Commission, 2011). While these are funded primarily through private insurance and out of pocket expenses, they are also indirectly funded by government sources through rebates and subsidies (Australian Institute of Health and Welfare, 2012).

The structure of the formal support system for people who had a stroke and their carers is complicated by the fact that, in many cases, stroke crosses the boundaries between health, disability and aged care. Many people who have had a stroke, a medical condition treated within the healthcare system, may require support for stroke related disabilities, and a majority fall under the aged care category because they are above 65 years of age. This can cause confusion. An informal conversation I had with a stroke support group coordinator exemplified this. The group had successfully applied for a Health Condition Support Grant, a one-off grant offered by the Victorian Department of Health to support and strengthen the work of health condition-specific peer support groups. The Victorian Department of Human Services also provides a Disability Self-Help Grants scheme, which also offers one-off operating grants for disability self help groups. Being successful for the Health Condition Support Grant, however, made the group ineligible for the Disability Self-Help Grant. While this is clearly stated in the application guidelines for the Disability Self Help Grants (Victorian Department of Human Services, 2012), the Health Condition Support Grant Program grants submissions document did not do so (Victorian Department of Health, 2012a). The application for the Health Condition Support Grants closed a week prior to the applications for the Disability Self Help Grants opened, so the support group coordinator read the Disability Self Help Grants application guidelines only after the application for the Health Condition Support Grants was already submitted. It is, as my interlocutor made clear, very difficult to foresee that being successful in one funding scheme will disqualify the application for another funding scheme offered by another governmental department.

Acute care starts at onset of stroke, and a person displaying signs of stroke is transported to the emergency department of a hospital unless he or she is already in a

hospital for other conditions. Ambulance is the most common mode of transport (81%) from a community setting to the emergency department (National Stroke Foundation, 2011b), although in one study conducted in 2009 only 39% of patients arrived at hospital within 4.5 hours of onset of symptoms (Boddice et al., 2010). Most people (83%) receiving acute stroke care (including care for transient ischaemic attack, also known as mini stroke, which causes stroke symptoms only for up to 24 hours) is provided in public hospitals (Victorian Department of Health, 2007). On arrival at hospital, brain imaging should be conducted as soon as possible to confirm the presence of ischaemia or haemorrhage in the brain (Victorian Department of Health, 2007). Of the brain imaging technologies, Magnetic Resonance Imaging (MRI) is more sensitive at detecting ischaemia than CT (Computer Tomography) scan, however it is not as widely available as CT scan. According to the National Stroke Foundation, while almost all of patients (99%) have brain imaging, only 51% of the patients received it within 4.5 hours of stroke onset (National Stroke Foundation, 2011b).

Once diagnosed, people with stroke may be cared for in a stroke care unit by a multidisciplinary team of medical and rehabilitation professionals specialised in stroke, or a general medical ward by general medical staff, if there is no specialised unit at the hospital. A stroke unit is defined by the following characteristics (Australian Institute of Health and Welfare 2006, p. 8):

- patients located in a geographically defined ward area;
- a coordinated multidisciplinary team comprising a stroke physician, nursing staff, occupational therapist, physiotherapist, speech pathologist, dietitian, social worker and, where possible, a psychologist;

- staff specialising in the management of stroke and having access to ongoing professional education;
- team meeting regularly to discuss management and discharge planning;
- care provided according to agreed protocols, and;
- early provision of rehabilitation.

Clinical guidelines published by National Stroke Foundation (Boddice et al., 2010) establish that the most effective acute care for stroke can be provided in stroke units and recommend that, where possible, patients be transferred to a nearest hospital with a stroke unit, if it is not available there. There are currently 18 hospitals in Victoria with a stroke care unit (National Stroke Foundation, 2012).

In recent years, efforts have been made to ensure acute stroke patients are admitted to a stroke unit either directly or indirectly through the transfer from another hospital with no stroke unit (Boddice et al., 2010). As a result, most patients (65%) in Victoria are now treated in a stroke unit (National Stroke Foundation, 2011b). In addition, a new state-wide Acquired Brain Injury (ABI) rehabilitation service centre is being built at Alfred Health's Caulfield Hospital for patients with a severe ABI, mainly from road trauma but also other causes such as stroke. The Stroke Units' coverage in the rural regions is comparatively limited (Balzac & Groot, 2012).

While the intensity and type of rehabilitation vary, many people require rehabilitation following stroke (Australian Institute of Health and Welfare, 2006). The assessment for suitability for rehabilitation is usually conducted in the acute setting, ideally by a multidisciplinary team. However only 30% of patients in Victoria are assessed by a multidisciplinary team that can include physiotherapist, occupational therapist, speech pathologist, social worker, and dietitian (National Stroke Foundation, 2012b). Patients are discharged home if they do not require

rehabilitation, or are transferred to an in-patient rehabilitation program. Where high level of care and medical complications are involved, or if there are no bed vacancies in the sub-acute settings, the patients may continue rehabilitation in the acute setting. The acute hospitals are impelled to facilitate the flow of patients through the hospital system by maintaining a high level of bed utilisation and a short average length-of-stay (Victorian Auditor-General, 2008), to ease the pressure for bed space. Alternatively, a patient may be discharged home with rehabilitation provided in outpatient settings, community rehabilitation centres, community health service providers, or at home.

On admission to the in-patient rehabilitation hospital, individuals should meet with a team of multidisciplinary team to discuss desired goals in rehabilitation (National Stroke Foundation, 2012b). This rehabilitation plans aim to improve function and/or maintain function to achieve the highest level of independence, physically, psychologically, socially and economically and to facilitate reintegration of the person with stroke into the community (National Stroke Foundation, 2006). Ideally, the rehabilitation plan is regularly reviewed and modified, and appropriate discharge planning and follow-ups are conducted in a holistic approach to ensure the individual's needs in areas of functional, physical, psychological, social, educational and vocational domains are met (Australian Institute of Health and Welfare, 2006). Individuals who had a stroke and their family members often do not receive appropriate information about stroke during a meeting with a multidisciplinary team (in Victoria, only 55% did), and only 31% of individuals who had a stroke and 33% of carers receive psychological counselling prior to discharge from a sub-acute hospital (National Stroke Foundation, 2012b).

An allied health care professional who I met during fieldwork explained to me that the current funding system implicitly offers incentives for public rehabilitation hospitals to discharge patients at or before 32 days from admission and that they are reluctant to take individuals whose rehabilitation would take much longer than 32 days. However, the Victorian Government uses an activity based funding model called CRAFT (Casemix and Rehabilitation Funding Tree) to determine funding for sub-acute hospitals (Victorian Department of Health, 2012b). CRAFT classification first divides people who had a stroke into high functioning (HB, or High Barthel, i.e. the person scored highly in the Barthel Index for ADL and mobility) and low functioning (LB, or Low Barthel). CRAFT also sets out a ‘typical’ stroke patient for HB and LB categories based on the hospital admission data in 2009-2010. For example, the average length of stay for HB patients is currently 32 days, and the lower boundary between the length of stay for the typical and atypical patients is set at 28 days, while the upper boundary is 37 days. Funding for stays beyond 37 days is capped at 90% of per diem funding for a ‘typical’ stay, “in recognition that the days at the end of a patients stay are less resource intensive than days at the beginning of a patients stay” (Victorian Department of Health, 2012b, p. 24). On the other hand, a length of stay on or below the lower boundary (but at least four days, otherwise it would be considered a ‘short stay’ and so would only be eligible for a lower funding rate) attracts the maximum per diem rate for funding purposes. While rehabilitation programs that address ‘holistic’ needs are encouraged in clinical guidelines, economic considerations provide financial incentives for rehabilitation hospitals to shorten the stay, which may limit rehabilitation to progress beyond a basic functional recovery.

Once discharged from the sub-acute setting, most people return home (Australian Institute of Health and Welfare, 2006), and can be put on an ISP

(Individual Support Package), a Victorian government funded program. Ongoing rehabilitation can be provided in out-patient settings, day care centres and community rehabilitation centres, or through on-going rehabilitation in the home (National Stroke Foundation, 2006). Community rehabilitation can also be provided by community health service providers. The HACC (Home and Community Care) program funded by the federal government except for in Victoria and Western Australia where the program is co-funded by the federal and state governments. The assessment of needs for the HACC program is usually conducted by the local government. As mentioned earlier in this appendix, stroke care and support services for carers involve of a complex set of funding from different levels of government, and government and non-government service providers, and it is not always easy to find out who provides which services.