**Appendix**

**Figure 1.** Major themes with sub themes.

**Table 1: Carers’ demographic details**

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
| Carer & relationship | Age (years) & gender of carer | Caring for | Carer Co-morbidities | Carer Background |
| Ted (spouse) | (92) M | Ruth | Severe spinal stenosis; hearing loss (HL) | Reside in small unit together; owner/occupier; married many years; no additional services and limited family support. |
| Gail (spouse) | (64) F | Clive | Osteoarthritis | Gail is active; attends gym & recently retired; no additional services. |
| Paul (spouse) | (88) M | Betty | Mobility issues and HL (wears hearing aids) | Live in sheltered housing together; good family support; no other services. |
| Karen (daughter) | (67) F | Ina | Osteoarthritis | Shares care with sister (Sarah, also interviewed); lives with parent 6 months per year; attends Vision Impairment (VI) support group with parent. Works part time. |
| Maggie (spouse) | (87) F | Stuart | Diabetes; osteoarthritis | English second language; limited family support; attends VI support group with spouse. |
| Sarah (daughter) | (70) F | Ina | Chronic pain | Shares care of parent with sister, Karen (above); lives overseas for 6 months and resides with parent for 6 months; attends VI support group with parent. Works part time. |
| Eve (daughter) | (52) F | Mary | Osteoarthritis | Works full time; resides with parent; uses Vision Australia services. |
| Mary (spouse) | (67) F | Jim | None discussed | Retired health professional; active socially; no services used. |

**Table 2A**

**Sensitising concepts (Siegler, 2014) used in semi-structured interviews.**

|  |  |  |
| --- | --- | --- |
| Social capital dimension | Themed question for interviews |  |
| #1. Participation, social engagement & commitment | **Social impact of DSI** explored the following:  Impact on social participation/engagement; on family members; on their social life | **Personal relationships:** This aspect of social capital refers to the “structures and nature of people’s personal relationships (OECD, 2013) and is concerned with who they know and what they do to establish and maintain their personal relationships. |
| #2. Control & self-efficacy | **Emotional impact** (including but not limited to):  Impact on levels of dependence and independence; changing circumstance; sense of control over life; decision-making; future plans & empowerment | **Social network support:** This refers to the “level of resources or support that a person can draw from their personal relationships” (OECD, 2013), but also includes what people do for other individuals on a personal basis. |
| #3. Perception of community level support | **Community support:**  Support for family carer; peer & professional support for carer (e.g. General Practitioner; counsellor); use of social and community services (that include famiy carer); satisfaction of and ease of access to support; specific services for DSI e.g support groups | **Civic engagement:** This refers to “the actions and behaviours that can be seen as positively contributing to the collective life of a community or society” (OECD, 2013). It includes activities such as volunteering, political participation and other forms of community action. |
| #4. Trust, reciprocity & participation | **Relationships and trust** (including but not limited to):  Professional trust e.g. with health professionals (e.g. audiologists; GP.); community relationships- trust in neighbourhood support; safety; ease of access | **Trust and Co-operative norms:** This refers to the trust and norms of shared values that shape the way people behave towards each other and as members of society; trust and values that are beneficial to society as a whole (e.g. equity) may determine willingness to co-operate. |

**Table 2B**

**Example question and answer**

(*This question is a typical opening question used to initiate conversation. Interview with Ted, carer to Ruth)*

|  |  |
| --- | --- |
| Initial open-ended question (Interviewer, MD) | Response (Ted, carer for Ruth) |
| *So, tell me when you first started noticing Ruth’s vision and hearing loss, what was it like for you?* | *Well, we'd been married years when she actually got Myasthenia Gravis.* |
| *Right.* | *And that was very serious for a while and then she went into remission with that. She's always had a sight - it's a lazy eye and it was always - the vision was never really good, but it's only I'd say the last 20 years it started to go, slowly, slowly, little things.* |
| *In both eyes?* | *Yeah. But now, now it's really bad, she can't see things. We used to go overseas travelling, we've been to Phuket about 30 times in 40 years, and China, Vietnam, we travelled a lot but now we can't do that because she can't see. Can't go to the movies, things like that. Even**television.**We've got the front – a seat right up against it for her to see but she still can't see, it's all a blur, sometimes she can listen to the voices.* |