

Provoking the debate on Euthanasia in Dementia with design

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Abstract: Dementia affects 47 million people world-wide. It is a collection or consequence of many illnesses with symptoms including deterioration in memory, thinking and behaviour; it is a terminal disease. The fear of dementia leads people to request euthanasia. Euthanasia in dementia rarely happens because the dementia symptoms conflict with the due care criteria; a person requesting euthanasia must confirm the request at time of death and must be undergoing hopeless suffering. Once dementia has progressed, the euthanasia ‘wish’ can no longer be confirmed, and assessing suffering in a person with dementia is hard. Having a reliable dementia diagnosis is essential in order to be able to make a decision for an ‘early’ euthanasia. This paper describes a Speculative Design to explore what options should be considered for receiving a dementia diagnosis in order to plan a death. A branding strategy was developed for the Planned Death company, who advocate an early diagnosis for making end-of-life decisions. The branding includes company identity, website, diagnostic kit, diagnostic delivery strategy, and end-of-life support. Additionally a short documentary was developed describing the Planned Death Company’s motivation and a client testimonial. Responses to the documentary were collected with a carefully selected group of participants through a survey and in-depth interviews. The responses were rich and sparked debate. Many new questions arose to do with patient autonomy and social structures.

Keywords: Speculative Design;
Critical Design; Prototyping;
Euthanasia; Dementia



CO Wikimedia user Cadastral

Introduction

Decision making for a good death in dementia is complex. The first essential step in making end-of-life decisions in dementia, is having a reliable dementia diagnosis, before the disease has progressed too far. This paper describes the use of Speculative Design to explore how and when to get diagnosed and how to plan for a good death once a diagnosis has been received.

Dementia affects 47 million people worldwide with 9.9 million new cases each year (WHO, 2017). Dementia is a collection or consequence of many illnesses, including Parkinson's disease, vascular dementia and Alzheimer's disease. There is a set of similar symptoms in which there is deterioration in memory, thinking and behaviour; it is a terminal disease.

Euthanasia has many definitions from the Greek origins of 'good death' or 'easy death' (dictionary.com, 2017) to the Nazi euphemism for the deliberate killings of physically, mentally, and emotionally handicapped people, leaving the term with extremely negative connotations (Wikipedia, 2017). The definition used in this paper is *"The act of assisting someone who is terminally ill and whose suffering is unbearable and untreatable, to be in control of the manner of their dying."*

As euthanasia is illegal in most of the world, this paper will use the Dutch guidelines and legal framework which states *"euthanasia is not punishable if the attending physician acts in accordance with the statutory due care criteria. These criteria hold that: there should be a voluntary and well-considered request, the patient's suffering should be unbearable and hopeless, the patient should be informed about their situation, there are no reasonable alternatives, an independent physician should be consulted, and the method should be medically and technically appropriate"* (Dutch euthanasia Act, 2002).

Euthanasia for people living with dementia is a complex issue because the symptoms clash with the due care criteria for euthanasia; unbearable suffering is difficult to assess in dementia (Buiting et al., 2008; Hertogh, 2009; Rietjens et al, 2009; Emanuel, 1999), and it is hard for a person living with dementia to consent to euthanasia at the point of death because of the decline in their cognitive functioning (Rurup et al, 2005). In 2017 only three people with advanced dementia received euthanasia versus 166 cases of euthanasia in early stages of the disease, out of a total of 6,585 euthanasia cases in 2017 (NRC, 2018).

The ethical challenge of diagnosing a terminal disease in order to perform euthanasia is addressed in this paper by offering a fictional solution (speculative design) as a framework for stimulating and supporting discussion. Speculative design can be used to initiate or stimulate dialogue between experts and the users of the proposed design (Auger, 2013). The discussion tool designed here is a diagnostic kit which can accurately predict onset of dementia(s) in order for the diagnosed individual to make decisions about their end-of-life. This speculation questions if a planned death be a good death? (Rachels, 1986).

"The people that ask for euthanasia are the ones that have knowledge of dementia. A mother, a brother, a sister, a father, they have seen their loved ones enter this domain, they have been very engaged with it, have visited often, despaired about the diagnosis, and these are the people who say themselves, this is not for me."

Bert Keizer in personal interview, June 2018

Control in Dementia

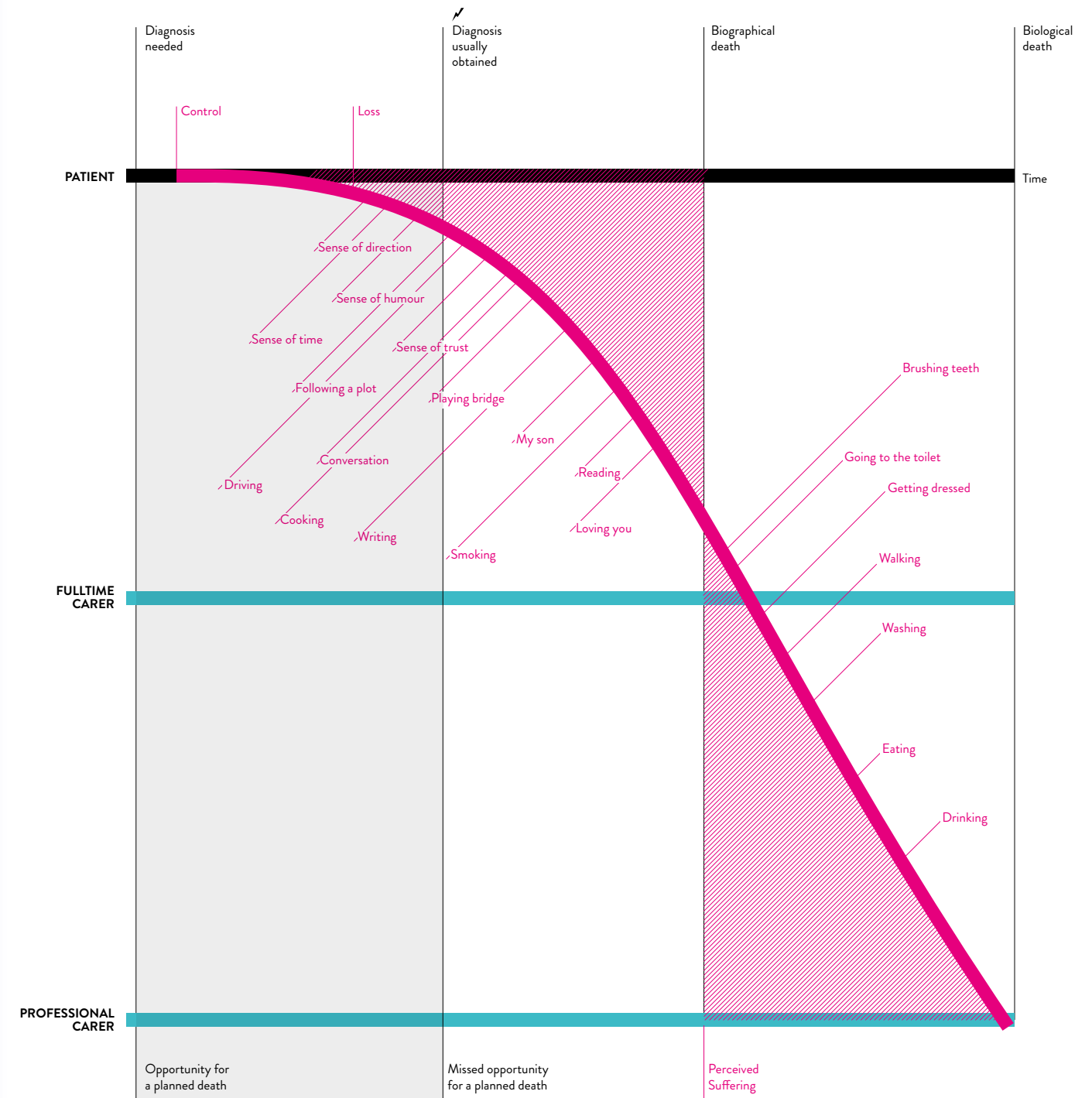


Figure 1. Control in Dementia. Graphic: Marije de Haas. This visual summarises various issues found in the literature. a_ The shift of control over a life with dementia from the individual in question, to the primary carer and to professional care. b_ The need for an early diagnosis in order to make end-of-life decisions and c_ the various qualities of suffering experienced by the person with dementia and their loved ones.



Figure 3. Suffering.

Video: Marije de Haas.
<https://vimeo.com/251459676>.
 A Speculative Design video to address the Suffering theme; Smart jewellery to track quality of life, being measured in physical, psychological, social and spiritual aspects (WHOQOL, 1997). This is part of the government initiative to be able to assess suffering in conjunction with assigned individual Quality of Life Team (2020).

This speculation explores who could make decisions about a person when the person in question is unable to do so themselves.

Literature

With a controversial topic such as euthanasia and to acknowledge personal perspective (potential bias), a systematic review method was chosen to attempt greater objectivity.

As part of the inclusion/exclusion criteria the stance was taken that death is final so research literature about objections to euthanasia based on religious belief were not included.

The literature was categorised into the following themes: Suffering, Autonomy and Planned Death. This paper addresses the Planned Death theme only, but will mention in brief the key points from the literature review on all themes to provide more context:

Suffering:

Euthanasia is possible and does happen, but only at “5 to 12”, when there is no cognitive decline yet. At this time there is not yet any suffering specific to the symptoms of dementia, only the anxiety about living with the diagnosis. Assessing suffering is complicated in dementia when there is no meaningful two-way communication. Additionally it is impossible to remove the inherent bias of the assessor. Currently suffering is assessed by the person’s physician and an independent SCEN (support and consultation in euthanasia).

Autonomy:

Advance Euthanasia Directives in Dementia are rarely adhered to because the symptoms of dementia clash with the euthanasia due care criteria; a person requesting euthanasia must be able to confirm the request at time of death and must be undergoing hopeless suffering. Once dementia has progressed, the euthanasia ‘wish’ can no longer be confirmed, and assessing suffering in a person with dementia is hard. This creates difficulties for physicians supporting patient wishes.

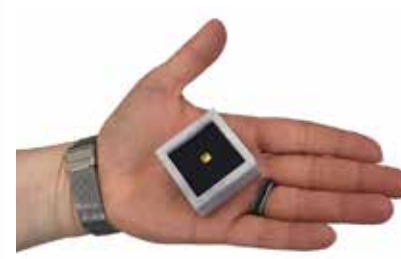


Figure 2. Autonomy, The Plug.

Prototype & visuals:
 Marije de Haas.
<https://aed-plugin.com/>
 A Speculative Design to address the Autonomy theme; The Plug (2020), an Advance Euthanasia Directive implant that triggers a swift and painless death, once the conditions described in the Advance Euthanasia Directive have been reached.

This scenario explores the dilemma between the need for consent and the challenges in obtaining it, as well as who should be responsible for decision making about end-of-life in dementia.

The video developed for this theme was used in a public debate to help trigger discussion between panel members and the audience in Pakhuis De Zwijger in Amsterdam, The Netherlands, on 22 October 2018, <https://dezwijger.nl/programma/mijn-dood-is-niet-van-mij>.

Planned death

There is a lot of fear for dying with dementia, this drives people to sign Advance Euthanasia Directives. Can a planned death be a good death in dementia? Guides for dying well have existed for centuries; the Egyptian book of the dead dates back to 1250BC, the Tibetan Book of the dead, Bardo Thödol, dates around 1350 (Oxford Research Encyclopedia). The Christian book of the dead, Ars Moriendi ‘the art of dying’ dates back to 1415 and was one of the first books to be printed with movable type and was widely circulated in nearly 100 editions before 1500 (Wikipedia).

Natural death

Death used to be a normal occurrence; with most people dying in the home, before the medicalization of society. Nowadays about 80% of people die in hospital or a care facility (WHO, 2017). It was found after studying two decades of legal euthanasia in the Netherlands that there are differing opinions about what a good death is. Some people prefer to slip away in deep sleep. In such a case, continuous deep sedation at end of life is a better option. Active euthanasia is usually preferred earlier in the dying process, this is particularly beneficial for people who want to maintain control about their end of life (Rietjens et al 2009). Raus et al (2012) hypothesize that the popularity of continuous deep sedation at the end of life is because it resembles a ‘natural death’, but labeling a death ‘natural’ doesn’t necessarily make it ‘good’. What is perceived as a good death can vary hugely between individuals and cultures. A good death can be as unique as the individual it belongs to. “*Continuous deep sedation should not be sold as the best solution to dying.*” (Raus et al, 2012). Rachels’ Principle of Agency (2005) gives us another viewpoint on the idea of naturalness. He claims that if a good situation occurs naturally, it would be permissible to bring this same situation about artificially. The reason many people feel uncomfortable with this is because they attribute to nature some kind of mysterious force with its own kind of moral authority – they attribute to nature the characteristics of God (Rachels, 2005).

Rational death

Distinguishing between a rational choice and a depressed desire to die is complicated and no clear consensus on how to do so has yet been reached. This conundrum often fuels the ‘slippery slope’ debate: “*Fear of suffering and loss of dignity was more important; neither of these reasons by itself would seem to satisfy the criterion of unrelievable suffering*” (Hendin, 2002). Finding ways to assess mental competence of people who make euthanasia requests is the subject of various research papers (Farrenkopf & Bryan, 1999; Galbraith & Dobson, 2000). Depression can magnify emotional and physical pain, creating the desire to end the pain. This has been considered key ‘irrational’ decision making, because it is impairing ability to draw accurate conclusions about the patient’s condition (Fenn & Ganzini, 1999). Others say that depression is actually a rational ingredient for a desire to hasten death. The presence of a depressed mood or social difficulties in addition to a terminal illness might constitute an additional reason why one might consider assisted dying (Rosenfeld, 2000). Rational suicide has been seen through the ages as an appropriate action for those that suffered from intense physical pain and the elderly (Abel & Barlev, 1999). Werth provides considerations to determine if a suicide is rational: The person can realistically assess their condition, they do not suffer a psychological condition, their situation can be understood by an unbiased onlooker, the decision is considered and consistent over time, and if possible, the decision was deliberated

with significant others (Werth, 2000). Vink defines a good death as an autonomous, considered death that is carefully executed without adding suffering, planned with loved-ones, is dignified, and performed by the dying person (Vink, 2016).

A duty to die?

For some people conditions such as dementia should be avoided at all cost. In this case the rational option would be to prevent this situation, and take your own life (Cooley, 2007). Hardwig argues that we have entered a time period where a duty to die has resurfaced; medicine allows us to live beyond our capacity to look after ourselves, or even to be ourselves (Hardwig, 1997). Davis also argues that preventative suicide is a reasonable action for those diagnosed with dementia. She gives three main reasons; autonomy, not wanting to burden anyone and economics: *“Death is irreversible, but so is dementia”* (Davis, 2014). Some decisions for euthanasia are financial. The cost of receiving end-of-life care is expensive and can be a reason for patients to request assisted dying (Bilchik, 1996). This argument applies to countries where health care is not free, in the Netherlands healthcare is provided and thus this argument is not relevant, but worth being aware of. The cost of caring for dementia patients is huge. In the United States the cost of caring for the terminally ill constitutes of 10% of the total healthcare bill. There is growing apprehension that money may be a potent force influencing patients who ask their doctors for help in hastening death (Bilchik, 1996; Onwuteaka-Philipsen et al., 2003).

Practical issues

If a desire to die (in dementia) is rational, it still leaves the problem of actually acting upon this desire. The rational decision of the person before they became demented can conflict with the demented person's point of view, and the issue of who has to ‘choose sides’ and act upon this wish arises. The dilemmas in euthanasia for dementia can be summed up by pointing out inconsistencies in the law: A voluntary and well-considered request; unbearable and hopeless suffering; informed consent; no reasonable alternative. With this in mind, the moral framework provides three ways to act, the first is to reject euthanasia, providing palliative care. Second is compassion, if staying alive would be worse than death, euthanasia should be permissible, but how can we confirm that this life is worse than death? Third, autonomy; patients want to decide their own fate, but is it fair to ask a physician to decide over the patient's fate? (van Delden, 2004).

A major barrier has been the difficulty of pinpointing a time to act: *“not so early as to lose many good years, but not so late that the subtle onset of dementia robs one of the ability to appreciate the situation and to act in accordance with one's goals”* (Davis, 2014). There is a small window of opportunity in early dementia when cognitive functioning is still relatively intact (Hertogh, 2009). Patients must carry out the impossible task of choosing the time of death, as, there is no possibility to change your mind once this has been decided (Gastmans & De Lepeleire, 2010). In a study to see if physicians could conceive of performing euthanasia under morally complicated cases, the same timing issue arose. Physicians found it impossible to decide the time the advance directive is to be carried out, if a patient can't determine this themselves (Bolt et al., 2015).

Performing euthanasia, even if this is legal, is not easy. Physicians, who currently are the only ones who can legally perform euthana-

sia, operate by the Hippocratic oath ‘do no harm’. Exploring how general practitioners feel about euthanasia revealed that euthanasia is accepted as a tolerable practice but not everyone is happy to perform it. GPs acknowledged that there are situations where a euthanasia request is completely understandable, and most would want to help to relieve their patient's suffering, but many felt that giving a lethal injection was a harrowing experience. (Sercu et al., 2012; Stevens, 2006; Georges, The, Onwuteaka-Philipsen, & van der Wal, 2008). Moreover, it was found that the GP's feelings about the performed euthanasia was biased by their own opinions, their feelings toward the individual case and the relationship between palliative care and end-of-life choices (Georges et al., 2008).

Nuances between active euthanasia and physician assisted suicide come in to play. A hastened death through terminal sedation is called the double-effect (Buiting et al., 2010; Stevens, 2006). Many of the quoted involuntary euthanasia cases (Hendin, 2002), fall under the double-effect; patients are so sick, they are not mentally capable to make any decisions, they are in terminal sedation and their death is minutes or hours away. When life support is withheld or withdrawn, the patient is not killed, for which the physician would be responsible, but merely ‘allowed to die’, distancing physicians from feelings of responsibility for those deaths (Brock, 2000). The difference between ‘letting die’ and ‘killing’ can be hard to assess. A study on how care providers respond to administering terminal sedation shows that they have problems distinguishing continuous terminal sedation from euthanasia (Kerkhof, 2000).

There is little support for physicians to help make these distinc-

tions. When studying decision making in intensive care about continuation or withdrawal of life support, it was found that there was no consistent or objective method or process for making such decisions, causing distress amongst the staff and care-givers (Ravenscroft & Bell, 2000). Physicians have much more guidance with their decision making in countries where physician assisted death is legal, and have better ways of dealing with their experiences, as there are explicit guidelines and discussions can be held openly (Voorhees et al., 2014). In a study to test conceivability of complicated euthanasia cases it was noted that the ‘freedom to refuse’ is highly valued by Dutch physicians. Personal moral objections do play part in some euthanasia cases and can affect the emotional well being of physicians (Bolt et al., 2015). It has been proposed to set up ‘suicide service’; a multi-disciplinary team of people to make life and death decisions, not exclusively doctors (Bosshard et al., 2008). Similarly, it is observed that personal preference is only one dimension in the complexity of dying. Other dimensions should be investigated too; how decisions are made and what institutions facilitate these decisions (Daly, 2015).

Summary

Being able to plan your death after receiving a terminal diagnosis is seen as a good death for those who want to remain in control of their lives. Rational decisions to die can be based on wanting a ‘good’ death, to end suffering, or based on ‘a duty to die’; not wanting to put pressure on family or society.

Key points on the planned death theme:

- Whether a death is natural or not has nothing to do with it being good, it merely takes the responsibility of the death away.
- Euthanasia in dementia has to be a rational, well considered, decision. A rational death in dementia can be a good death.
- With advanced medical care, dying is becoming a choice. When a life can no longer make contributions to society or family, a duty to die may arise.
- Even if a death is planned rationally, executing this plan is still hard, deciding the time to die and actively killing a healthy person are difficult actions.

Outlining the problem space: Planned death

With euthanasia in dementia only possible in the early stages of the disease (Keizer, 2017), euthanasia in dementia has to be a rational decision, where the motivation for euthanasia depends on the person with the dementia diagnosis in close connection to their close social networks. The difference between choosing life and death lies between *“having a life and merely being alive”*. If a life is reduced to a biological life without having the option for developing or maintaining a biographical life (aspirations, projects, desires, relationships) it is not a life worth living (Rachels, 1986).

In order to be able to make decisions about your end-of-life in dementia, it is essential that you receive a diagnosis early. The Planned Death Company offers a dementia diagnosis kit, and if the dementia diagnosis is positive, support would be offered about making end-of-life decisions. This scenario explores key issues around planning death and the dilemma between a planned death and a natural death. Framed as a commercial venture to steer discussion toward questions of ethics and freedom of choice.

Speculative Design as a method to explore this debate

A speculative design method was chosen to explore the euthanasia in dementia debate. The design was approached as an applied thought experiment, in order to clarify the themes at play, and to engage the research participants. The speculations were shared with a carefully selected participant group (Dutch citizens for a cultural understanding of the practice of euthanasia with personal and/or professional experience with dementia), in order find answers to the question: *Who should be involved in making end-of-life decisions in dementia?*

The term Speculative Design was coined by Dunne & Raby as design used to stimulate discussion and debate amongst designers, industry and the public about the social, cultural and ethical implications of existing and emerging technologies (Dunne and Raby, 2013). Design Fiction is described as a thoughtful exploration of speculative scenarios; a way to prototype other realities (Bleecker, 2009); this practice has also been called Speculative Design, Critical Design, Design Probes and Discursive Design. All these design research practices are similar in that there are no commercial constraints, all use fiction to present a diegetic alternative to existing issues, and prototypes as a method of enquiry (Auger, 2013); for this research the term Speculative Design will be used.

Ways of collecting data from Speculative Designs vary greatly. Speculative Designs are often placed in an exhibition context and left for public debate (Auger, 2013), or used as a tool to aid discussion (Tseklevs et al., 2017; Malpass, 2013). Tanenbaum positions design fiction as storytelling *“Situating a new technology within a narrative forces us to grapple with questions of ethics, values, social perspectives, causality, politics, psychology, and emotions”* (Tanenbaum, 2014). These stories are important, as the prototypes created exist only within these stories, and this is precisely what makes them fictional (Lindley & Coulton, 2016). For this research, Speculative Design is approached as a practical thought experiment. A thought experiment considers a hypothesis for the purpose of thinking through consequences – thought experiments are frequently used in philosophy and physics. The thought experiment can make the offered choice more real to result in a different kind of discussion (Stanford Encyclopedia of Philosophy, 2014).

There are a few guidelines on how to construct a successful speculation: A design speculation is a concept about a possible future. This speculation can be critical about a likely future, or it can be more like a ‘what if’ scenario for a desirable future (Dunne and Raby, 2013; Blythe, 2014). It is suggested that a speculation should sit in-between normal life and fiction. The story should be probable and credible, the viewer should be able to *“suspend their disbelief”* about the proposed prototype (Sterling, 2009). Auger (2013) proposes that the speculation should offer a bridge between reality and the fictional element of the concept; in order to get the audience engaged, provocations can be used but they must be dealt with carefully, especially for controversial subjects (such as death), as the provocation can lead to revulsion or shock. He calls this *“managing the uncanny”*, shifting focus between familiarity and the proposed idea are ways to manage the experience of the uncanny (Auger, 2013). In this research, within the context of euthanasia and dementia, design is used as a thought experiment to further the debate amongst stakeholders. The designs are presented in a realistic way, using contemporary vernacular in order to *“suspend disbelief”* (ibid.).

Design decisions: Why the speculation was constructed

This section will explain why the Speculative Design was constructed to illustrate the problem space. The designed prototypes aim to make the euthanasia in dementia debate more tangible and accessible. The speculation seeks responses to the question: *Who should be involved in making end-of-life decisions in dementia?* or *Who should be involved in deciding if one could be diagnosed for dementia?*

Concept

This design treats dying as a rational choice, and suggests that being in control of the way you die may make for a good death. A ‘natural’ death is long seen as the best way to die, but ‘natural’ deaths are becoming more rare. A natural death would put the responsibility of choosing the time of death in nature’s control, it is as if people see nature as a special kind of moral authority (Rachels, 1986). 80% of people in the western world die in care facilities of terminal conditions (WHO, 2017). This calls for the need to make choices about how we die.

Here it is posed that individuals may want to be in control of the manner of their dying depending on the symptoms that different terminal illnesses bring. The major obstacle in being in control of making end-of-life decisions in dementia is loss of cognitive functioning. Therefore having a reliable (early) diagnosis is essential.

The service of receiving a diagnosis and support in options for end-of-life care has been packaged as a company; The Planned Death Company. The aim here is not to criticise capitalist economies, but as a way to signify a normality in planning death within our current economical climate – the government would avoid taking a moral stance. The hope is that this would trigger discussion points if such a service should exist and who should take responsibility for this.

Receiving a terminal diagnosis is hard. This is why the Planned Death Company is designed as a full service, providing advice on receiving a diagnosis, deciding the best time to diagnose, offering psychological support before and after diagnosis. This is based on the current diagnostic system for determining early-onset Alzheimer’s disease in the Netherlands who were consulted on receiving such a diagnosis (floda31.com/marije/). DNA tests are seen as a trustworthy way to diagnose almost anything (Independent, 2018). This is why the Dementia Diagnosis Kit has been designed to look like a DNA sample test. Please note that the authors are aware that not all terminal conditions can be tested through DNA testing. What the scenario is designed to communicate is a future possibility of reliable testing for the terminal condition of dementia.

The results of this diagnostic test have been designed in a clear manner based on Wired magazine’s The Blood Test Gets a Make-Over (2010). The data is contextualised giving it relevant meaning to the individual in question. *“It’s your body. It’s your information. Now it’s yours to understand”* (Leckart, Wired 2010). Inspired by this exercise, in the Dementia Diagnosis test results medical terminology is avoided and focus is on the main message; When will I get dementia? What can I do now? The aim is to put emphasis on leading a life full of quality until time of (a planned) death.



Figure 4. Gillian Bennett. Photo from deatnoo.com. Gillian Bennett took her own life at 11:00AM on August 18, 2014. Gillian has shared her story online to advocate for a better death in dementia. Her story has been adapted for the purpose of this research with permission of her family.



Figure 5. Euthanasia Note. An edited version of Gillian Bennett’s suicide note. You can view the full version here: deatnoo.com. Gillian’s note has been edited to fit the created speculation, information about healthcare cost has been omitted as this is not relevant for the Netherlands where healthcare is free. The note has been reproduced with permission from the family: *“Yes, you have our permission to use my Mum’s story and website in your research and writing. My Mum wanted these matters to be talked about and she would be grateful to know that you and others are talking and writing about important end of life matters.”* Sara Bennett Fox

Design decisions: How the speculation was constructed

In order to address the concept of choreographing death, a scenario was developed where planning death would be a normal part of life. To push this idea, a commercial company, the Planned Death Company, was developed. The Planned Death Company sells reliable dementia diagnosis kits, and offers a complete service starting with a consultation about receiving a diagnosis. If the ‘client’ decides to go ahead and take the diagnostic test, and finds out they will develop dementia, then the Planned Death Company will help them plan for the future; optimize their quality of life and decide a dignified departure that suits the client.

For a speculative design to be successful, it needs to be credible; the audience needs to be able to believe in its existence. A Design Speculation requires a connection to exist between the audience’s perception of their world and the fictional element of the concept (Auger, 2013). This is why a commercial company structure was chosen to convey the concept of ‘being in control’; as a customer you get to make decisions about a service you require, and as a company you need not adhere to governmental ethical constraints. Based on current commercially available DNA tests such as 23andMe, GenetiConcept and ViaMedex, the Planned Death Company has bespoke diagnostic tests for dementias specifically.

The Service

The Planned Death company is designed in current day medical vernacular, the look and feel is based on numerous medical services based in northern Europe. From the colour palette to the language addressing its ‘customers’, the Planned Death company has a rational, honest and reliable ethos.

To know or not to know

The service starts with a simple intake form, followed up by an in-depth conversation with a specialist. Receiving a terminal diagnosis is a life changing event, and the Planned Death company wants to make sure this test is not taken lightly.

The Kit

Once a diagnosis has been approved you receive the diagnostic kit. The diagnosis requires a blood sample, and the kit is designed to secure clean blood sampling and eliminates the risk of contamination.

The result

The test result has been designed in a clear and matter-of-fact manner, there is no opportunity for misinterpretation. The person diagnosed receives a clear visualisation of their timeline; when symptoms will start, when there is the opportunity for euthanasia, when biographical and biological death will take place.

The video

The video starts with the rationale of the Planned Death Company, explaining why they developed the Dementia Diagnosis Kit. This is followed by a personal account of an individual using the service. The personal story serves as a reminder that although this approach is very rational, the act of planning death is a very individual and emotional experience.

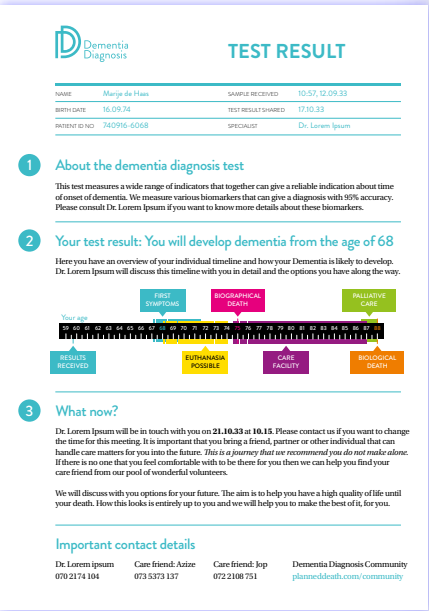
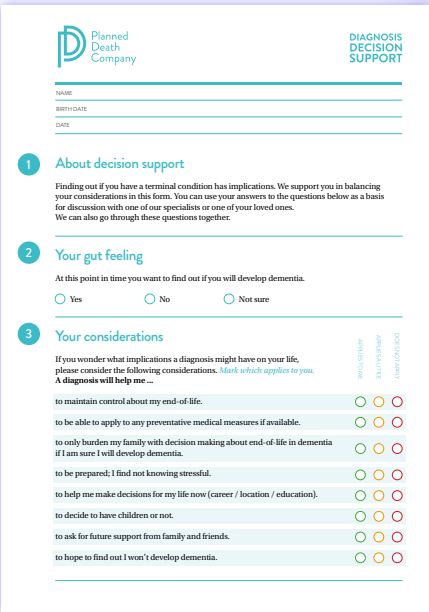


Figure 6. Dementia Diagnosis Kit, Dementia Diagnosis Decision Support and Dementia Diagnosis Test Results.

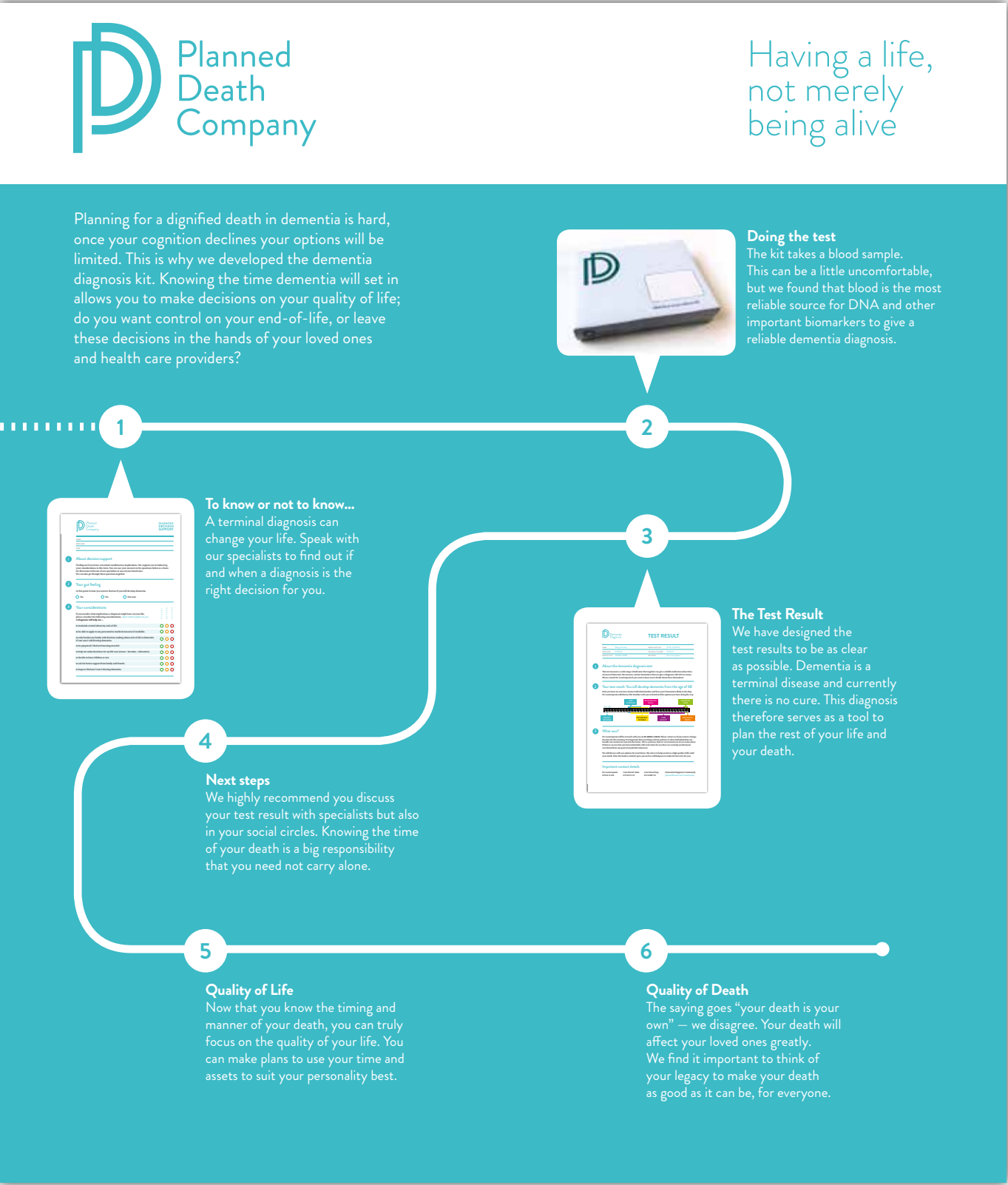


Figure 7. Planned Death Company Service Blueprint. Visual: Marije de Haas. Six steps to a planned death; first there will be an assessment if a diagnosis is a good idea, and when it would be best to plan this, if a diagnosis is advisable the diagnostic kit will be posted. Thirdly, the results from the diagnostic kit will arrive and an appointment is booked to discuss the results, from this the last steps follow on choreographing an individual’s death.



Figure 8. Stills from A Planned-Death video.
Video: Marije de Haas.
<https://vimeo.com/263111400>
Part I of the video contains the rationale of The Planned Death Company's CEO, explaining why they developed the Dementia Diagnosis Kit.

Video

The footage was chosen to bring into question a natural death. Nature is not a moral entity and as such can't deliver a value to a death.

Script I: We felt it important to be able to plan for a dignified death. Deaths come in many shapes and forms, but few are 'natural'. A natural death has long been seen as the best way to die – it was as though people were thinking of nature as a great mysterious force with its own special kind of moral authority. Nature, in this sense, would supposedly allow you to die painlessly and peacefully. Statistics tell us however, that less than 15% of people die that way in the western world. More than 80% die in some form of care from a terminal condition.

Being aware of in what manner you might die will help you plan your future, and the future of your loved ones. For example dying of (certain types of) cancer might cause you physical pain, you decide about life-prolonging treatment versus quality of life. If your cognition is intact, you can make these kind of decisions, discuss them with your loved ones, and weigh them up for things that are important to you.

Dying of dementia poses different problems. As soon as your cognition goes, your options will be limited. It is for this condition we developed the Dementia Diagnosis kit. Knowing the time dementia will set in – we can predict this very accurately these days – allows you to make decisions on your quality of life; do you want control on your end-of-life, or leave these decisions in the hands of your loved ones and health care providers?

The Planned Death Company feels strongly that there is a deep difference between having a life and merely being alive, and we want to help you have a meaningful life for as long as possible.



Figure 9. Stills from A Planned-Death video.
Video: Marije de Haas.
<https://vimeo.com/263111400>
Part II of the video is the personal account of a planned death. It is the story of Peter's mother who planned her own death in dementia. Peter reads his mother's euthanasia note, the footage supporting this moving letter is showing controlled demolition as an analogy for euthanasia in dementia. Footage taken from Koyaanisqatsi (permission to use granted) backed up with a soundtrack from Godspeed You! Black Emperor, Storm (permission to use granted), which continues into black after the note and footage are finished to emphasize the gravity of the situation.

Script II: I will take my life today around noon. It is time. Dementia is taking its toll and I have nearly lost myself. I have nearly lost me. My loved ones will be at my side as I depart.

I have known that I have dementia, a progressive loss of memory and judgement, for a decade, and I have been living with it for the last three years. It is a stealthy, stubborn and oh-so reliable disease. I find it a boring disease, and despite the sweetness and politeness of my family I am bright enough to be aware of how boring they find it, too.

There comes a time, in the progress of dementia, when one is no longer competent to guide one's own affairs. I want out before the day when I can no longer assess my situation. Understand that I am giving up nothing. All I lose is an indefinite number of years of being a vegetable in a hospital setting, eating up the country's money but having not the faintest idea of who I am.

All members of my immediate family; daughter, son, two granddaughters and four grandsons, know that it matters to me not to become a burden to them, or to society. I have discussed my situation with them all. In our family it is recognized that any adult has the right to make her own decision.

Just in case anyone is tempted to think I must be brave to decide to die, you should know that I am not. I am sorely fearful of being alone in the dark. I do not want to die alone. Who wants to die surrounded by strangers, no matter how excellent their care and competence?

Each of us is born uniquely and dies uniquely. I think of dying as a final adventure with a predictably abrupt end. I know it's time to leave. Today, now, I go thankfully into that good night.



Responses and debate

This design speculation is being used to address the dilemma of euthanasia in dementia with a carefully selected group of participants; participants are Dutch or Belgian (cultural acceptance of euthanasia), and they have personal and/or professional experience with dementia. The participants completed an online survey and their responses are being discussed in semi-structured in-depth interviews. Amongst the participants are professionals in palliative care, a SCEN (Support and Consultation on Euthanasia) physician, philosophers, business owners, artists, writers, designers and designers specialised in dementia.

Very interesting results are emerging, for example it is very clear that people with personal experience of dementia feel much stronger about the subject and have a need for a possible euthanasia option. Professional people without this personal experience feel strongly that euthanasia should be avoided and suggest ways of doing so.

No unified answer emerged in response to the question *Who should be involved in making end-of-life decisions in dementia?* Responses ranged from: the person diagnosed with dementia, to physicians, to those affected by the decision. Most participants felt this was a decision best not made alone and professional help was recommended.

A lot of new questions and issues were raised:

- How can a past 'self' make decisions on a future 'self'?
- What are the rights of the future (cognitively less competent) 'self'?
- What if we transfer end-of-life decision making to a loved one?
- The need to address social care: if the outlook of being in social care is terrible enough to want to die, we may need to address how this care is conducted.
- The need to address the suffering and health of the carer.
- What if we would alleviate carer and societal burden (make it so the person living with dementia would not feel like a burden)?
- What if we could improve the care for dementia patients to remove the negative stigma?
- The need to discuss options in dying more openly, together.
- Physicians take the lead in opening up discussions about end-of-life.

Figure 10. Exhibition pilot as part of the PhD Festival at Umeå Institute of Design, on 4 October 2018.

As part of a challenge to create an exhibition from research this set up was created showing two sides of a planned death experience. The one side shows the Planned Death Company; a rational step by step approach. The flipside shows a personal story and the huge impact a death has beyond the individual.

All participants found the designs a helpful tool, it made the material more engaging, easier to imagine and respond to. The professional people felt that the video was clever and rich, and even though they at times felt it was provocative, it was found that this was useful to help discuss the more complicated ethical issues.

Discussion

In creating a Design Speculation to explore the concept of planning death, there is a need to acknowledge bias. The focus was to explore a good death in dementia. It is important in this discussion to be aware that euthanasia requests are rarely fulfilled in dementia, the only time euthanasia does happen in dementia is very early on in the disease. At this time there is no real physical suffering (unless an unrelated condition is causing this), but there is serious psychological suffering, especially in those individuals who are more familiar with the course of the disease. An early diagnosis is essential for making end-of-life decisions. To avoid paternalistic care systems a commercial approach was taken by creating a company, this would put the responsibility of receiving a diagnosis with the individual. The Planned Death Company is portrayed as a responsible entity, they do not simply provide a diagnosis, but pre-diagnosis and post-diagnosis care as well. The euthanasia note functions as a sort of testimonial in this context. We can never know if a death was indeed 'good', but in this particular case, the option to plan it, together with family and friends seemed like the best possible scenario. The main point made is about acting upon a diagnosis and planning for a good death in dementia.

As a critique of the method (Speculative Design) one issue is the credibility and quality of the Design Speculation; the way that it is crafted may have an impact on how it is perceived. To address this potential bias, it is important to document and reflect on the purpose of speculation. Few guidelines exist on how to create a good Speculative Design and it is important to *"suspend disbelief"* – Auger (2013) has suggested guidelines on how to achieve this. However, further research is needed to develop ways to critically access the quality of design speculations. This is a challenge as there may be little or no comparative material within the same context so a critical review of literature on the crafting of design fictions may offer some ideas and insights. This paper has tried to describe how the speculation was designed and why the specific design decisions were made, as a knowledge contribution to future guidelines/education on crafting evidence-based design speculations. However, as with any design, quality can only really be judged in relation to the context and purpose (usability, functionality) of the design created.

Conclusion

The euthanasia in dementia debate is at an impasse. The intention for producing a Speculative Design was to offer a new perspective on this dilemma by designing a platform for reframing questions. This research has shown that there are benefits in presenting a dilemma, such as euthanasia in dementia, in a different format. The Speculative Design has potential to aid discussion between various stakeholders, without each party needing to be a specialist. The use of a provocative speculation was found to spark debate, but a caveat is the importance of boundaries whereby stakeholders are made aware of the greater context of the problem space so that inherent bias is addressed.

"What can you do with this dementia? Keep going? Suicide? Everyone is stuck there, and people find it hard to develop an opinion. You don't present a solution, but a thought experiment ... I think it is done very well."

Bert Keizer,
SCEN physician
June 2018

"It is much better then just describing a few ethical questions and asking how you would relate to those, this is a much more powerful way. It definitely touches you."

Organiser of DementiaLab
June 2018

"I can completely imagine that someone would say, "I simply want to spare the other from this suffering". And this is a different way of looking at it. It is a really good option to consider very seriously."

Individual with extensive experience in dementia, death and euthanasia
June 2018

"Watching your videos was a surprising experience, it opened up a different way of looking at this on-going debate. I think it will be a nice edition to our programme."

Femke Awater, organiser of Mijn dood is niet van mij at Pakhuis de Zwijger, Amsterdam.
October 2018

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