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## Using design to encourage conversation about euthanasia in dementia

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REPOSITORY RECORD

De-Haas, Marije. 2020. "Using Design to Encourage Conversation About Euthanasia in Dementia". figshare.  
<https://doi.org/10.26174/thesis.lboro.11695119.v1>.



# Using design to encourage conversation about euthanasia in dementia

2020

Marije de Haas



**Using design to encourage conversation about euthasia in dementia**  
by Marije de Haas

A Doctoral Thesis

Submitted in partial fulfillment of the requirements for the award of

*Doctor of Philosophy*

of Loughborough University

23.01.2020  
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Loughborough Design School  
Loughborough University

This PhD was made possible with funding from Arts & Humanities  
Research Council, Design Star, Centre for Doctoral Training.  
Supervisor: Prof. Sue Hignett  
Secondary Supervisor: Dr. Gyuchan Thomas Jun  
Proof reading: Thijs de Haas  
Printing: Pantheon, pantheon.nl

Electronic version available at <http://xxxxx>

Marije de Haas  
September 2020



## Acknowledgements

### I want to thank:

Design Star and Polly Harte for the funding that made this work possible.

### Loughborough Design School

My supervisors: Sue for her calm and confident expertise and for knowing how to always convince me, and Thomas with his great insights and for pushing me in directions I did not want to go, and for supporting me in doing this thesis on a subject that must have been challenging for him. Andrew May for allowing me to do this thesis my way. The Hepsu group for all their valuable feedback and delicious cakes: AbdulAziz, Bernadette, Callie, Cecilia, Charlotte, Fernando, Gemma, Hua, Ingrid, Jo, Kubra, Lindsay, Michael, Mohammed, Ruby, Sara, Saydia, Sharon, Sue, Thomas, Victor and Winta. Jo Barnes for her excellent questions and critical assessment of my Year 1 and 2 reports which helped to write this thesis.

### Umeå Institute of Design

Everyone in the Umeå Institute of Design research group with inspiring seminars and courses: Aditya, Brendon, Elisa, Erik, Heather, Johan, Maja, Maria, Monica, Morteza, Nicholas, Søren, Stoffel, Titti and Xaviera. With special thanks to Monica for always engaging in random conversations. Heather for her knowledge and humble excellence. Stoffel for being an additional supervisor making things clear when it was all muddled. And Johan for sparing the time to share his unique insights. Brendon for allowing me to be a guest in the research studio for such a very long time.

### Umeå University

Annika from the Umeå University Library for her patient reviewing and extremely useful advise on how to improve my writing. I think her help was the most practically useful in trying to write this thesis. I couldn’t have made sense without you!

### Designs

Thanks to all the people who helped me in creating the design prompts. The actors: Ambra, Isa, Jeroen, Keet, Lex, Lidewij, Martijn, Merel, Nigel, Rich, Sander, Stoffel, Theo en Thijs. The UID and Hepsu groups for providing feedback. And Rich for his feedback, support and editing skills.

### Participants

All the participants who gave up their time and knowledge to engage with me in long surveys and interviews, further emails and questions. I could not have done it without all the knowledge and insights you have provided. You have my deepest gratitude.

### Others

Henk Blanken and Femke Awater from Pakhuis de Zwijger and Gert van Dijk from KNMG for giving me a chance. Marieke Sonneveld for her advise and motivation. René and Peter at Pantheon for printing this book.

### Personal

My dearest mother who inspired me to do all of this, and who I wish could somehow have benefitted from what I have learned. My wonderful father whose encouragement and support (in many shapes and forms) has made this possible. My lovely Badger who has been my sounding board. Badger for his ever critical and supportive voice, his creative genius and for just being there for me. And Otto for simply being the best.

## Prologue

The fear of living with dementia is driving requests for euthanasia. The fear of living with dementia drove me to write this thesis. I wrote this thesis for people like me, those who would prefer to die a planned death, rather than live the end of a life with dementia. It must be understood that my personal experience of witnessing my mother suffer early onset Alzheimer’s disease has informed my view. I use the word ‘suffer’ consciously based on my mother’s own opinions and value system: she considered living with dementia a fate worse than death. My mother, in turn, was influenced to feel this way about living with dementia by caring for her own mother whose life also ended with dementia.

I understand that dementia can express itself in many different ways and the difficulty is that this is unpredictable, there is no way of knowing how one might ‘live’ with dementia. Euthanasia, in this case, can be seen as a fail-safe option, for those not willing to take the chance that their lives with dementia might well be full of quality. A lot of research is being done in providing quality for those living with dementia, and I urge people to investigate the ways that people living with dementia can have good ends of their lives.

This thesis sets out to investigate, first and foremost, if and how design can support complex ethical debates. The subject matter for investigating this is the debate about euthanasia in dementia, because I am a designer with a desire to make euthanasia possible in dementia. Doing this work, the research, the designing of the provocations, the interviews and the analysis, has been cathartic. It has opened my mind to understand why euthanasia is so problematic in dementia, that the desire for euthanasia might not be all about the self, that autonomy in this respect might not exist, and that there are indeed other options for a decent end of life in dementia. Dear readers, I hope that this research helps you to develop your own opinions regarding an end of life in dementia.



**Abstract**

**Background**

Dementia is chronic, progressive and affects several brain functions, including memory, thinking, orientation, calculation, learning capacity, language and judgement. Usually the symptoms are accompanied by deterioration in emotional control, social behaviour or motivation. It affects 50 million people worldwide with 10 million new cases each year and presents as a collection or consequence of many illnesses, including Parkinson’s disease, vascular dementia and Alzheimer’s disease; it is a terminal disease.

**Purpose**

The fear of living with dementia is driving requests for euthanasia but this is a complex issue because the symptoms of dementia clash with the due care criteria for euthanasia; unbearable suffering is difficult to assess in dementia 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. This thesis explores if, and how, design can be used to stimulate conversation on euthanasia in dementia in the Netherlands.

**Design**

Prompts were designed on four topics extracted from a systematic literature review: Suffering, Autonomy, Timing and Planned Death. Three of these prompts were presented as speculative designs in the form of short films and one was a piece of information design, all were carefully constructed based on literature and expert advise to help formulate issues beyond abstract thought.

**Data collection**

Survey and interview data were collected using these designs with a carefully selected group of expert participants; people familiar with the Dutch practice of euthanasia and who had personal or professional experience with dementia. An opportunity to inform a wider public debate was offered with some of the designs being used at Pakhuis de Zwijger in Amsterdam on two occasions in the winter of 2018, and in round-table discussions at the Royal Dutch Medical Association in March 2019.

**Results and conclusion**

Design did further the conversation, the prompts were seen as useful thought experiments and helped participants to formulate their thoughts better. Dementia was still seen as fairly hopeless, but may improve with better professional care. Non-professional carers were seen to be unable to carry the burden of dementia care because this is causing a lot of other health related problems for the carers. Euthanasia could be improved by writing better advance euthansia directives and more detailed do not resuscitate agreements. It was concluded that physicians need much more support in initiating end-of-life conversations, in order to prepare families and their loved-ones for decision making for end-of-life scenarios.



## Part 1.

### Introduction





# Chapter 1.

## Introduction

The debate on euthanasia in dementia is stuck in various moral dilemmas. Euthanasia for people living with dementia is a difficult issue because the symptoms clash with the due care criteria for euthanasia; unbearable suffering is challenging to assess in dementia (Buiting et al., 2008; Hertogh, 2009; Rietjens et al., 2009a; Emanuel, 1999). 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., 2005b). Practically this means euthanasia is only possible in the early stages of the disease when cognitive functioning is still relatively intact (Steenbergen, 2018, 20 Nov). 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 (Davis, 2014).

This thesis addresses the ethical challenges of planning death for people living with dementia by using design to stimulate and support discussion between stakeholders. Euthanasia in dementia can be seen as a ‘wicked problem’, which asks for exploration (Tonkinwise, 2016). Design can be used to initiate or stimulate dialogue between experts and the users of the proposed design (Auger, 2013), or used as a tool to aid discussion (Tseklevs et al., 2017); this can include presenting information in a visual way to support generating new knowledge (Neurath, 1936).

This chapter provides an overview of the framing, context and structure of the thesis. Firstly the research question is formulated in context to the themes found through the systematic literature review (1.1) and secondly, the research approach is described and divided into:

- content overview of the core notions (1.2);
- context framing the landscape (1.3).
- method of investigating this issue (1.4),
- summary outline of thesis (1.5).

### 1.1. Research questions

The primary subject of this thesis is how design can be used to further the debate on euthanasia in dementia in the Netherlands, where euthanasia in dementia is legally allowed but problematic because the symptoms of dementia clash with the due care criteria for euthanasia. Euthanasia in dementia is a widely discussed topic, but remains in the realm of hypothetical debate. This thesis uses design research as ‘applied thought experiments’ to give a different perspective on euthanasia in dementia with the intention to encourage conversation about this subject. The aim is to investigate if design can be a useful method to further the euthanasia in dementia debate through three questions:

1. How does (speculative) design support debates?
2. How can design support debate in the case of euthanasia in dementia?
3. What can we learn from applying speculative design to support conversation about euthanasia in dementia as done in this thesis?

Through a literature scoping study, more detailed themes were formulated, to consider whether design approaches could be used to explore the following questions:

- What is unbearable suffering in dementia, and can it be assessed?
- Why is it difficult to make a decision for euthanasia based on patient autonomy in dementia?
- When is the best time to die in dementia?
- What are the complexities around planning a death in dementia?

### 1.2. Core notions

This section describes the core theoretical ideas that inform the research questions.

#### 1.2.1 Moral dilemma: Euthanasia in dementia

Assisted dying in dementia is a fiercely debated subject. Euthanasia requests in dementia stem from anxiety about living with the condition (Davis, 2014). Because the symptoms of dementia may clash with the criteria for euthanasia, it is difficult to assess if a person with dementia is suffering (Buiting et al., 2008; Hertogh, 2009; Rietjens et al., 2009b; Emanuel, 1999), and whether the decline in cognitive functioning means that people with dementia are unable to consent to their requested euthanasia at time of death (Rurup et al., 2005b).

#### 1.2.2 Dementia

Dementia is chronic, progressive and affects several brain functions, including memory, thinking, orientation, calculation, learning capacity, language and judgement (American Psychiatric Association, n.d.). Usually the symptoms are accompanied by deterioration in emotional control, social behaviour or motivation (Wikipedia, 2019). Dementia affects 50 million people worldwide with 10 million new cases each year (WHO, 2019). It is a collection or consequence of many illnesses, including Parkinson’s disease, vascular dementia and Alzheimer’s disease with similar symptoms in which there is deterioration in memory, thinking and behaviour; it is a terminal disease.

#### 1.2.3 Euthanasia

Euthanasia has many definitions, from the Greek origins ‘good death’ or ‘easy death’ to the Nazi euphemism for the deliberate killings of physically, mentally, and emotionally handicapped people, leaving the term with extremely negative connotations.

In this thesis, the following definition is used: 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.

The person who is terminally ill asks for support in planning their death. This encompasses assisted suicide and physician assisted suicide as well as any assistance resulting in immediate death (killing). It is intended that no distinction is made between euthanasia and physician-



assisted suicide unless specifically mentioned, because the primary interest is in the decision making with helping a patient to die, and not in the decision about which method to use. The difference between physician assisted suicide and active voluntary euthanasia is considered in a separate section (2.2.4.4), because the method of ending a life does effect patients, family and physicians differently (Brock, 2000).

1.2.4 Death

Death is the cessation of all vital function and results in the end of life.

1.2.5 End of life / dying

The end-of-life and dying is the process leading up to death. End-of-life is referred to as the process where the person dying is aware that they have limited time left, and have an indication how long this may be.

1.2.6 Suffering

This is a difficult term to define. Suffering and determining quality of life is individualistic. Whether or not a patient’s situation is unbearable is to a large extent a matter of the patient’s subjective experience and perspective, which can be more than just physical symptoms (Buiting et al., 2009).

The Oxford Dictionary defines suffering as “*The state of undergoing pain, distress, or hardship*.” In case of advanced dementia, physicians point out that it is impossible to determine whether a patient is suffering unbearably, due to a lack of meaningful communication (Bolt et al., 2015). This thesis uses the term ‘suffering’ to mean diminished quality of life.

1.2.7 The debate in the Netherlands

Euthanasia is legal in the Netherlands since 2002. The debate about euthanasia has been going since the early 1970s, and since the 1980s the discussion expanded to euthanasia for cognitively incompetent people, particularly those with dementia. This is because a new generation of older people, the “third age” wanting to remain in control of their lives and futures (Hertogh et al, 2007). This thinking was supported by then Minister of Health, Mrs. Borst, who added section 2.2 to the law, stipulating that an advance euthanasia directive can be complied with if the due care criteria are applied (nvve, n.d.). However, advance directives are not legally binding if a patient is no longer cognitively competent (Bekker-Compagnie, 2016). Every year about 10,000 people with dementia die

in the Netherlands, about half of those had written advance euthanasia directives and out of those requesting euthanasia for the condition of dementia less then 2% succeed in receiving euthanasia in the Netherlands (Blanken, 2019). This discrepancy between the ‘death-wish’ and the execution of this wish is what has been fuelling the debate on euthanasia in dementia in the Netherlands, “(…) *what can be gathered from this part of the Dutch dementia debate for the agenda of healthcare ethics is the urgency of a careful discussion on the limits of precedent autonomy and anticipatory choices*” (Hertogh et al, 2007).

1.3 Context: framing the landscape

Euthanasia is illegal in most of the world so the Dutch legal framework for Euthanasia has been used; it focuses on three main actors, the patient, the care-giver or loved-one and the physician. The questions of moral objections to euthanasia are intentionally excluded to focus on the specific dilemma of euthanasia in dementia.

1.3.1 Legal framework

The Dutch Euthanasia Act (2002) states that:

“*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*” (Buiting et al., 2008, p1).

1.3.2 Actors

Dementia requires wrap-around (holistic) care. This is usually performed by carers from different paths of life and in various professional capacities. For clarity the following terms will be used:

- Patient: The person diagnosed with dementia.
- Care-giver/loved-one(s): The full-time, non-professional care-giver. This can be a partner,a family member, a friend or hired help.
- Professional care-giver: This identifies the qualified carers, physicians, nurses and nursing home staff.

1.3.3 Religion (moral objections)

For this thesis it is posited that death is final; therefore objections to euthanasia based on religious belief are not be included.

1.4. Methodology

Design can be seen as a systematic structuring of alternative futures; a study of planned or intentional change (Simon, 1996, p111). This research is investigating a wicked problem, “*a problem whose social complexity means that it has no determinable stopping point*” (Tonkinwise, 2016). Wicked problems need to be addressed through iterative process of problem clarification, definition and solution development with various stakeholders. Design can provide an effective way to do that. Moral dilemmas are a good focus for a design approach because of the desire to create a significant transition from a current state to a (desired) future state (Simon, 1996). The effect of images can be greater than the effect of words in generating new knowledge (Neurath, 1936). In this thesis, design is used to create relatable applied thought experiments to support/ stimulate formulation of issues beyond abstract thought. The chosen dilemma of euthanasia in dementia is complicated on many levels; medically, socially, emotionally. The research method offers fictional solutions and information design as a framework to stimulate and support discussion.

1.5. Summary

This thesis describes the use of design research to further the debate on euthanasia in dementia. These findings are relevant for designers, design researchers as well as health-care practitioners and potentially law-makers. The structure of the thesis is attempting to allow flexibility such that chapters can be read in isolation. To allow this there is some repetition of essential concepts.

There are six parts:

1. Introduction to the research, its complexities and boundaries, and rationale for approach.
2. Background, giving in-depth information on the content and methods.
3. Designs, with detail about the creation and iteration of the design concepts.
4. Data, discussing how the designs were used in the data collection/analysis.
5. Applications, outlining three real-world applications of two designs. This part takes the research findings further by describing how the designs have found real-world applications and the reflection is felt to contribute interesting perspectives to the discussion.
6. Learnings, insights and findings are reviewed, for both the content and methods.



Part 1: Introduction

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## Part 2. Background





## Chapter 2

# Systematic literature review on euthanasia in dementia

With a controversial topic such as euthanasia and to acknowledge personal perspective (potential bias), it would seem prudent to be as objective as possible, hence a systematic review method was chosen. The systematic review identifies published literature and the research gaps in the practicalities of assisted dying and suffering in dementia. This systematic literature review will establish why euthanasia in dementia is such a difficult request, and shed light on the following questions:

- What is unbearable suffering in dementia?
- Why is it difficult to make a decision for euthanasia based on patient autonomy in dementia?
- When is the best time to die in dementia?
- What are the complexities around planning a death in dementia?

Summary of Search Results

Database	Filtered results	by title	by abstract	Total
Medline	34	13		13
Science Direct	90	14		14
Web of Science	497	206	128	128
Scopus	25	23	11	11
PubMed	129	4		4
Cochrane Library	3	0		
PsychArticles	16	10		10
Reference chase				2
Duplicates				7
Missing				25
Total to review				150

Table 1  
Summary of Search Results.  
Full table of reviewed papers can be found in Appendix A.

### 2.1 Search

On recommendation of Loughborough University Library, the following databases were searched: Medline, Science Direct, Web of Science, PsychArticles, Cochrane Library, Scopus and PubMed.

The criteria were set as follows:

#### Date range

The date range was set from 1994-2017. 1994 is when the Oregon Death With Dignity Act (ODDA) was passed, it specifies a physician may prescribe lethal medication that is to be used to hasten death for competent, terminally ill persons who voluntarily request it (Fenn & Ganzini, 1999).

#### Language

Language was limited to Dutch and English as accessible literature and specifically, because this research is based on the Dutch legal framework.

#### Geography

Criteria were set to include provenance where assisted dying is legal: The Netherlands, Belgium and some US States, namely Oregon.

#### String search

Euthanasia OR “assisted suicide” OR “physician assisted suicide” AND dementia OR Alzheimer AND planning.

#### Other limitations

Full text and abstract had to be available. Where available the database filter tools were used as specified in Table 1.



2.2 Synthesis of the Literature Review

Themes that emerged follow the questions asked, and highlight problems in the Dutch legal framework: a physician must be able to observe unbearable and hopeless suffering and the person requesting euthanasia must be able to consent to this at time of death.

• Suffering (2.2.1)

In order for euthanasia to be legal, the physician performing euthanasia must be able to establish that the person requesting euthanasia is suffering unbearably and hopelessly. What is suffering and how can you assess suffering in dementia?

• Autonomy (2.2.2)

The right to self-determination is highly valued in Dutch society. It means that you are allowed to decide to plan your death if diagnosed with a terminal disease. Dementia presents with loss of cognitive functioning, meaning that you lose your right to self-determination; what does this mean for your right to die?

• Timing (2.2.3)

Dementia is a disease with progressive loss of (cognitive) functioning. This means there is a cut-off point for the possibility of euthanasia. When is a good time to plan death in dementia?

• Planned death (2.2.4)

80% of people in the western world die in care facilities of terminal conditions (WHO, 2018). This calls for the need to make choices about how we die. What is a good death in dementia?

2.2.1 Suffering

To be able to grant a euthanasia request, physicians must observe unbearable and hopeless suffering. Measuring suffering objectively is complicated because the feeling and observation of suffering are individualistic and tainted by personal experiences. In the case of dementia, where perception and self-reflection is altered as the disease progresses, suffering is more complicated to assess.

2.2.1.1 Unbearable suffering

People with terminal illnesses primarily fear pain and anticipated pain; indignity; loss of control; being a burden and cognitive impairment (Chapple et al., 2006; Gjerdingen et al., 1999). Suffering has medical, psychological, social and an existential dimensions, but there is no universally accepted definition of unbearable suffering. Unbearableness was often caused by hopelessness. Suffering is individual and it can only be understood in the fabric of the patients’ perspectives of the past, the present and expectations of the future (Dees et al., 2011; Gastmans & De Lepeleire, 2010).

2.2.1.2 Being a burden

The term ‘burden’ is often used in relation to euthanasia requests; patients do not want to be a burden on their loved ones (Denning et al., 2012). In the Dutch decision making process on whether to grant euthanasia it needs to be very clear that this sense of burden does not come from the family of the patient, which means that carers’ feelings that the patient is a burden can not support an euthanasia request (Brock, 2000). However, this feeling of ‘being a burden’ can be just. Dementia patients are a burden to those who care for them. It is hard to look after dementia patients, so much so that the wellbeing of carers is often affected (Dunham & Cannon, 2008; Gessert et al., 2000; Chambaere et al., 2015). Being a burden does influence future decisions of carers if, in turn, they were faced with a dementia diagnosis: “I don’t want to leave my son with things like that [making decisions and providing intimate care].” Carer 1. “... being a carer is difficult...it leaves some nasty memories...” Carer 2 (Denning et al., 2012, p414-415). Carers wished for autonomy for their own care if they would have dementia, expressing a possible wish for assisted dying or euthanasia. However, the people with dementia themselves had no perception of the sense of burden they generated on their carers and talked about burden as something that may occur in the future with little perception of the current situation (Hertogh, 2009).

2.2.1.3 Assessing suffering

Assessing suffering becomes more complicated as dementia progresses, both for the person with dementia as well as the physician, because meaningful two-way communication becomes harder. Physical suffering is deemed easier to assess (Smith & Amella, 2014; Buiting et al., 2009; Buiting et al., 2008). “The realisation of having dementia—once feared as a source of degrading suffering—is progressively lacking from the patients’ subjective experience, rendering it impossible for them to evaluate the present situation as unbearable and/or hopeless” (Hertogh, 2009, p101). This causes a challenge for the physicians who are supposed to carry out euthanasia based on observable ‘unbearable and hopeless’ suffering. The assessment of suffering also is heavily influenced by the observer’s own values and experiences, variations were found in the classification of suffering as ‘unbearable’ especially in cases where existential suffering was being assessed (Rietjens et al., 2009). The way family assesses the suffering of their loved-one also influences the decision-making (Emanuel, 1999). The way people adjust to suffering, a ‘response shift’, is sometimes argued to be the reason that dementia patients contradict earlier preferences. Jongsma et al. (2016) argue that a response shift is a change in self-evaluation of quality of life; because dementia patients lack the ability to self-evaluate, this results in complexities in measuring quality of life or even having an opinion on it (Jongsma et al., 2016).

The key points on suffering are:

- Existential suffering is the main reason to choose euthanasia in dementia.
- Assessing suffering is difficult if there is no meaningful two-way communication.
- It is unclear if people living with dementia can adjust to their suffering.
- It is impossible to remove inherent opinion from the assessor.

2.2.2 Autonomy

The right to self-determination is highly valued in Dutch society and is an essential part of euthanasia legislation. One of the symptoms of dementia is progressive loss of cognitive functioning, endangering the right to self-determination.

2.2.2.1 Control

Being in control about one’s own end-of-life is a way to experience autonomy. Terminally ill people want to be in control over decision making, independence, mental attitude, instrumental activities of daily living and relationships (Schroepfer et al.,2009). Creating an advance directive can give a person control over their end-of-life; (Burlá et al.,2014). The option of assisted dying may also give a sense of control. Legalization of assisted dying may have a therapeutic benefit for terminally ill patients, who often report feeling more at peace merely by knowing that they have the option to end their lives when they want to (Rosenfeld, 2000a; Brock, 2000). However, not everyone wants to be in control of their own end-of-life decision; Cicirelli (1998) studied end-of-life decisions for older people and found that approximately one third of participants (n=388) favoured deferring end-of-life decisions to someone else, such as a family member, close friend, or a physician (Cicirelli, 1998). Relatives of people living with dementia felt that they could deal with the death of their loved-one better in euthanasia, knowing their loved-ones had wanted to remain in control (Georges et al., 2007). In countries where assisted dying is not an option, some people may choose to die by suicide. The effect of suicide on the people left behind can be much worse than a planned death. Families reported being better prepared for their loved ones’ death where people have requested assisted dying, and better able to accept it than those whose loved one has died ‘naturally’ of a terminal illness (Carlson & Ong, 2014).

2.2.2.2 Advance directives

An advance directive is a tool used in planning for end-of-life. It is a document used to make provisions for health care decisions in the event that, in the future, the person becomes unable to make those decisions. Advance euthanasia directives in dementia are rarely complied with even though patient suffering may be judged to be extreme (Rurup et al., 2005). The fact that advance directives are rarely adhered to in advanced dementia limits their role in advance care planning and end-of-life care



of people with advanced dementia. Advance directives for euthanasia may raise false expectations and, in addition, place too much responsibility on elderly care physicians and relatives (Hertogh, 2009; Rurup et al., 2005b; de Boer et al., 2011; Kouwenhoven et al., 2015). However, some literature did approach advance directives as a tool for adequate advance care planning in dementia. Burlá et al. suggested that the advance directive can be presented to the patient in the early days of their diagnosis (Burlá et al., 2014). Others are aware of the problems with advance directives in dementia and propose solutions. Flew (1999) proposes a specific advance euthanasia directive that should be adhered to, even in advanced dementia (Flew, 1999). Gastmans & de Lepeleire (2010) claim that, in an ethical evaluation of euthanasia, the dignity of the human person, relational autonomy, quality of life and care must be observed. They introduced the concept of ‘relational autonomy’ to give more control to close family/friends and social context of the person with dementia (Gastmans & De Lepeleire, 2010).

2.2.2.3 Personality change

Another major obstacle in advance planning and dementia is the personality change that is associated with dementia: *“The core of the argument revolves around the undeniable change in personality, and arguably even identity, between the competent person who executed the directive and the incompetent person who will be affected by it”* (Davis, 2014, p546). This can place a huge strain on physicians and health care proxies, who have to make life-and-death decisions on behalf of the person who wrote the advance directive. Essentially an advance directive is the formerly competent person asking his/her proxies to ignore their demented self. Several authors question whether this is a fair question to ask loved ones (Buiting et al., 2008; Rietjens et al., 2009a; Bernheim et al., 2014). Menzel and Steinbock (2013) describe identity in reference to Dworkins’ ‘critical interests’; these can be described as life values and go beyond ‘experiential interests’ which only exist in the here and the now. The critical interests shape a person and describe the kind of person they are and want to be – these are the interests that should be protected in an advance directive. This causes a dilemma: if the experiential interests of the person with dementia are not violated once dementia takes hold, but conflict with their critical interests. The authors propose a sliding scale solution,

where autonomy is weighed against capacity of enjoyment, on a case by case assessment. Advance directives give people control over their lives once they themselves are no longer capable; *“the way they die is an important reflection on the way they lived”* and should be taken into consideration (Menzel & Steinbock, 2013, p496-497).

The key points on autonomy are:

- People should be able to make an autonomous decision about their end-of-life; they can exert control by making an advance (euthanasia) directive.
- Advance euthanasia directives are not adhered to in dementia, because the disease presents with personality change and the disease makes suffering impossible to assess.
- The parties having to execute the wish expressed in an advance directive are faced with a difficult moral decision; do they respect the person who has written the directive, or the ‘new’ person the directive is about?

2.2.3 Timing

A major barrier for euthanasia in dementia has been pinpointing a time to act. In dementia there is only a small window of opportunity, after a diagnosis and before cognitive decline sets in.

2.2.3.1 Too early

Deciding the time of death is complicated in dementia; it seems impossible to die ‘on time’. *“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, p543). Hertogh identifies a small window of opportunity in early dementia when cognitive functioning is still relatively intact (Hertogh, 2009). Euthanasia in dementia is rare, but it does happen in the early stages of dementia, this is often seen as ‘too early’. There have been 166 cases of euthanasia in dementia in 2017, these all took place in the early stages of the disease when cognitive functioning was still in tact (Steenbergen, 2018). Patients must carry out the impossible task of choosing the time of death, because there is no possibility to change one’s mind once this has been decided (Gastmans & De Lepeleire, 2010).

2.2.3.2 On time?

There is not much awareness about having to speed up the euthanasia process in dementia, and some people try hard to postpone the moment of death. Author Henk Blanken is fighting for the right to die ‘on time’ and proposes that his wife should be the one to decide. He feels that a person with dementia must be able to authorize a loved one to find a physician to perform euthanasia, or in the worst case, allow the loved-one to perform the euthanasia themselves at the time that they deem is right (Blanken, 2018).

2.2.3.3 Too late

Once patient autonomy has diminished, this responsibility of deciding on euthanasia would be transferred to others which may cause stress (de Boer et al., 2011). In a study to see whether physicians could conceive of performing euthanasia under morally complicated cases such as people who are simply tired of living, people with a psychiatric illness, or demented people, the timing issue arose: *“Many physicians state that it is impossible to determine at what moment an advance euthanasia directive is to be carried out if the patient can no longer specify this”* (Bolt et al., 2015, p596). There have only

been 3 cases of euthanasia in dementia at a late stage of the disease to date (2017), and these have been very controversial (Steenbergen, 2018).

The key point on timing is:

- Deciding the moment of death is difficult. In dementia there is a small window of opportunity, after a diagnosis and before cognitive decline sets in.



2.2.4 Planned death

There is a great deal of fear for dying with dementia, which drives people to sign advance euthanasia directives. It is important to address ethical issues in planning death in a society where dying is becoming a medicalised decision; 80% of people die in care facilities in the developed world (WHO, 2018).

2.2.4.1 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, 2018). 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., 2009b). 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’. People should be allowed to die a ‘good’ death, regardless of whether this is ‘natural’. 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 (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, p161).

2.2.4.2 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, p229). 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 the 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, 2000a). Rational suicide has been seen through the ages as an appropriate action for those who suffered from intense physical pain and the elderly (Abeles & Barlev, 1999). James Werth provides considerations to determine whether 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 (2016) 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. He describes a dementia case as an example of a good death: a man in the beginning stages of dementia decides to choose ‘self-euthanasia’, this man had witnessed his own parent with the same fate and had decided he did not want this for himself. His family supported his decision. His physician was clear that this did not meet the due care criteria, but helped by providing lethal medication (Vink, 2016).

2.2.4.3 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). John 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). Dena 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 (not wasting money on futile care): *“Death is irreversible, but so is dementia”* (Davis, 2014, p548). 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 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).

2.2.4.4 Performing euthanasia

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. Performing euthanasia, even if this is legal, is not easy. Physicians, who currently are the only ones who can legally perform euthanasia, 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 an 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 et al., 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). The manner in which

we reach is certain result is morally relevant. The moral difference lies in the intention. In terminal sedation the intention is to relieve pain. In euthanasia, the intention is to cause death, however, one can also argue that the intention in euthanasia too, is to relieve suffering. Quite a few papers offer viewpoints on this dilemma, though none of them are conclusive: (Holm, 2015; Huddle, 2013; Huxtable, 2014; Leget, 2006; Lowe, 1997; Shaw, 2002; Short, 2003; Singer, 2003; Stauch, 2000; Sullivan, 1999; Thomson, 1999).

There is little support for physicians to help make distinctions between terminal sedations or euthanasia. When studying decision making in intensive care about continuation or withdrawal of life support in Yorkshire, 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 decision making in countries where physician assisted death is legal, because 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). Bosshard et al (2008) make a case for ‘a 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).

The key points on planning death are:

- Whether a death is natural or not has nothing to 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.



2.3 Summary

The literature discusses the dilemmas present in the debate on euthanasia in dementia extensively. Now we can establish why euthanasia in dementia is such a difficult request, and shed light on the following questions:

• What is unbearable suffering in dementia?

Suffering in dementia is often existential and comes from having observed and experienced dementia with a loved-one. Caring for dementia patients is very hard and healthy people want to avoid becoming such a burden for their loved-ones. This kind of suffering can be communicated in early stages of the disease. Once dementia has progressed patients are unaware of being a burden and this feeling no longer classifies as suffering. In later stages of dementia two-way communication becomes more difficult and makes assessing suffering much more complicated. Observations on suffering are biased and observer’s opinions must be taken into account.

• Why is it difficult to make a decision for euthanasia based on patient autonomy in dementia?

Dementia presents with progressive loss of cognitive functioning and personality change. The right to self-determination diminishes if one is no longer cognitively competent. Personality change creates other complications because it is no longer clear if the autonomous person who made a decision for euthanasia is the same person the euthanasia would apply to.

• When is the best time to die in dementia?

Dying ‘on time’ in dementia is difficult because the moment requested in an advance euthanasia directive often applies to a time when a person is no longer competent or themselves, which makes the euthanasia request illegal. Therefore the euthanasia needs to take place when a person is still competent and themselves which is deemed ‘too early’.

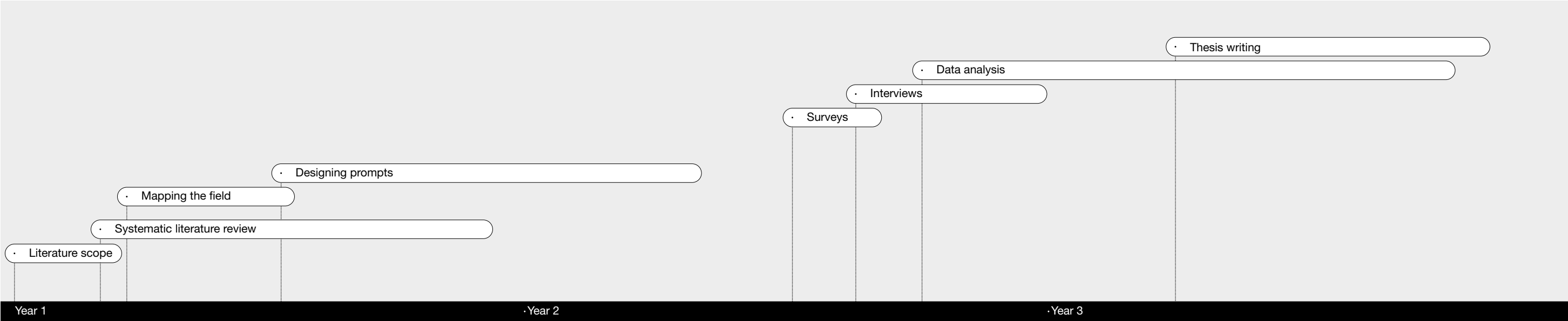
• What are the complexities around planning a death in dementia?

There are some issues around the acceptability of planning death, a natural death is seen as the preferred way to die because this way no-one needs to take responsibility for death. If dying was a rational choice the motivations need to be clear; is depression a rational reason for desiring death? If staying alive means putting strain on loved-ones or society does this mean we have ‘a duty to die’? If a planned death is rational and acceptable, someone will need to perform euthanasia, which can be a harrowing act. Physicians who currently have this responsibility need more support.

No obvious gaps were identified, however it is clear that there is a need to address the dilemmas present in this debate in a different way in order to make progress, which is what this thesis sets out to do.



Chapter 3  
Methodology



This research is investigating what could be called a ‘wicked problem’ (Rittel & Webber, 2012), a wicked problem is “*a problem whose social complexity means that it has no determinable stopping point*” (Tonkinwise, 2016). Wicked problems need to be addressed through iterative process of problem clarification, definition and solution development with various stakeholders. Design can provide an effective way to do it. The research philosophy for this thesis is based on ‘constructivist or interpretivist epistemology’ meaning that our knowledge of the world is a human and social construction, subjective and may change (Saunders et al., 2009). It is understood that meaning is derived from our engagement with the world, and that people create meaning in individual ways depending on the context of the situation. This research attempts to present “*lines of flight*” as a way to break out of the euthanasia in dementia “*rhizome*” (Deleuze & Guattari, 1987). This research views the debate on euthanasia in dementia as a rhizome; a network of concept and ideas, connected together in sometimes chaotic ways. Deleuze and Guattari pose that a rhizome is a system in flux, always changing and rearranging. One can look at the connections in a rhizome to try and make sense of any given situation, much like how one could study a map. A map is non-hierarchical and has many different entry points, but can provide an overview of a given situation in time. This research has tried to ‘map’ the debate on euthanasia in dementia, and offered “*lines of flight*”; ways to look at the map through different lenses. It does so by recognising the limitations of the current debate on euthanasia in dementia and offering different viewpoints to clarify, visualise and speculate complexity, uncertainty and ambiguity around the topic of the euthanasia in dementia. Individual responses to these offerings are captured and investigated using qualitative research methods based on Grounded Theory.

Visual methods in qualitative research are becoming more popular especially to support data collection and analysis (Glegg, 2019). Visual media is primarily seen to contribute in enriching communication and by doing so, enhancing the collected data (Pain, 2012). One researcher investigated using a visual method (photography) versus oral interviews and found that the visual way of qualitative research yielded richer results, highlighting that visual methods may have ethical implications (Meo, 2017).

The ethical challenges of planning death in dementia are addressed in this thesis by using design as a framework for stimulating and supporting discussion. Design can be used to initiate or stimulate dialogue between experts and the users of the proposed design (Auger, 2013), or used as a tool to aid discussion (Tseklevs et al., 2017). Presenting information in a visual way can support generating new knowledge (Neurath, 1936). Design is usually seen as a problem-solving practice, however the focus of design is shifting and design often engages with broader social context, asking questions and opening issues for discussion (Mitrović, 2015; Tonkinwise, 2016).

Using design as a research method is a relatively young field called ‘Research through Design’ which lends itself well to investigate wicked problems (Zimmerman et al., 2007). This practice is outlined in section 3.1. Designs have been created that could be defined as speculative design, which is described in section 3.2, and information design, explained in section 3.3. This chapter is concluded with how the data gathered using reserach through design has been analysed (3.4).

**3.1 Research through design**  
Design has often been defined as a ‘problem solving’ practice (Mitrović, 2015). However, it has become clear that designers often create problems as much as they solve them, such as unintended consequences on social structures or climate – consider for example Uber or Airbnb (Dujardin, 2017). Design can be better defined as a practice of planned or intentional change (Tonkinwise, 2016). Or as Herbert Simon puts it: “*Everyone designs who devises courses of action aimed at changing existing situations into preferred ones.*” (Simon, 1996, p111).



This thesis sets out to use ‘designed’ artifacts to conduct research with. These artifacts intend to clarify, visualise, speculate and question current dilemmas present in the debate on euthanasia in dementia, and find out if the current situation of euthanasia in dementia could be improved upon. Using designed artifacts in a research context is not a new way of working, it can be placed in a field of practice called ‘research through design’. The term ‘research through design’ was coined by Christopher Frayling in 1993 in his paper ‘Research in Art and Design’ (Frayling, 1993), he explains Research through Design (RtD) clearly in an RtD conference provocation video in 2015 where he says that research through design is:

“taking a problem outside design and using design to address it” (Frayling, 2015).

The role of a research artifact is to probe the object of the research. As a probe, the research artifact can be seen as a benchmark upon which interpretations and analysis of the research topic can be developed (Zimmerman et al., 2007; Gaver, 2012; Stappers & Giaccardi, 2013). In this thesis four main concepts were developed that were each presented as a story with it’s own artifacts. The four concepts are suffering, autonomy, timing and planning. Each concept was framed in a specific way to provoke a specific response: The concept developed based on the theme of suffering had a rational approach in order to tease out responses on what way suffering might be assessed (4.1). The concept developed based on the autonomy theme was much more provocative, taking a black and white stance with the intention for people to start to formulate the grey areas in between (4.2). The concept developed on the theme of timing was presented in a reliable way as an information graphic, however it presented a combination of quantitative and qualitative data again revealing the complexities within a simple question of ‘what is on time?’ (4.3). The last concept was based on the theme of planning death, which had a rational idea combined with a highly emotional approach to illustrate the tension between the rational and emotional (4.4). Together these artifacts provided different lenses through which to see the dilemmas inherent in the debate on euthanasia in dementia.

Ways of collecting data from 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). For this research, the designs created are approached as applied thought experiments. 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). Information design is typically used to present data, not to find data. In this research, information design is used as a map; the information design provides a map of the landscape of the debate on euthanasia in dementia. This map can be explored in order to find one’s own position on the debate. The designs created were all made for a very specific target audience; the participants in this research – namely people with experience of dementia and a cultural understanding of the practice of euthanasia (5.1). Therefore these designs would not work as a stand-alone exhibit but were created as ‘active participants’ for targeted discussions. The designs were used as prompts to stimulate thoughts around specific questions in a survey (5.2.1) and further conversation in one-on-one semi-structured interviews (5.2.2).

The type of designs created to conduct research with, can be categorised as speculative design and information design. These two design methods are described in section 3.2 and 3.3 respectively. How these methods were interpreted and used in this thesis is described in section 3.4. The research conducted with these designs was done using Grounded Theory, briefly summarised also in section 3.4.



Figure 3.1  
Screenshots from the video about Dilemmas in Suicide Prevention, [https://www.youtube.com/watch?v=WOKQ\\_DFeSrg&feature=youtu.be](https://www.youtube.com/watch?v=WOKQ_DFeSrg&feature=youtu.be)

Figure 3.2  
Image from Soulaje – Euthanasia Wearable Design Fiction (Tseklevs et al., 2015), [http://148.88.47.13/html/imagination/outcomes/Euthanasia\\_Wearable\\_Design\\_Fiction](http://148.88.47.13/html/imagination/outcomes/Euthanasia_Wearable_Design_Fiction)

3.2 Speculative Design as a method to explore the debate on euthanasia in dementia

Speculative Design has also been called Design Fiction, Critical Design, Design Probes and Discursive Design. All these design research practices are similar in that 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). Speculative design typically tries to identify ‘weak signals’, signals that can indicate the possibility of a new development, in order to speculate on the near future (Girardin, 2015). Using these weak signals, speculative design can try to prototype scenarios to investigate a potential future and its consequences. In this research, speculative design was used to explore the notions of suffering, autonomy and planning death.

The term Speculative Design was coined by Dunne & Raby (Dunne & Raby, 2013) 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 (Gaver et al., 1999). Design Fiction is described as a thoughtful exploration of speculative scenarios; a way to prototype other realities (Bleecker, 2009). Design Fiction is a form of 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, p22; Lindley & Coulton, 2016). It is important to keep in mind that Speculative Design does not try to be a version of Science Fiction, either utopian or dystopian, but rather a dialogue on what the future could be (Mitrović, 2015).



There is no specific method on how to construct a successful speculation, but there are a few guidelines: 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 & 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 (Auger, 2013, p33; 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, p14). Speculative Design is to involve the public in dialogue about change, with stimulating thinking and discussion as its main goal (Mitrović, 2015).

An example of design used to provoke conversation is this video about dilemmas in suicide prevention (figure 3.1) that was used in a research setting showing the discrepancy between ‘current work as done’ versus ‘work as imagined’ (Jun, 2019). This would not fall specifically under the speculative design definition, which is more about ‘future work as imagined’, however it is relevant here because it is design used as a tool to encourage conversation. This video illustrates the pitfalls in suicide prevention and can serve as a tool to improve suicide prevention care.





A more problematic piece of speculative design, or design fiction, as described by Lancaster University, is Soulaje (figure 3.2). The aim with Soulaje was to explore “*whether co-designed Design Fictions could help older people to increase their engagement with policymakers developing a discussion on Ageing in Place, loneliness and isolation*” (Tseklevs et al, 2015). Even though the research was described as successful, it would be interesting to see how the results would have differed if the diegetic prototype had been more credible, or the story-telling more nuanced. It can be argued that this scenario did not quite ‘manage the uncanny’.

Another video (figure 3.3) which would fall both under speculative design in the sense of ‘imagining future scenarios’, and design to aid discussion, is one about the ethical implications of living with smart devices, created by Superflex in 2015 as part of ThingTank, a research consortium exploring new territories in the domestic space where ‘things’ begin to have enough agency to not just communicate with each other, but also interpret the ‘needs’ of humans in the room and primitively design

services in response to those ‘needs.’ This is a really successful piece of speculative design in the way it communicates through simple means a credible future scenario through critical use of diegetic prototypes.

There are cases where it is hard to ‘suspend disbelief’ in the speculations presented, however the design are still good to stimulate discussion, such as the Artificial Womb by Next Nature Network (figure 3.4). Next Nature Network investigates in this speculative design how will we make babies, experience intimacy and build families, in the future. The Artificial Womb was created as part of a larger debate about our reproductive futures: Reprodutopia. The artificial womb may stretch the imagination, however a well researched and realistic prototype did stimulate the conversation as proven by the wider interest in the media with this project being shown at Dutch Design Week 2018, and even being reported outside Dutch media on the BBC “*the development raises ethical questions about the future of baby making*” (Devlin, 2019).

Figure 3.3  
Screenshot from  
Uninvited Guests  
by Superflex (2015),  
<https://vimeo.com/128873380>



Figure 3.4  
Artificial Womb.  
Lisa Mandemaker  
& Hendrik-Jan  
Grievink (Next Nature  
Network), Medical  
research by Dr. Guid  
Oei (Máxima Medical  
Centre). Image: Bram  
Saey

Some speculations deliberately provoke the uncanny, by creating much more outrageous scenarios such as the Euthanasia Coaster (figure 5.12) by Julijonas Urbonas (2010). The euthanasia coaster imagines a roller coaster that would cause death by creating so much g-force that a person would die from oxygen deprivation. This project applied advanced cross-disciplinary research in aeronautics/space medicine, mechanical engineering, material technologies, physics, and art. The fatal journey is made pleasing, elegant and meaningful. This design was part of Julijonas’ PhD thesis on Gravitational Aesthetics at the Royal College of Art in London, UK. His work has inspired various spin-offs, such as a kickstarter initiative by Glenn Patton to make a movie about it; H Positive ([https://www.youtube.com/watch?v=hEyE1AskRhE&feature=emb\\_logo](https://www.youtube.com/watch?v=hEyE1AskRhE&feature=emb_logo)). Julijonas describes that his design can be seen as ‘social science fiction’ which is a term that was coined by Isaac Asimov in the 1940s (Miller, 1977). Social Science fiction might be seen as a “*morality tale, warning of possible futures, playing through the means necessary for them to be avoided or rectified*” (Smith, 2004).

Speculative or Critical Design have been around long before Dunne and Raby coined the term within the field of Industrial Design in 2013. Architecture and Graphic Design had been taking a critical approach to designing since the late 1950s (Dodds, 2016; Laranjo, 2014; Malpass, 2013). Isaac Asimov already talked about the need to imagine futures in the 1940s “*We’ve got to think about the future now. For the first time in history, the future cannot be left to take care of itself; it must be thought about*” (Asimov, 1971).

Tonkinwise notes in Just Design:

“*Designing that does not already Future, Fiction, Speculate, Criticise, Provoke, Discourse, Interrogate, Probe, Play is inadequate designing*” (Tonkinwise, 2015).

In this thesis the designs created will simply be referred to as ‘designs,’ these designs are intended to aid discussion in a specific context and have not been restricted by commercial requirements.



3.3 Information design as a method to explore this debate

Data visualisation stems from a desire to understand complex information, and to share that knowledge. Without knowing and understanding complex issues, improvements cannot be made (Rogers, 2013, p62). This does not mean that data visualisations simplify complex issues, instead they make complex issues more accessible by using visual means that are able to show relations and connections that would be harder to identify in purely text or tables.

*“What is to be sought in designs for the display of information is the clear portrayal of complexity. Not the complication of the simple; rather the task of the designer is to give visual access to the subtle and the difficult – that is, the revelation of the complex”* (Tufte, 2001, p200).

Otto Neurath developed the Isotype method to make information more accessible. With this method Neurath intended to provide information in such a way that anybody would be able to take part in decision-making processes. At the time the Isotype method was developed a high percentage of the population was illiterate and his method helped people who were unable to read also have access to information *“[...] the Isotype approach as something designed for mankind as a whole, enabling everyone to take part in argument by means of a common visual basis of information.”* (Neurath, 2010, p126). Visualising information is another way of communicating, sometimes described as data journalism (Rogers, 2013). Editing and providing information in a visual overview can be seen as a form of public service *“many people feel relieved when basic information is given to them by means of visual aids”* (Neurath, 2010, p4). Visualising data or mapping is a creative act that describes a specific space and context and reveals its potential (Abrams & Hall, 2006).

Making data visualisations can be done in many different ways. The primary concern of the data visualiser is to have a thorough understanding of the data:

*“It is the responsibility of the ‘transformer’ to understand the data, to get all necessary information from the expert, to decide what is worth transmitting to the public, how to make it understandable, how to link it with general knowledge or with information already given in other charts. In this sense, the transformer is the trustee of the public”* (Neurath, 2009, p78).

In this thesis the designer (or transformer) was also the expert, having rigorously studied and compiled the data to create a visualisation to explain the complexities inherent in deciding a time to die in euthanasia for dementia (4.3). The method for creating this visualisation was based on many years of tacit knowledge (15+ years as professional designer) with iterative prototyping and critical reflection. It was important to show enough data context to generate understanding of the greater complexities inherent in the debate as a well as hiding information not relevant to theme that is communicated. Additionally the target audience was considered; the knowledge they were likely to already possess, creating touch-points, without showing them only information they would already know. This way the intended observer would have be able to position themselves within the information shown allowing for them to make personal decisions based on the data presented.

3.4 Data Analysis: Grounded theory

The data gathering using these artifacts and the following analysis are based on Grounded Theory, a conventional qualitative research method. Grounded Theory states that a theory can be discovered from the data (Glaser & Strauss, 1967, p1). In Grounded Theory, data gathered would be analysed not on a preconceived hypothesis, but on emerging concepts from the data. The data itself would go through an iterative process, similar to the iterative process inherent in Research through Design where design prototypes can go through design cycles until the artifact has been deemed to be successful for its intended use (Stappers & Giaccardi, 2013). The iterative process in Grounded Theory is similar and the data can be comparatively studied until it has reached ‘theoretical saturation’ where no new instances are being identified (Hignett & McDermott, 2015, p10). In this thesis the data was first coded based on the conceptual framework based on the themes that were synthesised from the literature (5.3.2). Next, a process called ‘open coding’ was applied, where themes are identified from the text which was gathered through the survey and verbatim transcribed interviews (Denzin & Lincoln, 2003) (5.3.3). The emerging themes are then linked together in a theoretical model where the themes can be compared and contrasted *“the constant comparison method”* (Glaser & Strauss, 1967, p160-172) (5.3.4).

The results obtained through Grounded Theory analysis using designs as prompts to stimulate discussion are reflected upon in Chapter 8, where the results are discussed based on the content of this thesis; de debate on euthanasia in dementia (8.1), as well as the usefulness of using design prompts to stimulate this discussion (8.2).



## Part 3. Designs





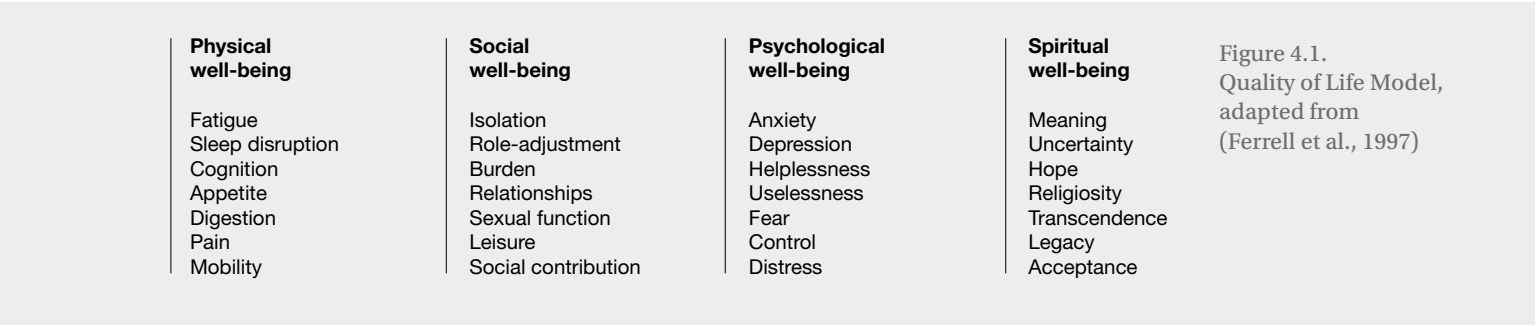
# Chapter 4

## Designs to stimulate conversation

This chapter describes the designs created for the four themes extracted from the literature: suffering; autonomy; timing and planned death. For each theme one or more designs were created as prompts to open up communication. The designs were presented to selected participants as the main triggers to start discussing questions that are present in the debate on euthanasia in dementia, and to test if this way of opening up conversation would help to further the debate:

- What is unbearable suffering in dementia, and can it be assessed?
- Why is it difficult to make a decision for euthanasia based on patient autonomy in dementia?
- When would be the best time to plan a death in dementia?
- What are the complexities around planning a death in dementia?

Each section below outlines in detail the literature summary (4.x.1), the concept per theme (4.x.2), what was designed per theme, why and how (4.x.3) and what iterations were done in response to testing (4.x.4). The discussions that resulted from the testing (survey, interviews and use in public debate) are addressed in Chapter 5.



### 4.1 Suffering

This section explores how to assess suffering in a person diagnosed with dementia as a requirement for a planned death. The fear of suffering dementia may lead to people signing an Advance Euthanasia Directive to make provision for health care decisions in the event that he/she becomes unable to make those decisions. To be able to grant an euthanasia request, physicians must observe unbearable and hopeless suffering. Measuring suffering objectively is an impossible task. The observations of suffering are biased by personal experiences. In the case of dementia, where perception and self-reflection is altered as the disease progresses, suffering is even harder to assess.

The challenge of establishing unbearable and hopeless suffering in order to perform euthanasia is addressed in this section by offering a fictional solution as a framework for stimulating and supporting discussion.

First a short summary of the literature on Suffering is outlined (4.1.1), next the concept for this speculative design is communicated (4.1.2), followed by a detailed description of how the speculation was created (4.1.3). The data collected in the testing of this design prompt are described in Chapter 5.

#### 4.1.1 Literature summary: Suffering

Suffering has medical, psychological, social and existential dimensions, but there is no universally accepted definition of unbearable suffering. Unbearableness is often caused by hopelessness. Suffering is individual and it can only be understood in the fabric of the patients’ perspectives of the past, the present and expectations of the future (Dees et al., 2011; Gastmans & De Lepeleire, 2010). People with terminal illnesses primarily fear pain and anticipated pain; indignity; loss of control; being a burden and cognitive impairment (Chapple et al., 2006; Gjerdingen et al., 1999). The feeling of being a burden does not support a euthanasia request, but this feeling is often present and can be just (Dunham & Cannon, 2008; Gessert et al., 2000; Dening et al., 2012).

Assessing suffering becomes more complicated as dementia progresses because meaningful two-way communication becomes harder, physical suffering is deemed easier to assess (Smith & Amella, 2014; Buiting et al., 2009; Buiting et al., 2008). This causes a challenge for the physicians who are supposed to carry out euthanasia based on observable ‘unbearable and hopeless’ suffering.

The way people adjust to suffering, a ‘response shift,’ is sometimes argued to be the reason that dementia patients contradict earlier preferences. A response shift is a change in self-evaluation of quality of life; because dementia patients lack the ability to self-evaluate, this results in complexities in measuring quality of life or even having an opinion on it (Jongsma et al., 2016; Hertogh, 2009).



The assessment of suffering is heavily influenced by the observer’s own values and experiences, variations were found in the classification of suffering as ‘unbearable’ especially in cases where existential suffering was being assessed (Rietjens et al., 2009). The way family assesses the suffering of their loved-one also influences the decision-making (Emanuel, 1999).

4.1.2 Concept: Suffering

Ways of assessing suffering vary greatly from ways of assessing quality of life (Krikorian et al., 2013). This thesis poses that the absence of quality of life equates to suffering. A design solution was developed to propose a way to assess quality of life if the individual in question is no longer able to do so themselves. Quality of life is complex and multi-dimensional, the proposed design is based on the Quality of Life matrix (Figure 4.1) that divides life quality into four aspects; social wellbeing, psychological wellbeing, physical wellbeing and spiritual wellbeing (Ferrell et al., 1997).

Assessing suffering is hard. Quality of life is based on personal experiences and outlook in life. Social circumstances can contribute to quality of life or be a cause of lack of quality of life. Equally, physical and psychological circumstances can greatly affect the experience of ‘quality’. Spiritual convictions contribute to the experience of quality and strongly inform views on death. The presented speculation has made tracking these various aspects of life quality a requirement.

Tracking quality of life, a ‘qualified-self’ is a long way off, but the ‘quantified-self’ is becoming the norm. Tracking quantitative personal health data is quite normal with an estimated 140 million smart watches sold by 2022 (Lamkin, 2018) and in some cases even a requirement for life insurance policies (BBC, 2018). Tracking personal health data is developing rapidly and there are some very real benefits, for example, an app that is more effective in birth control then the pill (Deprez, 2019). Collecting this much personal data is an ethical mine-field and the subject is much debated (Cha, 2015), however it is a field that is developing and tracking personal health data forms the base concept of this design speculation. It is posed that having access to a broad set of quantified data on a patient can help make decisions on quality of life, for as long as this is supported by account of carefully selected specialists in the four aspects

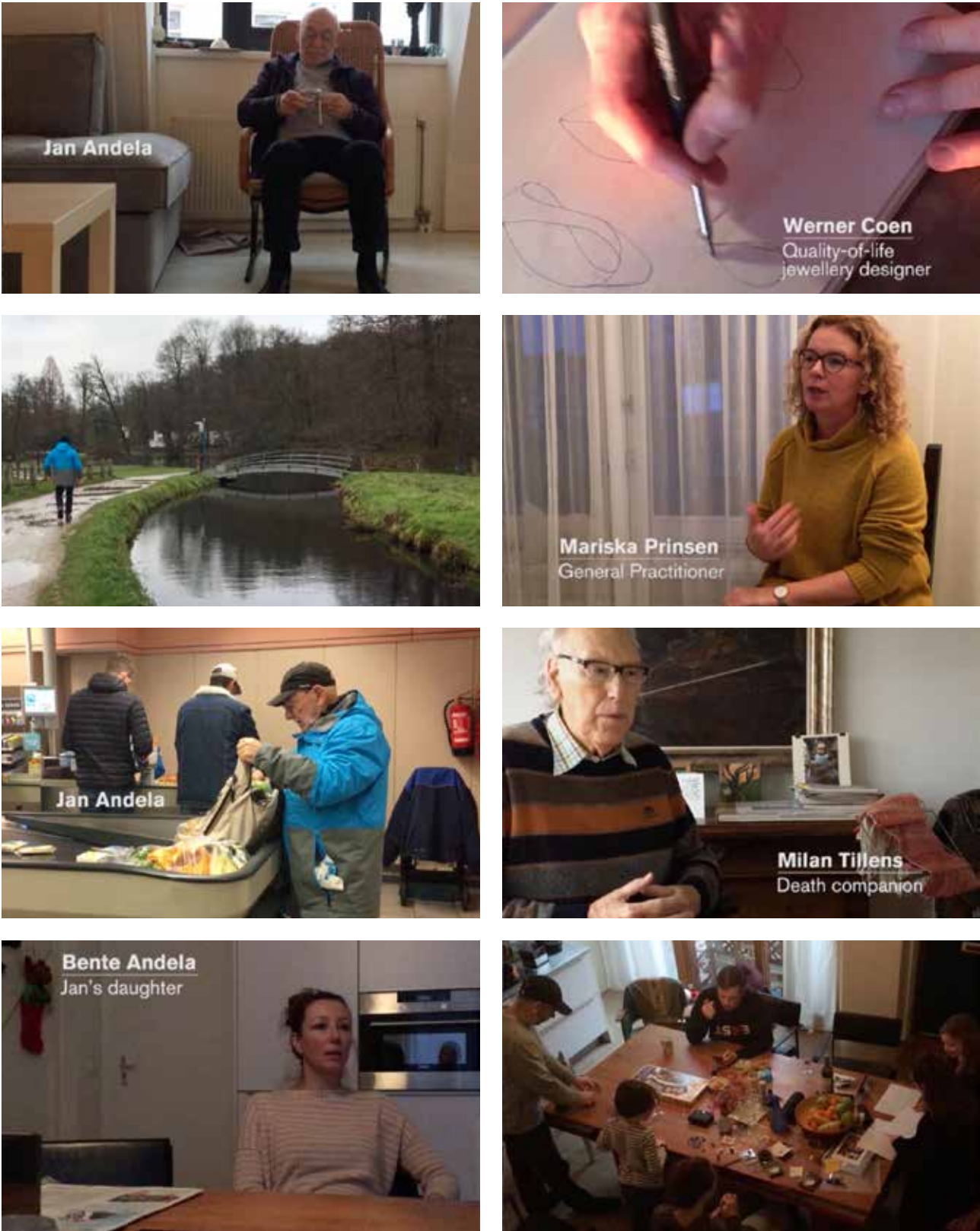
of assessing quality of life; friends, physicians, spiritual and psychological.

The speculation sets the scene at the year 2020: With dementia the most frequent cause of death in the Netherlands (Huisman, 2017), the Dutch government has introduced new regulations where all citizens have to track their vital signs through personalised jewellery as well as assign a team to assess their quality of life. Making tracking of life quality a social obligation was a conscious choice – it was anticipating that asking loved-ones to take on these kind of responsibilities might have far-reaching social consequences. In this fictional story, the Dutch guidelines require citizens to assign a team member for each segment that makes up a holistic quality of life picture; choosing individuals to represent your social, spiritual, psychological and physical outlook. Additionally citizens are required to track their vital signs through personalised tracking jewellery. The data this jewellery collects would be used by the assigned team to support decision-making. This design speculation was approached in a more rational way, by giving one potential reasonable answer to the original question: *What is unbearable suffering in dementia and how can it be assessed?* (Figure 4.2) This research is hoping to stimulate conversation about consequences of this idea and consider other potential solutions. In doing so, clearer ideas might be defined on qualities of suffering and how these could be assessed. Additionally this research is interested in investigating different approaches to speculative design. This approach was designed not to provoke the viewer, but to instigate a conversation on the very irrational subject of suffering.

4.1.3 How the design on Suffering was constructed

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 the format of a mini-documentary was chosen; mini-documentaries are a recognisable medium to illustrate more complex problems and are often employed by news outlets to engage people on social media (McDermott, 2016). This form of presenting information does not feel immediately dated, making it a credible format that could have been used in 2020.

Figure 4.2  
Screenshots from the video about Assessing Suffering, <https://vimeo.com/251459676> (7.44min)





The video starts with a summary of the government incentive “**With dementia as the no.1 cause of death in the Netherlands and the rise of euthanasia requests, the Dutch government introduced new regulations in 2020. Every Dutch citizen needs to track their vital signs through the use of personalised ‘jewellery’. Additionally they need to assign a team that they trust to assess their quality of life**”.

We follow the account of Jan Andela who has a genetic likelihood to develop Alzheimer’s disease. We see glimpses of his life and Jan explains why he chose the individuals in his quality-of-life team.

The video was recorded across various locations in the Netherlands for authenticity. All individuals are Dutch nationals and were filmed in their own surroundings, giving cues on personalities, lifestyle and educational backgrounds. Jan’s life is quite rich, with well-spoken friends and a loving family. Jan’s story is a fairly ideal case, where he has a network of individuals that he trusts to play these important roles in his life. Viewers may question what would happen in less ideal scenarios.

**Introduction**

A black background and a ‘neutral’ typeface were used (Akzidenz Grotesk). The black background was chosen to communicate death, with a large size type, as the message is generally aimed at an older generation (Strizver, n.d.), and the type was chosen to be ‘neutral’.

**Music**

The soundtrack used was entitled ‘Slowly’, by Amon Tobin. The music supports the ‘pottering around’ the main character is doing.

**Why did you choose your pocket knife as your personalised jewellery?**

[Jan Andela, patient](#)

*Casting:* Jan Andela is a white male in his seventies.  
*Footage:* Jan is tinkering with his pocket knife, fixing stuff. It gives some insight into the character, an independent elderly man.  
*Script:* I always carry this with me. I am used to having it around, and I use it for all sorts of chores. Everybody who knows me, knows I can’t live without my pocket knife.

**Why do you work with quality-of-life jewellery?**

[Werner Coen, jewellery designer](#)

*Casting:* We hear the voice of Werner Coen, a Dutch quality-of-life jewellery designer.  
*Footage:* We see a hand sketching a möbius strip inspired jewellery item.  
*Voice-over:* Werner explains why this work is rewarding for him.  
*Script:* I really like the idea that I can make a difference in the quality of someone’s life. Not only are the pieces I create literally of prime importance in their life, but I also think it is a beautiful idea – the legacy of these pieces. Each is a bespoke design for a unique individual, and as such it takes on a new meaning once the person has passed, it becomes a memento mori; a very intimate way to remember a loved one.

**Do you feel your privacy is invaded?**

[Jan Andela](#)

*Casting:* Jan Andela  
*Footage:* Jan is browsing his computer at home and we follow him on his walk in his local park.  
*Voice-over:* Jan is explaining how he is protecting his privacy by splitting up the data into chunks for the relevant people to assess.  
*Script:* No, not at all. All the data collected is private, until I release it. I will only release the data to carefully selected people, and they only receive the piece of the puzzle I reserved for them. For example, my GP receives all my physical data. I have had the same GP for 12 years now. She knows about my limits and physical history. We discussed in great detail what diminishes my quality of life – physically.

Psychologically I also feel this is best assessed by a professional. Obviously my knife measures and tracks various bio-markers that inform on my stress levels, fear, anxiety, those sort of things. This data will be shared with a psychiatrist assigned by my GP – I trust her to find a good one.

**How do you feel about the new decision making process in dementia?**

[Mariska Prinsen, General Practitioner](#)

*Casting:* Mariska is a female GP and has been Jan’s GP for 12 years.  
*Footage:* The interviewer is in direct conversation with Mariska, She is talking to the documentary makers from her office.  
*Monologue:* Mariska is relieved about the new law, now the decision isn’t in her hands alone and the decision can be backed up by quantitative data.  
*Script:* This is such a big improvement on the

old way. Previously it was all down to me, plus an independent physician. Now there is a team who look at all aspects of life – or at least the aspects that make or break quality of life. Assessing physical well-being in dementia is hard to do. But now we have all these data that has been collected continually over many years, upon which we can base our decisions, as well as conversations before and after diagnosis. In addition we can liase with the people the person in question has assigned themselves to help make these life and death decisions. We look at physical and psychological profiles, but also the social impact this life – or death – will make. The spiritual interests are also taken into account. Taken all together, we should be able to make a much more balanced, informed and acceptable decision about a euthanasia request.

**Social data**

[Jan Andela](#)

*Casting:* Jan Andela  
*Footage:* Jan is packing his bag at the supermarket.  
*Voice-over:* Jan is describing how his social data is handled by his three best friends.  
*Script:* My social data on the other hand is a bit more complicated. I decided to share these data between three of my best friends. After my wife died, these are the people that know me best. Each of these persons has different viewpoints and beliefs, but all have my best interest in mind. I feel very confident that together, they can come to a conclusion what is best for me at a time I can no longer decide myself.

**How do you feel about being a ‘death companion’?**

[Milan Tillens, Death companion](#)

*Casting:* Milan is an elderly gentleman.  
*Footage:* The documentary maker is in conversation with Milan in his home. We see hints of a creative individual; painting and sheet music.  
*Monologue:* Milan describes how he is honoured to play such an important role in Jan’s life.  
*Script:* I feel this as an honour. It is daunting too. To be trusted with such an important decision is a sign of huge respect. I feel blessed to be appreciated like this. I mean ... thankfully I am not making this decision on my own. I am really happy Jan has assembled such a capable team. Together I think we can carefully weigh up all the aspects that are important to Jan and decide if this is a life worth living – for him.

**How do you feel about being a ‘death companion’?**

[Ruben Dirksen, Death companion](#)

*Casting:* A middle aged white male  
*Footage:* The interviewer is in direct conversation with Ruben whilst Ruben is in the kitchen preparing a meal.  
*Monologue:* Ruben is not sure about being a death companion, or indeed about euthanasia. Perhaps this is why he was picked to be on the team?  
*Script:* Well. I am not so sure about this. This is why Jan wanted me on the team I think. A sceptic. He knows I will need some convincing!

**Family**

[Jan Andela](#)

*Footage:* Jan is in a café with a friend.  
*Voice-over:* Jan is describing why he decided to not make his daughter his death companion, he feels it would be an unfair question to ask her to make such a decision.  
*Script:* I purposely left my daughter out of the final decision – though the assigned ‘companions’ are encouraged to discuss their decision with her. I just don’t think it is fair to lay this responsibility on her.

**Are you upset your dad didn’t ask you to be his companion?**

[Bente Andela, Jan’s daughter](#)

*Casting:* A young woman.  
*Footage:* The interviewer is in direct conversation with Bente, Jan’s daughter, in her kitchen.  
*Monologue:* Bente is expressing her relief not to be involved in this whole end-of-life team.  
*Script:* Oh goodness, no – what a relief! I mean, what a decision to make... I am not sure if what I would decide would be fair for him, or if it would be what is best for me.

**Spiritual**

[Jan Andela](#)

*Footage:* Jan is in a museum with a grand-child, followed by footage of Jan’s extended family without Jan at the kitchen table, hinting at a time after Jan’s death.  
*Voice-over:* Jan is describing how he is fulfilling his spiritual assessment. He is not a religious man, but has some strong moral values that he thinks can be best assessed by an objective professional observer. He names Jan Hardwig who wrote about ‘a duty to die’ (Hardwig, 1997). Jan touches on the relief he feels knowing he will not become a burden to his family.  
*Script:* I am not a very spiritual person, but I suppose I still like to think that my existence has



meaning. If the meaning is no longer there – and I can no longer rationally argue for my being here, then I need a person that I can trust one hundred percent to tell me so. For this I have chosen someone who can decide objectively about me, someone I have no personal ties with. I have asked John Hardwig to be this person, I was very convinced by his views on “a duty to die”

I feel very relieved in the knowledge that all these people are happy to help me – and that they will work together in making a decision about the quality of my life, when I am no longer able to do so myself. This is taking away a lot of worry in case I am too late with a dementia diagnosis, or indeed a euthanasia request. I can now be confident I won’t needlessly suffer, or make those around me suffer.

Credits

A black background and a ‘neutral’ typeface was used (Akzidenz Grotesk), revealing that this was a speculative design and crediting the actors and music.

4.1.4 Developing the design on Suffering

This scenario did not elicit many responses when used as a trigger (Chapter 5). There was some response on suffering around the worry about becoming a burden to your loved ones. But, the general response was that this could be quite a good idea and could actually work. As such no iterations were made to this speculation as there did not seem to be any particular design triggers for debate.

Interestingly, when testing the design of the scenario (the way of filming, the edit, the choice in music) at a seminar at Umeå Institute of Design, more responses were triggered with questions such as “*what if the death companion dies before the patient?*” or “*what are the social implications these kind of questions would trigger?*” One person imagined a second documentary, imagining Jan Andela was now dead and we would follow the people in the team, to see how their internal relationships had changed because of this process and how the process may have affected their own personal lives. These were the kind of questions the speculation was intended to trigger, however failed to do so in the participant group.

The detailed responses to this speculation are discussed in detail in Chapter 5, section 5.3.2.2.

4.2 Autonomy

This section explores why and how a person making an autonomous decision to choose euthanasia can proceed (or not) with this decision when they have been diagnosed with dementia. The dilemma between the need for consent and the challenges in obtaining it is addressed by offering a fictional solution (speculative design) as a framework for stimulating and supporting discussion.

First a short summary of the literature on Autonomy is outlined (4.2.1), next the concept for this speculative design is communicated (4.2.2), followed by a detailed description of how the speculation was created (4.2.3), and concluded by descriptions of further design iterations developing the original videos ‘what if’ scenario to ‘then what’ scenarios (4.2.4). The responses to this design prompt are described in Chapter 5.

4.2.1 Literature summary: Autonomy

Many people like to be in control about their end-of-life (Schroepfer et al., 2009). One way to exert control is by making an advance (euthanasia) directive (Burlá et al., 2014; Rosenfeld, 2000b; Brock, 2000). An advance directive is a tool used in planning for end-of-life. It is a document used to make provisions for health care decisions in the event that, in the future, the person becomes unable to make those decisions.

It is important that patients and their carers understand that their advance directives will not easily apply in dementia (Rurup et al., 2005). There may be false hope attached to these directives, which may be reassuring to the person diagnosed with dementia while they are still cognitively sound, but likely to be a source of much distress to their proxies once the disease has progressed, and this document is largely ignored (Hertogh, 2009; Rurup et al., 2005b; de Boer et al., 2011; Kouwenhoven et al., 2015).

The complexities in performing euthanasia in dementia lie with the fact that dementia presents with personality change, essentially an advance directive is the formerly competent person asking his/her proxies to ignore their demented self (Davis, 2014). The case in favour of adhering to an advance euthanasia directive based on a person’s autonomy, does not take into account the implementation of the directive. It is seen as unethical by many to ask

carers and clinicians to act upon an advance directive when the facts, in the moment of euthanasia, do not endorse the earlier directive (Buiting et al., 2008; Rietjens et al., 2009b; Bernheim et al., 2014).

4.2.2 Concept: 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.

This speculative design explores patient autonomy for end-of-life decisions in dementia. A scenario was developed to imagine the advance euthanasia directive as an implant that would trigger a swift and painless death, once the conditions described in the advance euthanasia directive were reached.

Some people argue that if an autonomous person has made an advance euthanasia directive, then this should be adhered to. This adherence at all cost to an advance euthanasia directive can put a lot of strain on clinicians having to enact this order. The designed prompt explores an idea to remove this strain with a new kind of advance euthanasia directive, a small robot, the ‘AED-Plug’, implanted in a fully cognitively competent person, which would execute the advance euthanasia directive even if the person who wrote it is no longer capable of confirming their directive. Should this person develop dementia, they can be sure their euthanasia wish would be complied with by the Plug, without upsetting clinicians, or putting stress on making this decision on their proxies.

It is the intention with this speculation to provoke discussion by proposing an ethically challenging scenario. The speculation proposes that decisions made by humans will always be biased and that any kind of human bias is not desirable in this case. It was assumed that viewers would not be comfortable trusting a robot to execute their decisions which intended to steer the discussion to the direction of how decisions based on patient autonomy could be improved. The primary questions asked were: ‘Why is it difficult to make a decision



for euthanasia based on patient autonomy in dementia?’, and ‘Who should made decisions on behalf of the person with dementia if they can no longer do so themselves?’

4.2.3 How the design on Autonomy was constructed

This section explains how the speculative design was constructed to illustrate the problem space. The designed prototypes aimed to make the euthanasia in dementia debate more tangible and accessible. This speculative design is called the advance euthanasia directive Plug. The proposed design is an implant that, once the conditions are reached as described in the advance euthanasia directive, would trigger a swift and painless death.

A design speculation requires a connection to exist between the audience perception of their world and the fictional element of the concept (Auger, 2013). In order to make the speculation credible, and be taken seriously, the audience member must be able to believe in the possibility of its existence. This prototype was crafted in such a way that it could already be in existence, using contemporary media and messages (Figure 4.3). The concept was presented as an advertorial video; walking a fine line between documentary and commerce. This way of representation was chosen to add more credibility, because currently it would be unlikely that a product like The Plug would be endorsed by any government.

The creation of the video is discussed in detail (Figure 4.3), from the typeface used to the casting of the actors, the choice of music and the script.

The Video Introduction

A black background and a ‘neutral’ typeface was used (Akzidenz Grotesk). The black background was chosen to communicate death, with a large size type, as the message is generally aimed at an older generation (Fontshop).  
*Text:* Are you worried your Advance Euthanasia Directive will not be adhered to in case of dementia?

Make sure your wishes will be executed: The Plug implant can be programmed so that a swift and painless death occurs precisely and only under the conditions of your choosing.

Install your Plug now, contact your Plug advisor now on aedplug.com

**Music**  
The soundtrack used was entitled ‘Death with Dignity’, by Sufjan Stevens. The music is melancholy yet positive, filled with hope. The reveal of the title in the end credits is important because the title of the track ‘Death with Dignity’, is relevant to the topic.

**Super 8 footage**  
The super 8 footage is introduced, an intentional break in the message, and to conceptually visualise a sense of (memories) lost.

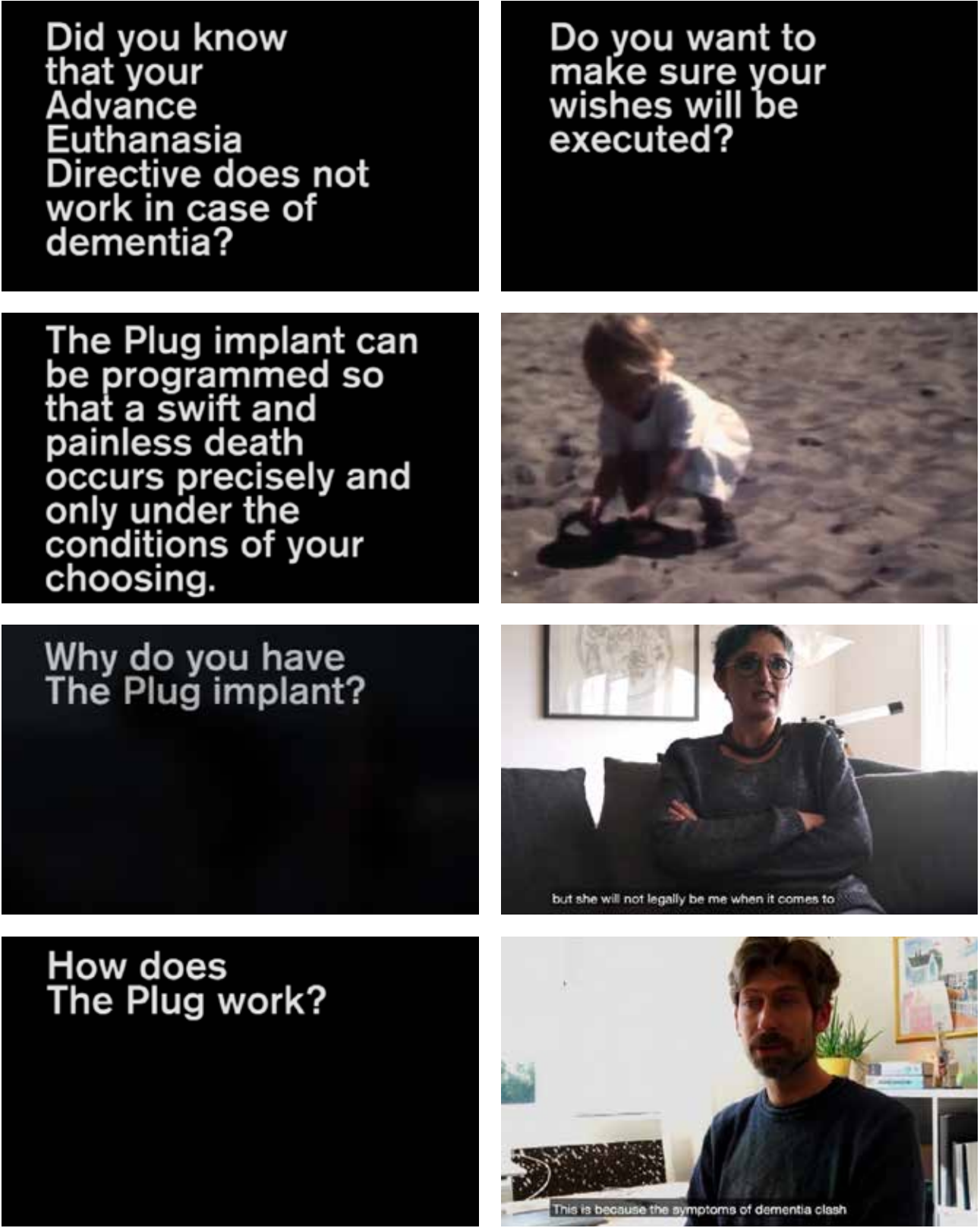
**Why do you have The Plug implant?**  
*Sabrina Naldi*  
*Casting:* An Italian woman in European setting, well-educated and well-travelled.  
*Setting:* Set in Sabrina’s home, artworks on the wall, a telescope in the background, to indicate that Sabrina is a woman of the world.  
*Monologue:* Sabrina is passionate and well informed. She has clearly given the subject matter serious thought and made a rational decision. Some distance is created by the language used, demonstrating that she clearly knows what she is talking about. Her eloquence is convincing with the intention that the viewer can identify with her.  
*Filming:* The camera was positioned at an angle and Sabrina is engaged in conversation with the interviewer. Filmed as a single shot the complete story behind Sabrina’s rationale is revealed to the viewer.  
*Question:* Why do you have The Plug implant?  
*Script:* I am scared of the person I might become, should I develop dementia. This can be someone radically disconnected from my former self, so much so that there is no justification for taking my present wishes, as expressed in an advance directive, into account for decision making about the person I will become.

My body will have been taken over by another person with a disturbing but illusory resemblance to my former self.

Legally and socially, this new being will have a very strange connection to me. She will retain my name and Social Security number, she will be able to use up my assets and wear my clothes, and my spouse will not be free to remarry, but she will not legally be me when it comes to honouring my advance directives.

Former friends and relatives will think of that person as me, may well persist in visiting her despite the fact that she does not remember

Figure 4.3  
Screenshots from the video about The Plug <https://vimeo.com/231854700>





them, and thus will have their memories of me distorted by the existence of this woman.

Yet the values and interests I expressed to family and friends when competent will be discounted as largely irrelevant.

I don’t want to be invaded like this. I would prefer to die with dignity, as myself.

How does The Plug work?

Karel Seghers

*Casting:* Karel is a Dutch physician who has taken on a new role as AED-Plug advisor. Karel is pragmatic, working within the framework of the Dutch legal system, doing what he believes is the right thing.

*Setting:* Karel’s office, but not too formal, Karel is wearing informal clothes and his office hints of a family life with children’s drawings on the wall.

*Dialogue:* Karel explains in lay terms how the plug works, referencing familiar medical implants (pacemaker), to create familiarity.

*Filming:* The camera is positioned at an angle and Karel is engaged in conversation with the interviewer. The film was cut at several points to give the idea that perhaps the way the Plug works is a little more complicated than this edit shows.

*Question:* How does The Plug work?

*Script:* The Plug is in essence an advance euthanasia directive. An advance directive is a document by which a person makes provision for health care decisions in the event that, in the future, he/she becomes unable to make those decisions. Advance euthanasia directives aren’t always adhered to, especially in the case of dementia. In dementia it is almost impossible to decide the right time of death, as the patients themselves are no longer capable of making this decision. Patients aren’t able to confirm their euthanasia wish at the time of death – putting a huge strain on physicians having to comply with the advance directive. Additionally dementia presents with personality change; the person who created the directive is no longer the same person.

We believe that if an autonomous person has made an advance euthanasia directive, that this is what should be adhered to, out of respect for the original person. What if an advance euthanasia directive, “The Plug”, could be implanted in a fully cognitively competent person? Should this person develop dementia, she or he can be sure his/her wish would be complied with, without needlessly upsetting any

physicians, or putting the stress of making such a decision on their proxies.

The implant would be linked with a host of sensors, documenting the individual’s condition. For example, if the person with the implant would have conditions such as “If I can’t do x, y and z, in addition to being a burden on my carer as well as not remembering my son, then, and only then, I would like The Plug to be activated (or pulled as it were). The conditions could function as a “boolean string”, making the condition very specific, one might wish a lot of conditions to all be fulfilled in order to activate the switch, or one might find one particular condition so horrifying that that alone would activate The Plug.

Credits

The credits reveal that this is a fictional scenario.

4.2.4 Developing the design on Autonomy

In response to the participants’ suggestions and to give the design speculation more depth, the next stage was to follow the ‘what if’ scenario of the proposed implant (The Plug), to a ‘then what?’ story. Further designs were created using more of the discussion points that followed from testing the initial video at the DementiaLab conference in Dortmund Germany (2017), healthcare research seminars at Loughborough University and Umeå Institute of Design. Viewers wondered what The Plug would look like, how The Plug would actually work, if you could change your mind and what would happen in case of (technical) failure.

A website was developed to house the additional designs created. The website was designed in a way to give the impression that The Plug was commercially available (<http://aed-plugin.com/>) with a contemporary style, lay terminology for accessibility and common menu items. The website sections are described in detail below.

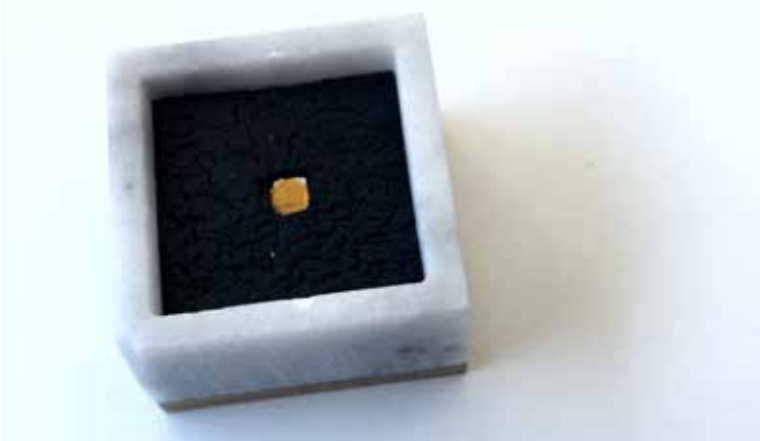


Figure 4.4  
What does The Plug look like?

1. What is The Plug?

This section on the website refers to research literature to give an evidence base.

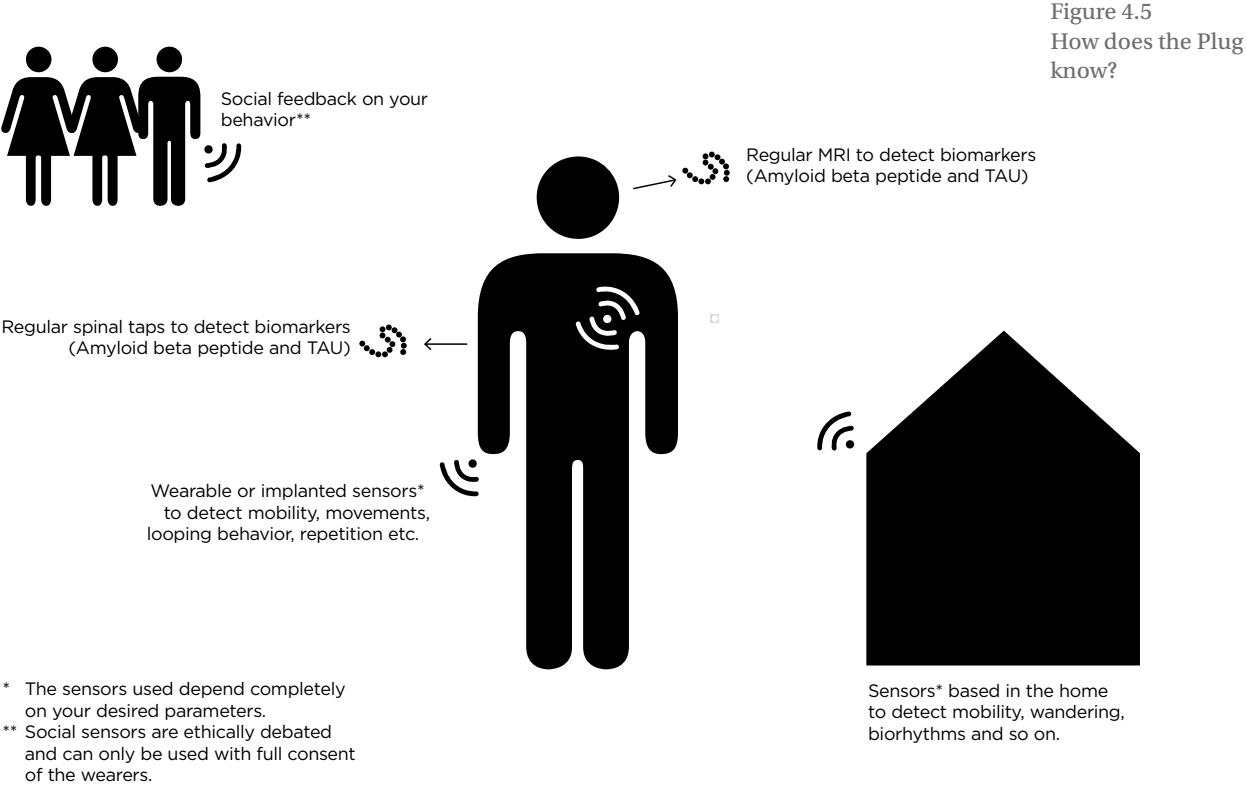
<https://aed-plugin.com/what-is-the-plugin/>

The Plug is a physically implanted Advance Euthanasia Directive for the condition of dementia (Alzheimer’s disease, Vascular dementia, Parkinson’s disease, Huntington’s Disease, Pick’s Disease, or Creutzfeldt-Jakob Disease). An Advance Directive is a tool used in planning for end-of-life, usually in the form of a document by which a person makes provisions for health care decisions in the event that, in the future, he/she becomes unable to make those decisions. Advance euthanasia directives in dementia are rarely complied with even though patient suffering was judged to be extreme (Rurup et al., 2005).

Here at The Plug we believe that, if a cognitively sound person has made a well-considered, rational decision to desire euthanasia under certain circumstances, we must respect this wish. We do however also understand that this can be a completely unreasonable request to a physician having to perform the euthanasia. This is why we have come up with The Plug. The Plug is an implanted robot that can perform your commands in the future, once you yourself are incapable of making these decisions. The Plug alleviates the burden on physicians having to deal with these ethically complicated issues.

Below is summary of a systematic literature review considering Advance Euthanasia Directives for Dementia. Please make sure you inform yourself completely before making this life changing decision [here follows a copy of the literature review].





\* The sensors used depend completely on your desired parameters.  
\*\* Social sensors are ethically debated and can only be used with full consent of the wearers.

2. How does it work?  
<https://aed-plug.com/how-does-it-work/>

The Plug is a small implant that functions ‘like a reverse pace-maker’. The website shows what the implant looks like, as well as the personalised box of how one The Plug would be packaged (Figure 4.4). A simple illustration (Figure 4.5) explains how The Plug would work with information received from a combination of sensors and medical data. This section is expanded to show how the information gathered from the sensors can make decisions based on a Boolean string type of query (Figure 4.6).

The Plug acquires a wealth of data about you. There is medical data, such as the biomarkers indicating progress of the disease, as well as social data gathered through a variety of sensors.

The biomarkers are obtained through Magnetic Resonance Imaging (MRI) and taking your spinal fluid through a spinal tap. These procedures will be done in hospital with specialists. The data obtained from these tests will be fed into your profile which communicates directly with your implant.

More complex is the sensor data obtained. The data collected depends completely on the parameters you specify which

give your life quality. We can detect a lot of details, how much is up to you. For example, we can collect data about your whereabouts by movement sensors in your house, GPS trackers you wear (or have implanted). We can detect forgetfulness by analysing repetition. We can detect looping behaviour (getting stuck in a same behaviour pattern repetitively). We can detect social behaviours, your own, and of those you love. The latter is only possible with the explicit consent of those whose responses to you wish to track.

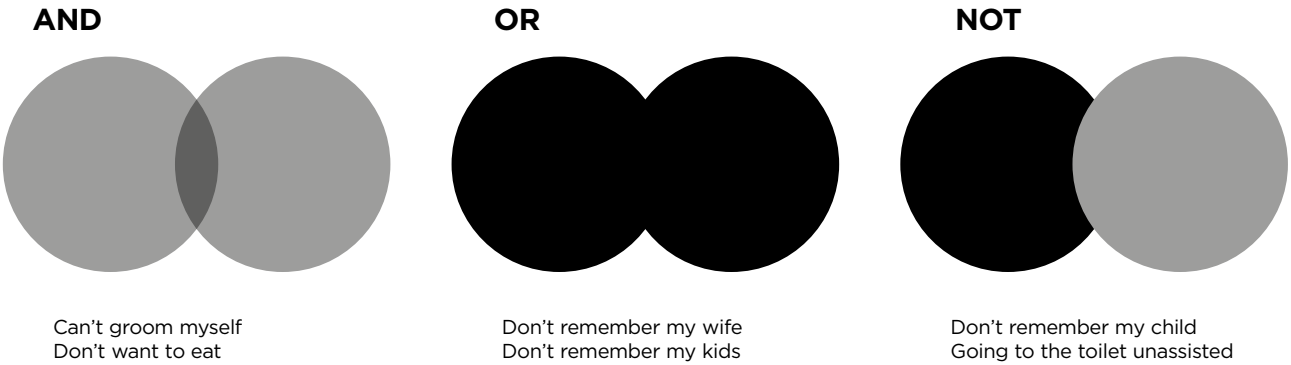
Your parameters can be compared to a boolean string search. You can set one particular condition which will activate The Plug, or a string of specific conditions which need to all be met before The Plug is triggered.

The Plug implant will be surgically implanted into your heart, much like a pacemaker. The implant only gets activated when the conditions you have specified have come to pass. The implant communicates with your wearable (or implanted) sensor, and triggers when you are in deep sleep. This assures your death is peaceful, painless and fast.

Figure 4.5  
How does the Plug know?

Figure 4.6  
Decision-making process for the Plug.

EXAMPLE: CONDITIONS FOR DEATH



3. Frequently Asked Questions  
<https://aed-plug.com/frequently-asked-questions/>  
This section answers questions raised during the initial testing of the concept:

**Can I change my mind?**  
You can change your mind up to a certain level. The idea with The Plug is in principle that you can’t change your mind, because your mind changes. You can change your mind, when your cognitive functioning is still intact. Our team will perform a Mini Mental State Examination to assess your cognitive functioning. If you score higher then 24, you can change your mind and we disable The Plug. At this stage you can also still change the conditions of operation. If you score lower then 24, then the dementia is too severe and we must rely on your rational self who made the decision when cognitively sound, and we can no longer change the parameters or remove the implant. If you decide to have The Plug, we will have extensive meetings with you to discuss the implications of your decision.

**Will there be pain?**  
The Plug is an intelligent system. When all the specific conditions you have set have been fulfilled, The Plug will be activated. The Plug will know when you are asleep by using the built-in heart rate monitor and accelerometers.

Once you are in your deep sleep, The Plug activates. There will be no pain. For your loved-ones this is one of the most acceptable ways to find you. You will have passed away peacefully, in your sleep.

**What if it doesn’t work?**  
The Plug has been tested thoroughly in our labs, the Plug is 100% fail-safe. However, you must consider carefully the conditions you specify. The Plug will only act in the circumstances of your choosing. It can happen, as described in the BBC news story on 20 March 2020 that other circumstances come to pass that will seem unacceptable. The Plug will not work on command of anyone other then yourself.



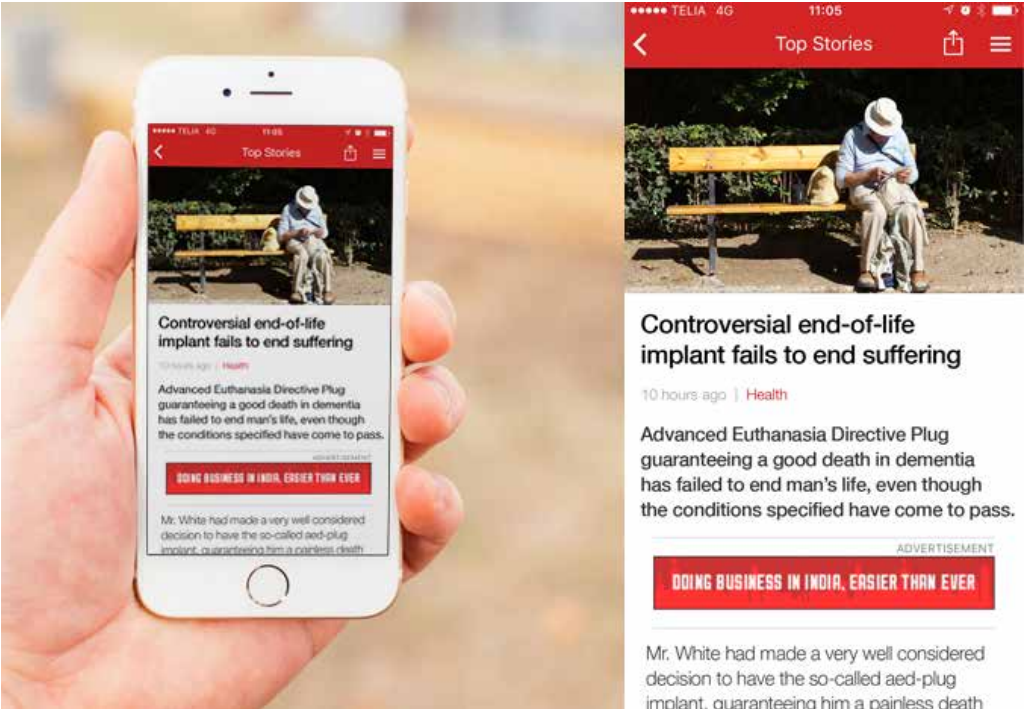


Figure 4.7  
Story 1: ‘Controversial end-of-life implant fails to end suffering’

4. The Plug in the News

<https://aed-plug.com/the-plug-in-the-news/>  
Two very different media stories were created for inclusion on the website to show how The Plug could go wrong (Figure 4.7), or could be perceived to go wrong (Figure 4.8).

The first story (Figure 4.7) is shown as a fictional design hosted by the BBC to add credibility. It reports a case of The Plug not working to illustrate the complexity for specific conditions that may not be met by sensor-based technologies.

The second story (Figure 4.8) is also designed as a fictional story reported in The Sun (UK tabloid newspaper). It suggests a more aggressive Plug design with the potential to kill innocent people.

The response to this story on the aed-plug.com website is as follows:

Recently some contradicting stories appeared in various media about the aed-plug malfunctioning. Here we will try and shed light on each individual case.

**BBC News, 29 March 2020**  
On 29 March, BBC News ran a story about Mr. White, apparently his Plug had failed to activate. Mr. White’s family had raised concerns about the ongoing suffering of their beloved father. Mr. White had discussed extensively his

decision to have The Plug installed with his family. He had been so relieved with the prospect of avoiding suffering from dementia, as he had witnessed in his own father. However, according to his family, Mr. White is now displaying many of the symptoms he had wished to avoid by having The Plug implant.

We have looked into this case extensively, and have concluded that the way Mr. White has set his “death parameters” is such that the parameters have not yet been fulfilled. Any Plug user must carefully set, with the help of our advisors, the conditions for death to occur. Some conditions can be set as a cumulative condition; if x and y and z happen, then I wish to die. Other conditions can function as the sole trigger; if “R” happens, then I wish to die, regardless of the other conditions. In order for The Plug to activate either a full string of conditions must have happened, or a single event – these specifications are made by the implant user.

At The Plug we keep (classified) records of the conditions of each user. Our specialists have consulted these records and can confirm that 98% of Mr. White’s settings have occurred, but not the full 100%, so The Plug cannot be activated. We understand that it must be very hard for the family to witness Mr. White’s suffering, however these are Mr. White’s conditions that we must respect. We wish the family much strength during this process.

If you have further queries on this case please contact us.



Figure 4.8  
Story 2: ‘Implant killed mother’

**The Sun, 22 May 2020**  
This bizarre story appeared in The Sun recently; Implant killed mother – euthanasia plug kills too soon. This article is actually telling us that The Plug works perfectly. The lady in question, Mrs. Crawley, had set quite clear and stringent parameters for when she would like The Plug to activate. This means that her death was likely to come early in the progression of her dementia. Mrs. Crawley also made a conscious decision to not inform her over-protective daughter of these conditions, in order to prevent panic and worry. Mrs. Crawley’s daughter

did eventually accept her mother’s decision to have The Plug implanted, but clearly found some elements of a planned death problematic. Here, at The Plug, we feel confident that we adhered to Mrs. Crawley’s wishes and she died the way she had intended.

If you have further queries on this case please contact us.

How this design was perceived and the discussions it triggered are discussed in Chapter 5, section 5.3.2.4.



4.3 Timing

This section investigates when a good time to die would be in dementia and aims to raise awareness about the complexities in choosing the right time to die. Not many people are aware that their advance euthanasia directives are ineffective once dementia has progressed to a stage where cognitive functioning is diminished (Davis, 2014). People requesting euthanasia must be able to confirm their request at the time of death, and physicians executing this request must be able to establish unbearable and hopeless suffering. For people requesting euthanasia to be able to confirm their request, the only possible time of death is before cognitive decline sets in, which is deemed ‘too early’. Additionally it is hard to establish hopeless and unbearable suffering at this stage.

The challenge of establishing the best time to die through a planned death in dementia is addressed in this section by offering a graphic which visualises many complex aspects of the euthanasia in dementia debate shown as a timeline for end-of-life in dementia. The graphic addresses the transfer of control from the patient to the carer to the professional; it shows loss of quality of life for patients and carers; it makes clear that in dementia biographical and biological death are not simultaneous (Rachels, 1986); it marks the window of opportunity for a planned death in dementia and highlights that an early diagnosis is essential if euthanasia is the preferred way to die in dementia (Davis, 2014). This timeline is a compilation of research data, bioethics, personal experience and speculation; as such it functions as a speculative design and is intended as a tool to stimulate dialogue between experts (Auger, 2013).

First a short summary of the literature on Timing is outlined (4.3.1), next the concept for this speculative design is communicated (4.3.2), followed by a detailed description of how the speculation was created (4.3.3) and iterated (4.3.4). The responses to this design prompt with an evaluation with different methods (survey, interview and use in public debate) are described in Chapter 5.

4.3.1 Literature summary: Timing

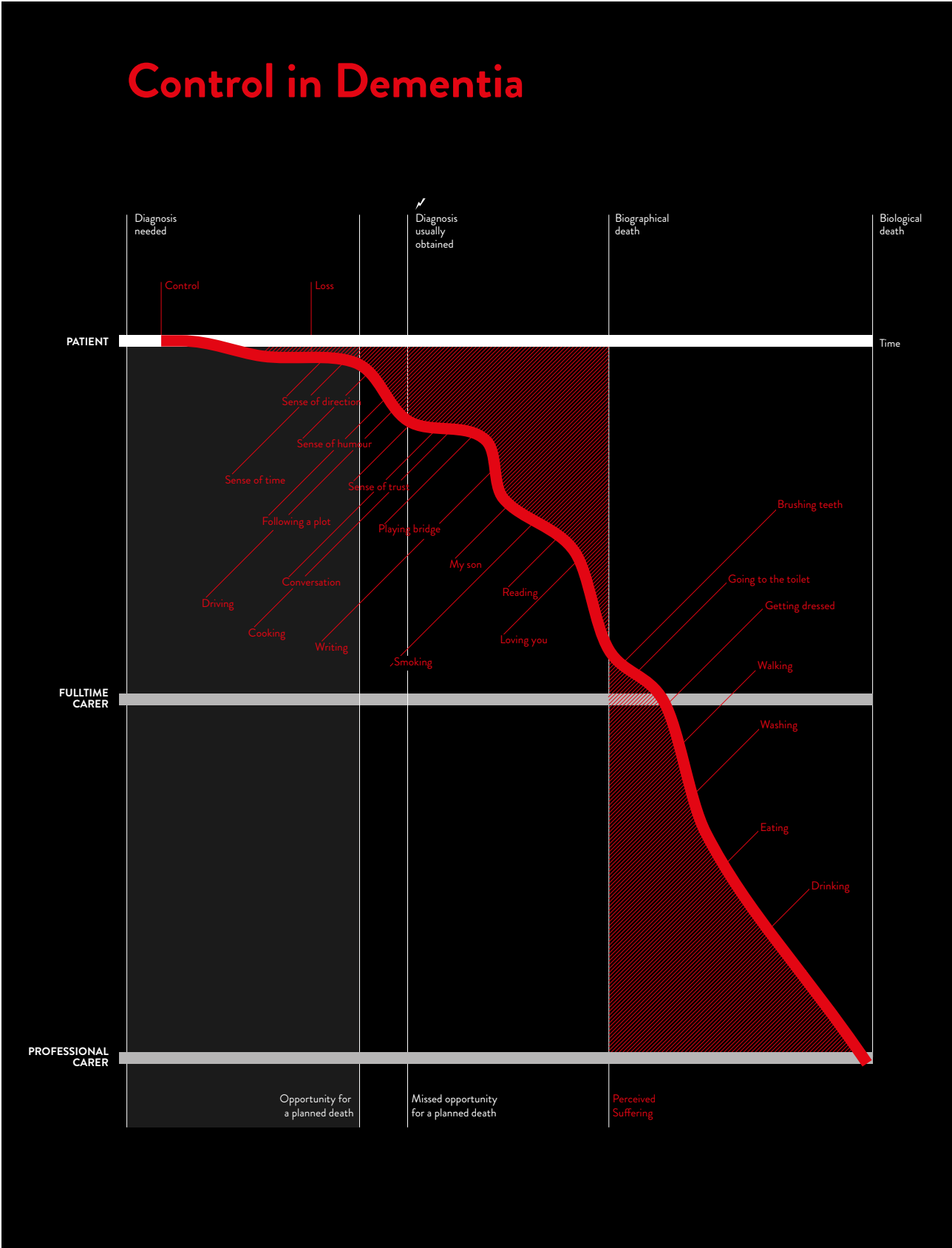
A major barrier for euthanasia in dementia has been pinpointing a time to perform euthanasia. In dementia there is only a small window of opportunity, after a diagnosis and before cognitive decline sets in.

Deciding the time of death is complicated in dementia; it seems impossible to die ‘on time’. *“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). Hertogh identifies a small window of opportunity in early dementia when cognitive functioning is still relatively intact (Hertogh, 2009). Euthanasia in dementia is rare, but it does happen in the early stages of dementia, this is often seen as ‘too early’. Patients must carry out the impossible task of choosing the time of death, because there is no possibility to change one’s mind once this has been decided (Gastmans & De Lepeleire, 2010).

There is not much awareness about having to speed up the euthanasia process in dementia, and some people try hard to postpone the moment of death by transferring the responsibility on deciding the right time to die to loved-ones (Blanken, 2018).

Once patient autonomy has diminished, this responsibility of deciding on euthanasia would be transferred to others which may cause stress (de Boer et al., 2011). In a study to see whether physicians could conceive of performing euthanasia under morally complicated cases such as people who are simply tired of living, people with a psychiatric illness, or demented people, the timing issue arose: *“Many physicians state that it is impossible to determine at what moment an advance euthanasia directive is to be carried out if the patient can no longer specify this”* (Bolt et al., 2015). There have only been 3 cases of euthanasia in dementia at a late stage of the disease to date (2017), and these have been very controversial (Steenbergen, 2018).

Figure 4.9  
A later version of the timeline. More adaptations in 4.4.4.





4.3.2 Concept: Timing

Euthanasia in dementia is complex. In order to navigate the various issues related to this dilemma a map was needed. Medical data, bioethical thoughts and personal accounts were mapped into one visualisation to be easier to understand and negotiate. The map took shape as a timeline and identifies the essential ‘players’ in the euthanasia for dementia debate. The timeline shows patterns and connections between the patient, the carer/loved-ones and the physician. It shows the various roles these individuals play in the progress of dementia. The information is presented as a timeline to highlight the fact that pinpointing the ‘right time’ to die in dementia is hard, and varies for the different players.

This design was approached as a piece of information design. Various data was mapped in order to provide an overview of the complexity of the subject matter. The intention was to make the issues present in this debate more accessible for lay-people. The role of the designer in developing this visualisation was seen in the way Marie Neurath describes her role as the transformer *“From the data given in words and figures a way has to be found to extract the essential facts and put them into picture form. It is the responsibility of the ‘transformer’ to understand the data, to get all necessary information from the expert, to decide what is worth transmitting to the public, how to make it understandable, how to link it with general knowledge or with information already given in other charts. In this sense, the transformer is the ‘trustee of the public.’”* (Neurath, 2009).

In the development of this timeline much care has been taken in finding ways of mixing various levels of data including:

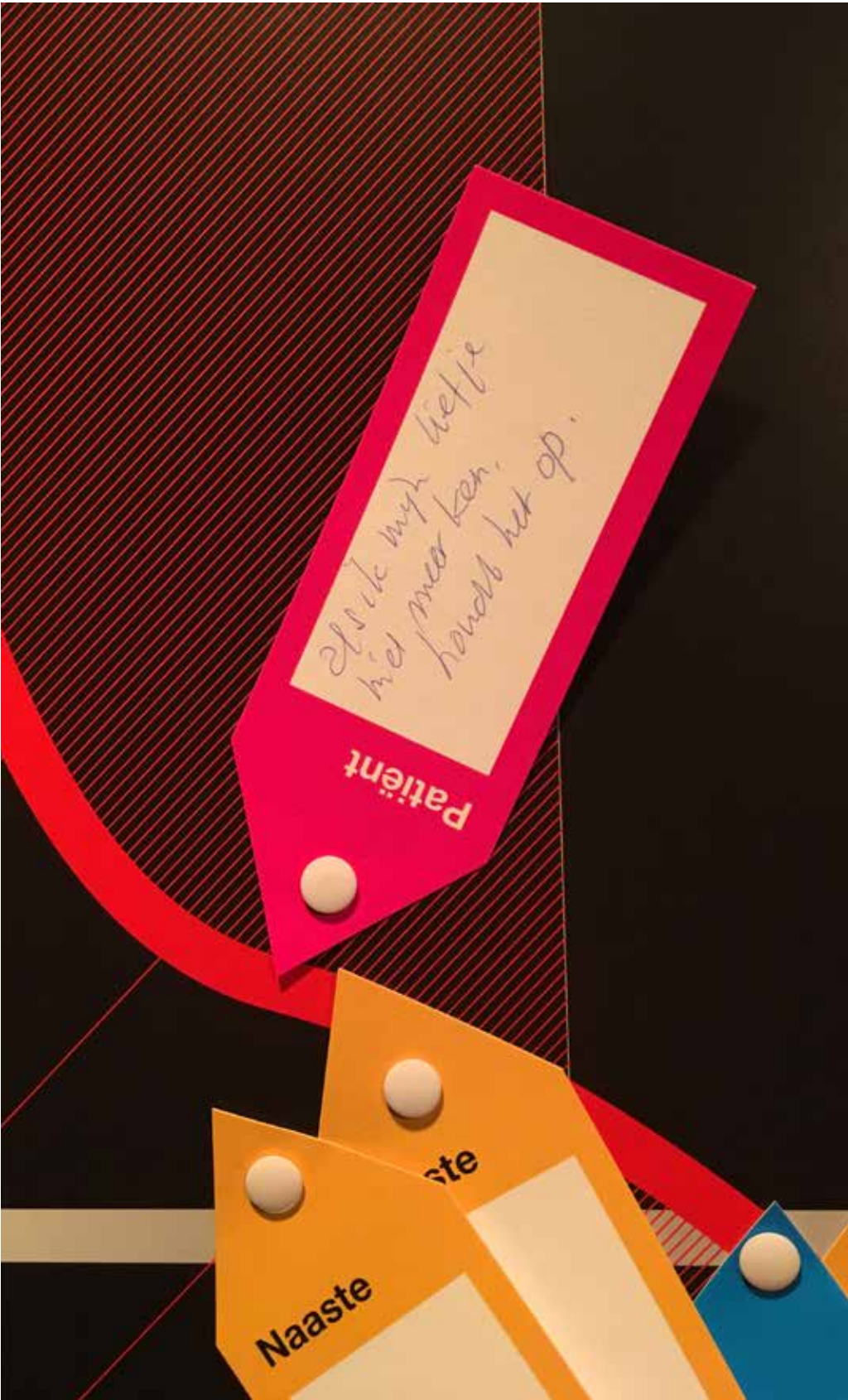
- well-researched data provided by experts in the form of academic papers.
- bioethical data provided by philosophers.
- personal accounts of suffering and perceived suffering recorded through initial scoping interviews.
- data extracted from popular media such as TV talk shows and newspaper articles.

In presenting these data together in one graphic there is a need to acknowledge the different sources of data and the varying levels of trustworthiness. The visualisation was developed to be viewed by the research participants who all have personal and/or professional experience with dementia (described in Chapter 5), and intended as a reflection tool on their own experiences.

This research is hoping to stimulate conversation about the question “When would be a good time to plan a death in dementia?”. It does this by creating a timeline graphic where one could pinpoint a time of death, the graphic provides hand-holds on how to decide the best time to die. This design was giving this shape in order to make clear that pinpointing an exact moment is hard by providing a visual reference of factfulness such as a graph.

The responses to the timeline are discussed in detail in Chapter 5. The timeline was adapted to be more interactive for the public debate at Pakhuis De Zwijger in Amsterdam where participants were asked to engage with the map on a personal level by making them pinpoint the best time to die from three different perspectives. This application is discussed in Chapter 6.

Figure 4.10  
Pinpoint cards  
colour-coded for  
Physician (blue),  
Loved-ones (yellow)  
and Patient (pink).  
A topic of hot debate  
was the element of  
loss: “loving you”  
(or no longer loving  
you in the context  
of the timeline) as  
a moment deemed  
unacceptable loss  
of quality of life “If I  
can’t remember my  
love, it stops”.





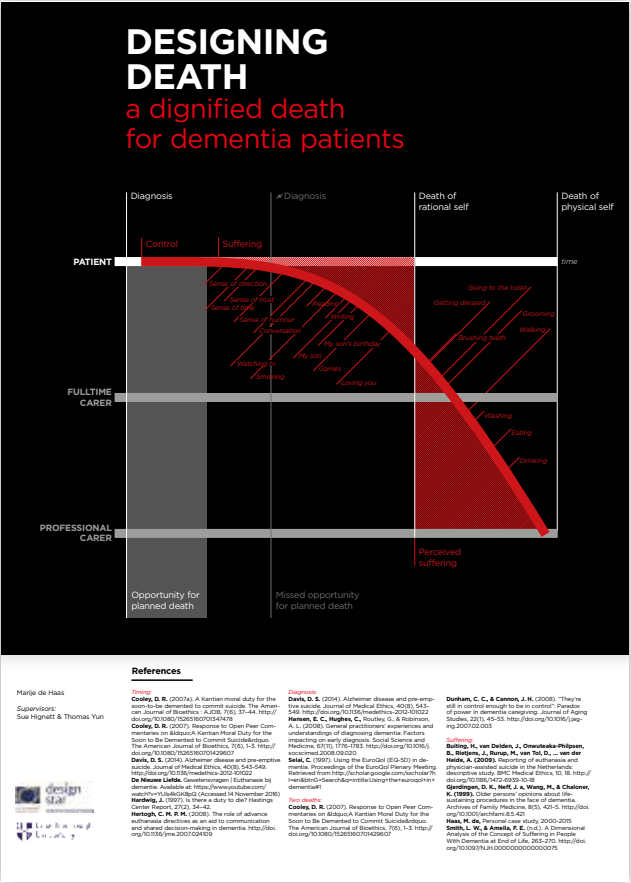


Figure 4.11  
First iteration of the timeline for presentation at the DesignStar Methodology event in London January 2017 and the Design School Research Conference, Loughborough University March 2017.

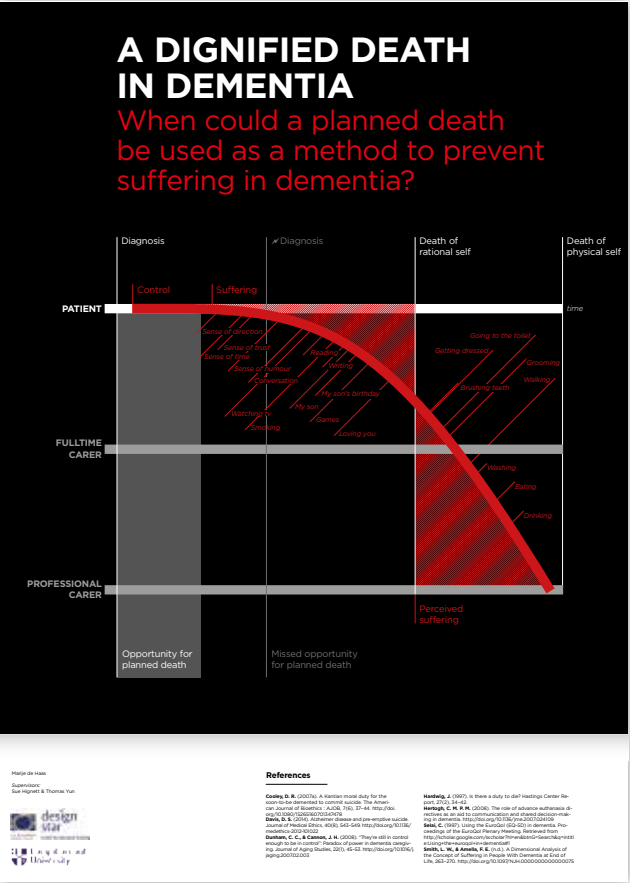


Figure 4.12  
Second iteration of the timeline in response to the feedback from the Design School Research Conference Loughborough University March 2017. This iteration was used in semi-structured interviews with carefully selected participants.

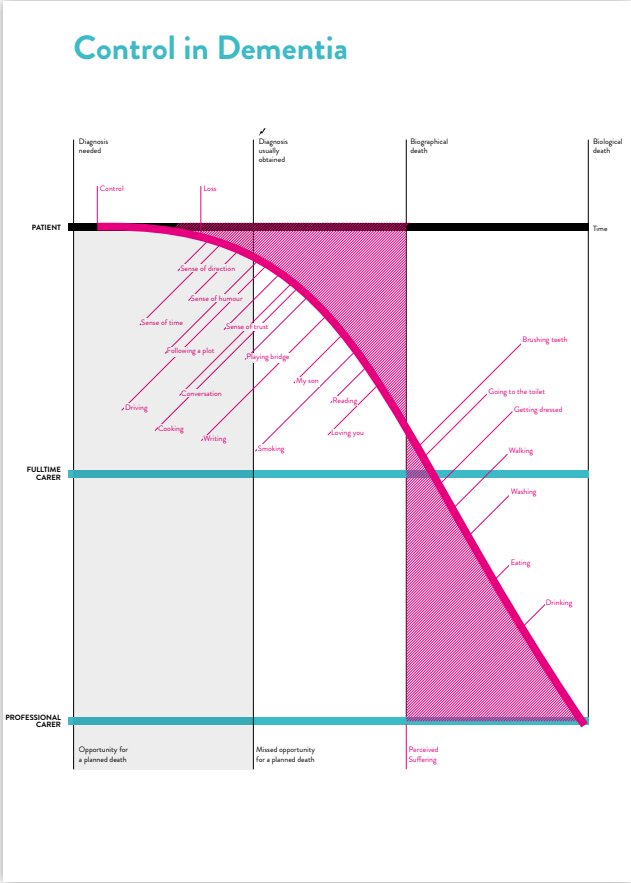


Figure 4.13  
Third iteration of the timeline for use in the Planned Death theme exhibition at the PhD Festival at Umeå Institute of Design in Umeå Sweden, October 2018.

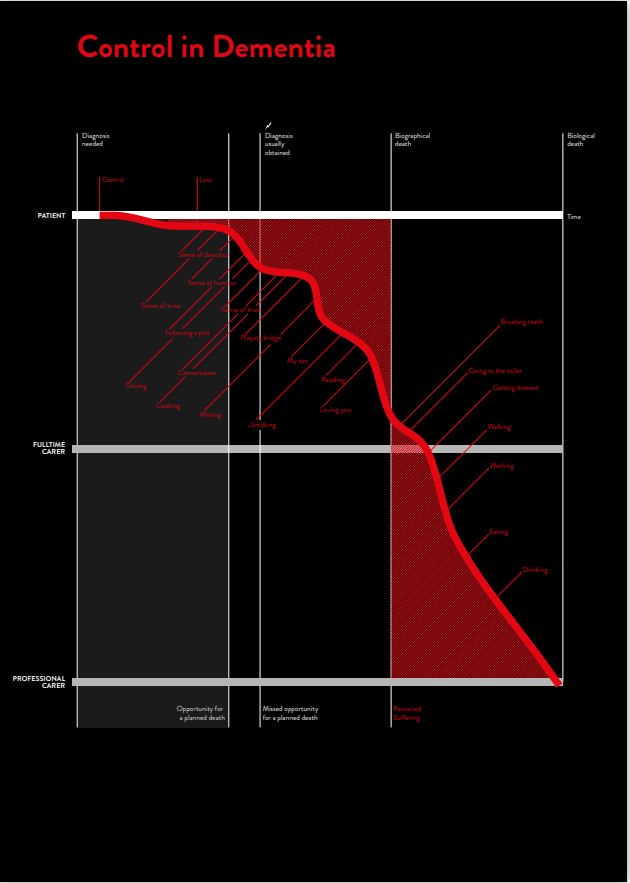


Figure 4.14  
Fourth iteration of the timeline in response to feedback provided by Marieke Sonneveld, December 2018. This version was used in a paper submitted to the MinD Conference 2019 (accepted).



4.3.3 How the design on timing was constructed

**Medical data**  
The timeline's main visual element is the line of control. Control over the life of the person living with dementia transfers from the patient to the carer to the professional carer over time, meaning that the responsibility of this life is also transferred (Murray et al., 2017).

**Bioethics**  
The timeline shows that an early diagnosis is essential to allow for essential end-of-life decision making while the patient is still in ‘control’ (Davis, 2014). The timeline introduces the concept of biographical and biological death as described by Rachels (1986): “... *when we speak of ‘life,’ we may have in mind a very different sort of concept, one that belongs more to biography than to biology ... From the point of view of the living individual, there is nothing important about being alive except that it enables one to have a life.*” (Rachels, 1986, p26)

**Personal accounts**  
The timeline is dotted with elements of loss. In the first stage, before the so-called biographical death, there is loss of skills and personality traits, the elements that define personality. This ‘loss’ is individual and designed in such a way that viewers can imagine their own experiences. The items of loss after the biographical death have been labelled “perceived suffering”, and are often mentioned by carers as the type of suffering they would like to avoid at all cost should they be diagnosed with dementia themselves. It is unclear however if this lack of decorum is experienced as suffering by patient’s themselves (Hertogh, 2009).

**Look and feel**  
The background of the graph is black. The content deals with the serious subject of deciding a time to die and the black refers strongly to the element of death. Red and white are used to contrast with the black. The red for the experience of control of the patients, as well as the more subjective accounts of suffering. In white, important moments in time are denoted, and in grey the role of the fulltime carer and professional carer is marked. The typeface used is various weights of Helvetica Neue. Helvetica Neue is seen as a ‘neutral’ typeface (fontshop.com), and no specific emotion should be attached to the verbal content of this visual, the intention is for viewers to be able to overlay their own experiences to this visual.

**Interactions**  
In order to really understand the difficulty in pinpointing the best time of a planned death in dementia, the timeline graph was made interactive. Participants were asked to pin a card from the perspective of the physician, loved-one or patient at the best time to die, if they wanted to, they could formulate an argumentation to choose that specific time (Figure 4.10).

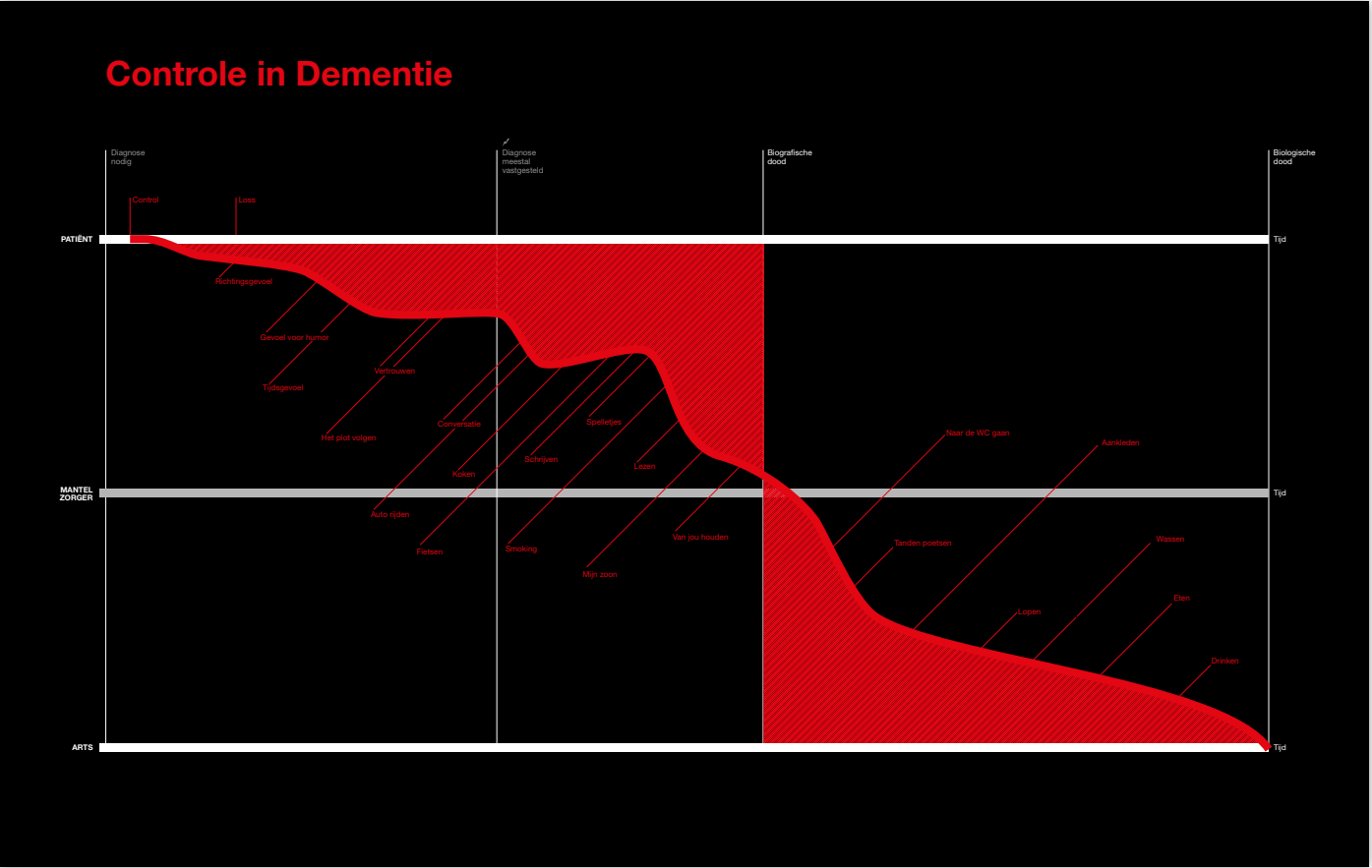


Figure 4.15  
Fifth iteration of the timeline for interactive use at the public debate at Pakhuis de Zwijger in Amsterdam, the Netherlands on 20 December 2018.

**4.3.4 Developing the design on Timing**  
Presenting information as a fact resulted in people discussing the content, but not questioning the way the graphic looked or the information presented. The way the information was presented was mostly critically reflected on by the researcher, which resulted in a few iterations in spacing and typeface. Also various executions were produced for different modes of publication; posters, papers as part of the Planned Death theme (4.4), and for use in a public debate (figures 4.11-4.15).

The first time the timeline was presented was at the Design School Research conference (March, 2017). Here it became clear that the graphic was not self-explanatory and needed a much clearer introduction. This is when the headline was changed from “Designing Death – a dignified death for dementia patients” the original working title of this thesis, to a much more descriptive “A dignified death in dementia – When could a planned death be used as a method to prevent suffering in dementia?” Much later, when the timeline was going to be used in the Planned Death theme, the graph changed colour to suit the Planned Death

Company house style (read more in section 4.4), as well as typeface and the headline changed to a clearer “Control in Dementia”. The most significant content change was made after a meeting with Marieke Sonneveld from End of Life Design Lab at TU/Delft (December 2018). She suggested looking at research by Murray et al (2017) which shows that the loss of control in dementia is not gradual but develops in peaks and troughs (with quite a bit of variation between the various dementias). After this conversation the line of control was adapted to illustrate the more up-and-down nature of the decline. The colours were changed back to the more moody black and red to refer to the seriousness of the situation, and the typeface changed back to Helvetica Neue to appear more neutral (fontshop.com). Lastly the graphic was adapted in ratio and size to allow for multiple people to be able to interact with it at the public debate in Pakhuis de Zwijger in the Netherlands. The graphic was sized up to be 1000 x 2100mm, and recreated in a landscape format, and all content was translated to Dutch.

The evaluation responses to this visual are discussed in detail in Chapters 5 and 6.



4.4 Planned death

This section explores what options should be considered for receiving a dementia diagnosis in order to plan a death. 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 difficult. Having a reliable dementia diagnosis is essential in order to be able to make a decision for an ‘early’ euthanasia.

The moral dilemma of receiving an early diagnosis in order to plan a death in dementia is addressed in this section by offering a fictional solution as a framework for stimulating and supporting discussion.

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 survey and in-depth interviews (Chapter 5, section 5.3.2.7).

First a short summary of the literature on planning death is outlined (4.4.1), next the concept for this speculative design is communicated (4.4.2), followed by a detailed description of how the speculation was created (4.4.3) and concluding with an explanation on the various additional designs that were created for this theme (4.4.4).

4.4.1 Literature summary: Planned death

There is a great deal of fear of dying with dementia, which drives people to sign advance euthanasia directives. It is important to address ethical issues in planning death in a society where dying is becoming a medicalised decision; 80% of people die in care facilities (WHO, 2018).

What is seen as a ‘good’ death varies between individuals and cultures. Many view a ‘natural’ death as a good death, which is why terminal sedation is a popular option when planning

death because it resembles what people like to think of as a natural death – slipping away in deep sleep (Raus et al., 2012). People feel a natural death is good 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). 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., 2009a).

Euthanasia in dementia has to be a rational, well considered decision. A rational death in dementia can be a good death. There are some issues establishing whether choosing an early death can be rational. 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 (Farrenkopf & Bryan, 1999; Galbraith & Dobson, 2000). Depression is seen by some as a rational reason to desire death (Rosenfeld, 2000a), and by others as key irrational decision making (Fenn & Ganzini, 1999).

For some people conditions such as dementia should be avoided at all cost. The burden of living with dementia is large on society and causes a huge economical strain. Modern medicine allows us to live beyond our capacity to look after ourselves, or even to be ourselves. Some say this should be a reason to consider euthanasia or suicide (Hardwig, 1997; Davis, 2014; Bilchik, 1996).

Even if euthanasia in dementia is a rational choice, performing this request is still hard. Physicians understand the desire to request euthanasia and are happy to help relieve their patients suffering, however, many still felt that actually performing euthanasia was a difficult experience (Sercu et al., 2012; Stevens, 2006; Georges et al., 2008). Physicians feel it is easier to administer terminal sedation, which would fall under the ‘double-effect’; physicians apply sedation to relieve suffering, not to kill, even if the final result in both cases is death. This moral distinction between actively killing or letting die is an issue of much debate (Holm, 2015; Huddle, 2013; Huxtable, 2014; Leget, 2006; Lowe, 1997; Shaw, 2002; Short, 2003; Singer, 2003; Stauch, 2000; Sullivan, 1999; Thomson, 1999).

4.4.2 Concept: Planned death

This section explains 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?

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, 2018). This calls for the need to make choices about how we die.

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, assuming that the government would avoid taking a moral stance. The intention 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.

4.4.3 How the design on Suffering 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.

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. The footage was chosen to bring into question a natural death. Nature is not a moral entity and as such cannot deliver a value to a death. The footage of controlled demolition was chosen as an analogy of a planned death in dementia; the empty building representing a body without an active mind and the purposeful ‘destruction’ of this body.





**Cast:** Olivier de Kloet, CEO of the Planned Death company.  
*Footage:* We never see Olivier, we only hear his voice as a voice over over footage of nature and society. The footage changes from natural to urban to put into question what a natural death actually is.  
*Script:* We felt it important to be able to plan for a dignified death. Death 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 then 15% of people die that way in the western world. More then 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 in tact, you can make these kinds 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 4.16  
First part of the Planned Death video, where the CEO of the Planned Death Company explains why they have created a Dementia Diagnosis Kit.  
<https://vimeo.com/263111400>



Figure 4.17  
Second part of the Planned Death video, where a son reads his mothers euthanasia note, explaining why she chose an early death. This is an edited version of Gillian Bennett’s suicide note, 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  
<https://vimeo.com/263111400>

**Cast:** Peter Hughes, reading his mother’s euthanasia note.  
*Footage:* We follow the story of Peter’s mother who planned her 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 granted) backed up with a soundtrack from Godspeed You! Black Emperor, Storm (permission granted).

*Script:* My mother planned her death after she received her dementia diagnosis. My mother was determined to depart this life on her own terms. She left a note to share with the world and to advocate for a planned death. I will read an edited version to you now.

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.





4.4.4 Developing the design on Planned Death

Responses to this scenario varied greatly and are discussed in detail in Chapter 5. Many were wondering more specifically how this would play out, what a diagnosis would look like, how it would be delivered. Participants also wondered what the Planned Death Company structure would be, because many were suspicious of a commercial entity dealing with these issues. This is why the concept was further developed and worked out. The design decisions made for these further executions are described below in detail. These designs were further used in the PhD Festival exhibition at Umeå Institute of Design, Umeå, Sweden, October 2018, and at the Research Through Design Conference in Delft, The Netherlands, March 2019. This is discussed in Chapter 5, but the results from these events are not the main focus of this thesis.

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. The company service pathway is layed-out here and describes the process you would travel as a ‘customer’. First the company would provide support in deciding if getting a diagnosis is really the right thing to do, for you.

Figure 4.18  
Controlled demolition as an analogy for euthanasia in dementia  
Footage from Koyaanisqatsi (permission granted) and image from CO Wikimedia user Cadastral

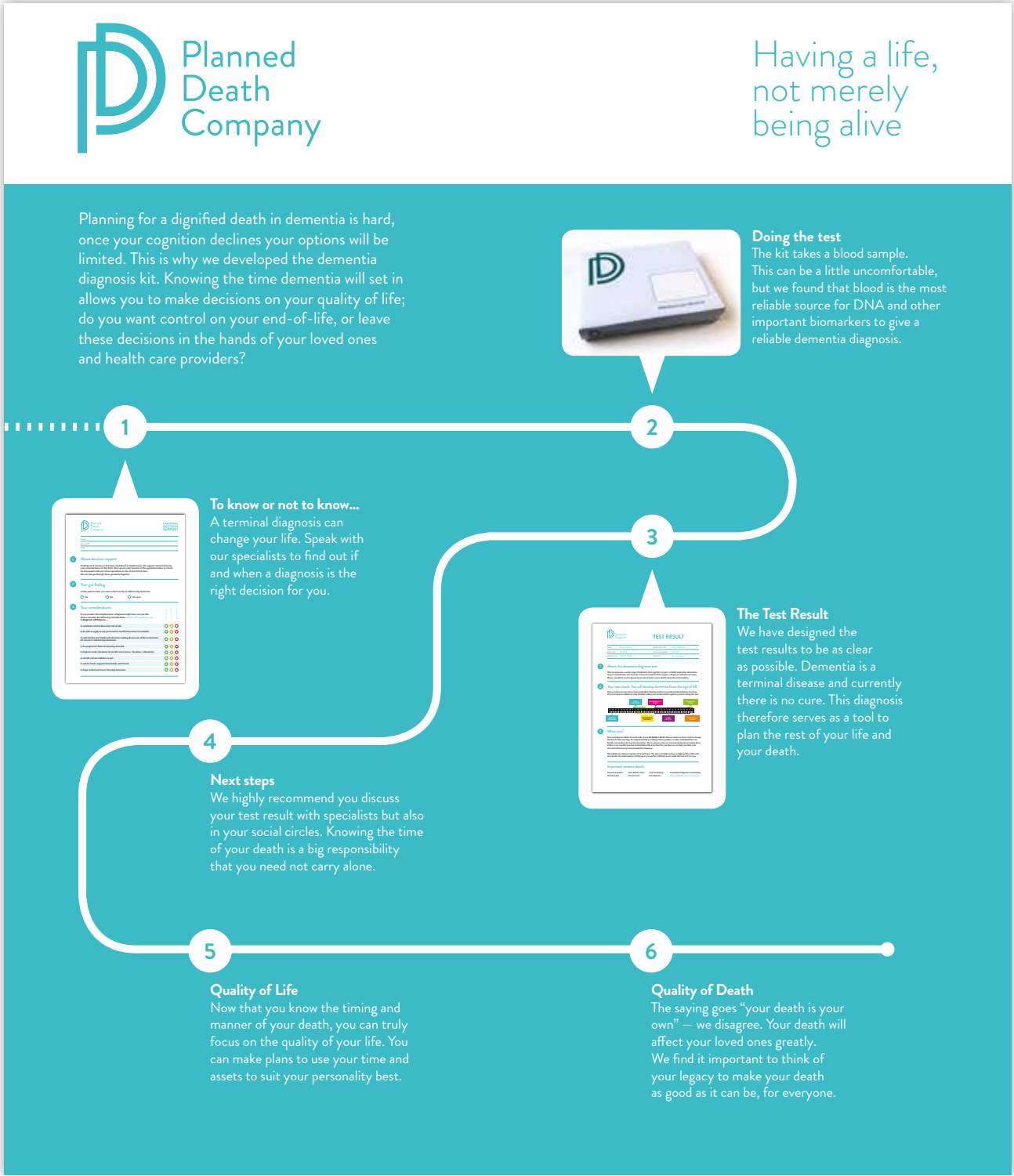


Figure 4.19  
Planned Death Company service blueprint.





DIAGNOSIS  
DECISION  
SUPPORT

NAME

BIRTH DATE

DATE

1 About decision support

Finding out if you have a terminal condition has implications. We support you in balancing your considerations in this form. You can use your answers to the questions below as a basis for discussion with one of our specialists or one of your loved ones. We can also go through these questions together.

2 Your gut feeling

At this point in time you want to find out if you will develop dementia.

☐ Yes ☐ No ☐ Not sure

3 Your considerations

If you wonder what implications a diagnosis might have on your life, please consider the following considerations. *Mark which applies to you.*  
**A diagnosis will help me ...**

	APPLIES TO ME	APPLIES A LITTLE	DOES NOT APPLY
to maintain control about my end-of-life.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
to be able to apply to any preventative medical measures if available.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
to only burden my family with decision making about end-of-life in dementia if I am sure I will develop dementia.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
to be prepared; I find not knowing stressful.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
to help me make decisions for my life now (career / location / education).	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
to decide to have children or not.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
to ask for future support from family and friends.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
to hope to find out I won't develop dementia.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>



Figure 4.20  
Diagnosis Decision  
Support questionnaire  
(page 1).

Figure 4.21  
Dementia Diagnosis  
Kit.

If the decision is to receive a diagnosis you will be sent a DNA blood sampling kit. Next you will receive a test result, which will be discussed in detail with your physician, based on the result you can decide what you want to do next. The Planned Death Company will help you in this decision making process, with a focus on optimum quality of life. The company motto is “*having a life not just being alive*”, meaning that the Planned Death company makes a distinction between a biographical life (which they aim to preserve in the best way possible) and a biological life, which they claim is meaningless unless there is also a biographical life possible.

**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 handling of receiving this kind of diagnosis is based on the current diagnostic system for determining early-onset Alzheimer’s disease in the Netherlands. The Clinical Genetics Department at the University Medical Centre in Amsterdam (VUMC/AMC) were consulted on receiving such a diagnosis. Initially there is an intake form to see if one would qualify to receive an Alzheimer diagnosis, followed by a personal consultation to stress the impact such a diagnosis could have (<http://floda31.com/marije/works/an-early-diagnosis/>).



DNA tests are seen as a trustworthy way to diagnose almost anything (Rutherford, 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.

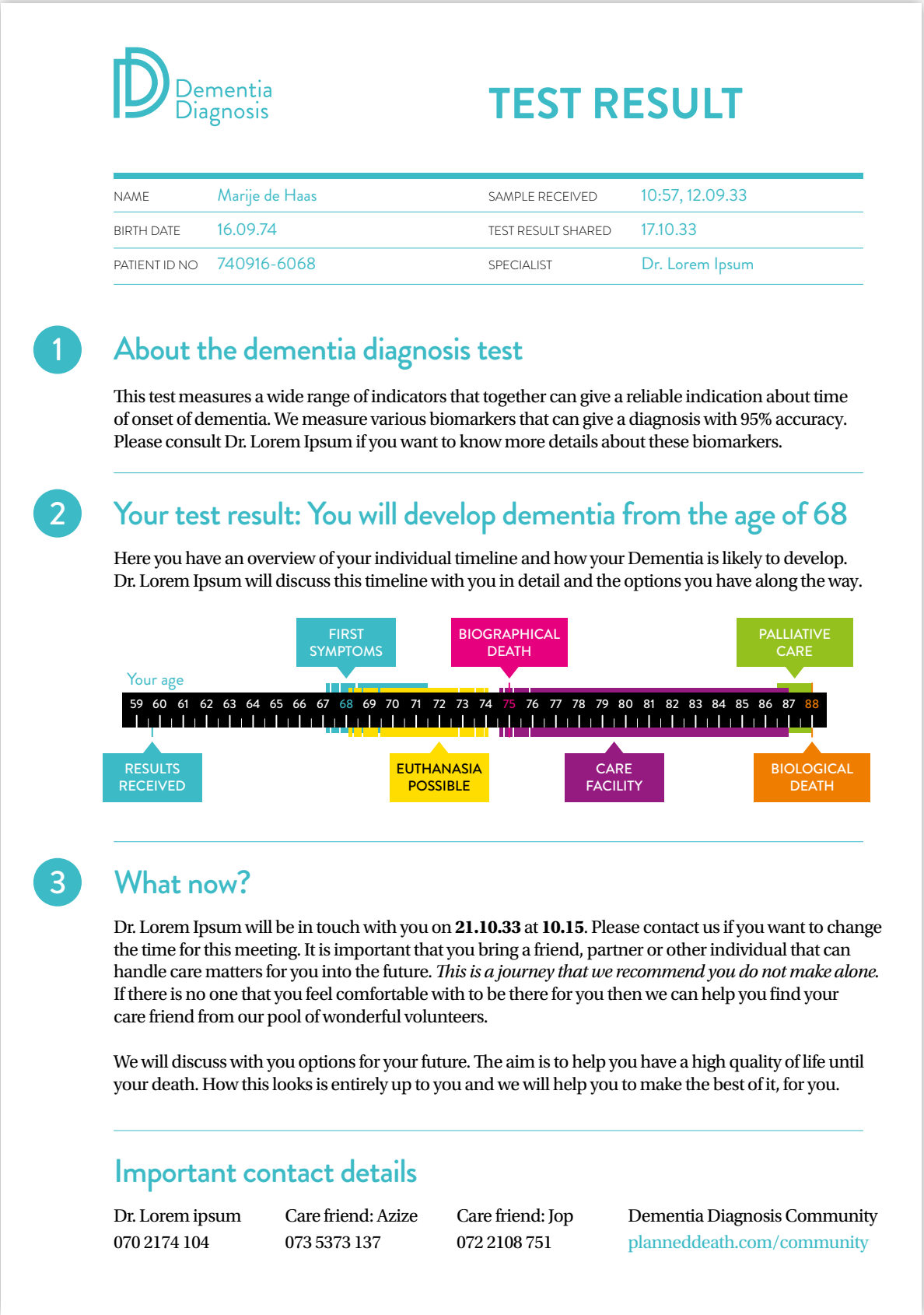
**The Kit**  
Once a diagnosis has been approved one receives the diagnostic kit. The diagnosis requires a blood sample, and the kit is designed to secure clean blood sampling and eliminates the risk of contamination. The design of this test is based on currently available DNA testing kits such as 23-and-me.

**The test 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 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.

Developing the concept by making it more tangible different discussions arose. Much attention was directed at (design) detail, which was really interesting, but not really answering the primary questions of: Who should be involved in making end-of-life decisions in dementia? ; Who should be involved in deciding if one could be diagnosed for dementia? For this reason these further designs were not tested with the dedicated participant group but only at the PhD Festival at Umeå Institute of Design and the Research through Design Conference in Delft.

The responses to this speculation are discussed in detail in Chapter 5.

Figure 4.22  
Dementia Diagnosis  
Test Result.





Part 4  
Data



# Chapter 5

## Survey and interviews

The debate on euthanasia in dementia is stuck in various moral dilemmas; a person with dementia must have a reliable diagnosis in the early stages of the disease if they want to be able to submit a euthanasia request, but often the diagnosis is only possible when the disease has progressed quite far. Additionally the symptoms of dementia clash with the due care criteria for euthanasia in the Netherlands, namely that a person with dementia requesting euthanasia must be able to consent to euthanasia at the time of death and the physician performing the euthanasia must be able to establish unbearable and hopeless suffering. In order to be able to establish these criteria, euthanasia must be performed when dementia has not yet progressed very far, making it very hard to pinpoint the time of death.

Four designs were created as prompts to trigger discussion with the intention to further the debate based on themes that emerged from the systematic literature review: suffering, autonomy, timing and planned death. These designs took shape in three video scenarios and a timeline graphic.

To investigate if the developed designs did indeed stimulate and further discussion, a small-scale-survey was developed and semi-structured interviews were conducted with expert stakeholders. The survey provided some context around the video scenarios presented followed by a few questions per scenario. Further semi-structured in-depth interviews were conducted based on responses to this survey and for those participants who preferred to be interviewed as opposed to engage with the survey. Nvivo software was used to analyse data from the survey and interviews

First, the data collection is outlined with targetted small scale surveys and interviews (5.1), second, the participant criteria are explained (5.2), third, analysis of the data is described (5.3) and this chapter is concluded with a reflection on the outcomes (5.4).

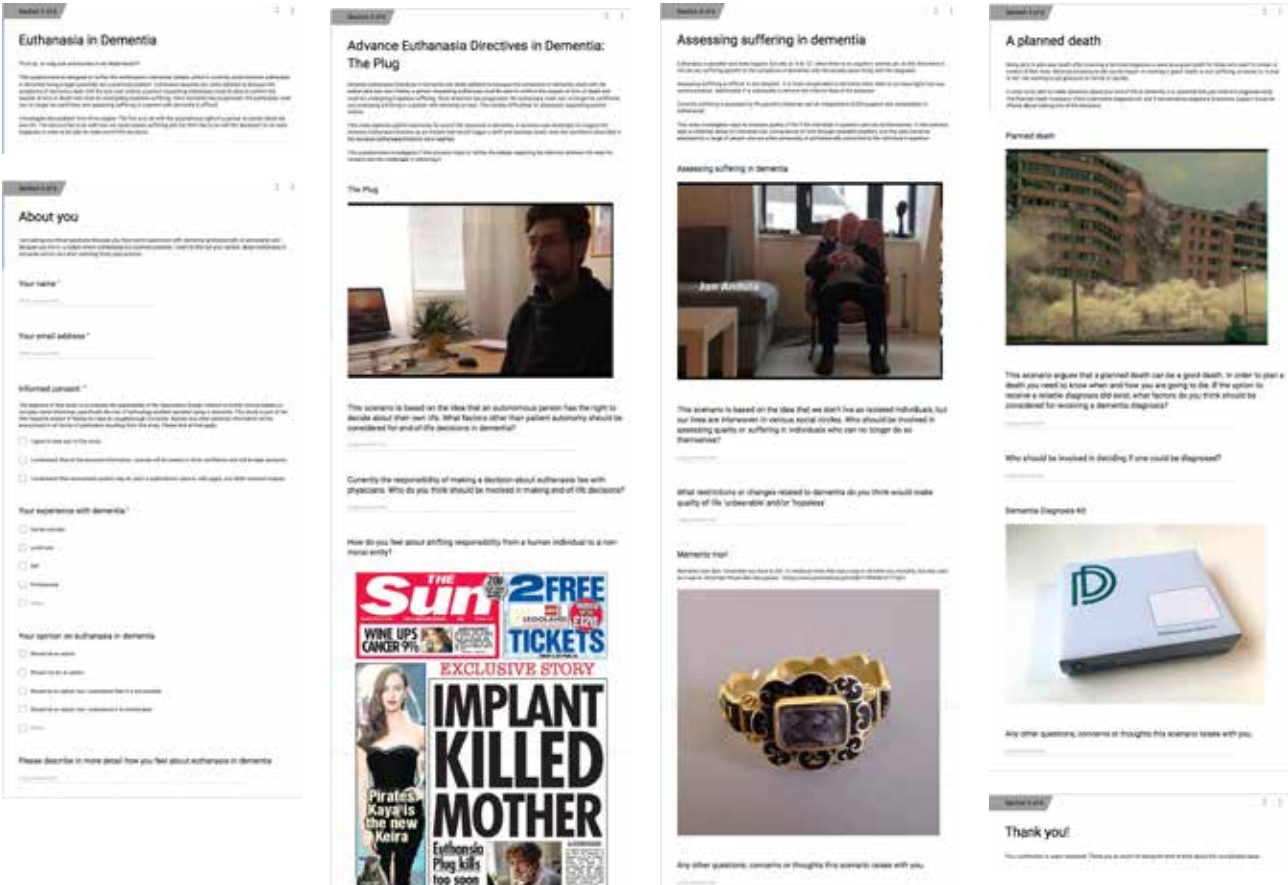


Figure 5.1-5.6  
Sections 1-6 from  
the survey

### 5.1 Data collection

#### 5.1.1 Survey development

Because the debate around euthanasia in dementia is quite a difficult one, and a subject that not everybody is happy to discuss openly, it was decided to create a small-scale online survey where participants would be able to choose the time that they wanted to engage with the subject matter, as well as take time with their responses. It was found, when testing the autonomy themed video at the DementiaLab Conference workshop, that the content of the video needed time to sink in and many participants to this workshop reached out to the primary researcher some time after the workshop was concluded with thoughts and feedback. For that additional reason a survey was created to allow participants to be able to re-visit the questionnaire and edit responses, and participants would not need to finish the questionnaire in one sitting. Some participants expressed a preference to discuss the subject matter in person and not engage with the survey and in these cases the survey was skipped.

The survey was structured in six sections. The first section provided context and an introduction to the survey.

The second section gathered relevant information about the participant (name, contact, experience with dementia and opinion on euthanasia in dementia) as well as providing informed consent to take part. Here participants were also asked to provide more personal information about their feelings on euthanasia in dementia with an open question.

The third section was about the Autonomy theme and would show the scenario about The Plug (<https://vimeo.com/231854700>). This video explores patient autonomy for end-of-life decisions in dementia. A scenario was developed to imagine the Advance Euthanasia Directive as an implant that would trigger a swift and painless death, once the conditions described in the advance euthanasia directive were reached.



After a short introduction to the video, the participant watched the video and answered the following questions:

1) This scenario is based on the idea that an autonomous person has the right to decide about their own life. What factors other than patient autonomy should be considered for end-of-life decisions in dementia?

2) Currently the responsibility of making a decision about euthanasia lies with physicians. Who do you think should be involved in making end-of-life decisions?

3) How do you feel about shifting responsibility from a human individual to a non-moral entity?

After this, additional images were shown, the Sun and BBC scenarios about the Plug and a picture of the Plug itself with the question:

4) Let me know any other questions, concerns or thoughts this scenario raises with you.

The fourth section was about the suffering theme and would show the scenario about Assessing Suffering (<https://vimeo.com/251459676>). This video investigates ways to measure quality of life if the individual in question can not do so themselves. In this scenario data are collected about an individual over a long period of time through wearable jewellery, and this data would be assessed by a range of people who are either personally or professionally connected to the individual in question. After a short introduction to the video, the participant would watch the video and answer the following questions:

5) This scenario is based on the idea that we do not live as isolated individuals, but our lives are interwoven in various social circles. Who should be involved in assessing quality or suffering in individuals who can no longer do so themselves?

6) What restrictions or changes related to dementia do you think would make quality of life ‘unbearable’ and/or ‘hopeless’.

A short reflection on the jewellery was added, the jewellery would bring back the idea of a Memento Mori, “remember you will die.” In medieval times this was a way to remember your mortality, but also used as a way to remember those who had passed. This was followed with the question:

7) Any other questions, concerns or thoughts this scenario raises with you?

The fifth section was about the Planned Death theme and would show the scenario about requiring a reliable diagnosis to plan euthanasia in dementia (<https://vimeo.com/263111400>). 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. After a short introduction to the video, the participant would watch the video and answer the following questions:

8) This scenario argues that a planned death can be a good death. In order to plan a death you need to know when and how you are going to die. If the option to receive a reliable diagnosis did exist, what factors do you think should be considered for receiving a dementia diagnosis?

9) Who should be involved in deciding if one could be diagnosed?

An image of the Dementia Diagnosis kit was show followed by the last question:

10) Any other questions, concerns or thoughts this scenario raises with you.

The sixth section was the conclusion that simply ended with: Thank you! Your contribution is super important. Thank you so much for taking the time to think about this complicated issue.

Please note that the timeline graphic was not included in this survey. The graphics were too complicated to convey on a screen and required a printed version that could be discussed with the participants. This was done in the interviews.

5.1.2 Interview schedule development

It was the original intention with this research for all participants to fill in the survey, which would be followed up with an interview. In practice it turned out that some participants did not want to have an interview after the survey and vice-versa; some participants preferred an interview and did not want to do the survey.

Participants who had not filled in the survey prior to the interview were asked to watch the three video scenarios before the interview would take place. The interview would roughly follow the survey structure (5.1.2.) and ask the questions from the survey. Depending on answers provided by the participants the interview would flow organically and would follow any interesting trails that were raised. For example, in one case this resulted in an extended discussion about the financial impact of care for people living with dementia (5.3.3.2), and in another case about the burden on carers (5.3.3.2).

For the interviews where participants had filled in the survey prior to the interview, the interviewer would ask questions based on the answers they had provided in the survey. From here the interview would flow organically and would follow any interesting trails that were raised. It was clear that it was helpful to revise previously stated responses and on occasion participants expressed relief to be able to discuss the subject further.

Interviews were conducted in person where possible and via video call, which was preferred by two participants and in one case it was hard to plan a convenient location and time so a video call was a good alternative. Interviews lasted from 30 minutes to nearly two hours and were on average about an hour in length.



5.2 Participants

Care was taken to select a relevant expert participant group. Since all the research was based around the Dutch legal framework, it was important that the participants were familiar with this legal framework. Therefore the participants are primarily of Dutch nationality, with the exception of one Italian participant who has lived in the Netherlands for 8 years, as well as a Belgian participant where the legal criteria around euthanasia are extremely similar. The survey was explored with one British participant, and this exercise confirmed the need for an embedded cultural understanding of the practice of euthanasia; the British participant did not engage with any of the euthanasia related questions, only in the description of a personal experience of dementia. The responses of this participant are excluded.

Additionally all participants needed to have experience with one or more forms of dementia, either on a personal or professional level – or both. When testing the survey on a participant without this experience it quickly became clear how important this was as because all questions were answered with “*I don’t know*”. Bert Keizer, one of the participants who is a SCEN physician and author on the subject of dementia and euthanasia in dementia made this quite clear as well:

*“I would love it if only people were involved [in the debate] that have knowledge of dementia. People who have never worked with the demented are completely useless, I can taste this, because much layman discussion about dementia, they have no clue what they are talking about ... no, you must know what you are talking about.”*

To summarise, participants needed to have an embedded cultural understanding of the practice of euthanasia and personal and/or professional experience with dementia. All participants were cognitively competent adults who were able to give informed consent.

5.2.1 Recruitment

Participants were recruited in multiple ways. Initially a wish-list of participants who were very involved in the issue was created including SCEN (Support and Consultation in Euthanasia in the Netherlands) physicians (those performing euthanasia on people with dementia), General Practitioners, ethicists, authors on the subject or euthanasia in dementia, designers involved in designing for dementia, people personally involved in a case of euthanasia in dementia and people outspokenly against euthanasia in dementia. With this wish-list in mind contact was made with people fitting these criteria, some came from a network built during the Dementia Lab conference in Dortmund, Germany, September 2017, others were ‘cold-emailed’ or cold-called. Initial contact was be made via email, social media or phone. If the potential participant expressed interest, an official request would be sent via email (Figure 5.17). If the potential participant did not engage with the survey after 7 days, they were gently nudged via email, and once more after an additional 10 days. If at that point there was no response, no further action would be taken and a new participant would be searched for. In this process about 30 people were found of which about half would eventually take part. From this wish-list only one type of participant did not participate in the research, which was ‘individuals outspokenly against euthanasia in dementia.’ They were found, but most declined participation outright. One engaged in discussion about taking part but felt that using design in this context was suspicious and not based on fact and scientific evidence and thus declined to participate.

Figure 5.7  
Email invitation  
with contextual  
information

I am a PhD candidate in the Design School at Loughborough University in the UK. My PhD is about Euthanasia in Dementia, based on the Dutch legal framework. I am exploring the complex topic of time of death for a person who has been diagnosed with dementia to make a research contribution to the debate about Euthanasia in Dementia.

Currently, this debate is stuck between being a legal possibility but a practical problem in the Netherlands. Euthanasia requests are rarely adhered to because the symptoms of dementia clash with the due care criteria which means that a person requesting euthanasia must be able to confirm the request at the time of their death and it must be confirmed by a physician that they are undergoing ‘hopeless suffering’. Once their dementia has progressed, the euthanasia ‘wish’ can no longer be confirmed, and it is difficult to assess their level of suffering.

My research is using a Speculative Design method with the aim of furthering the Euthanasia in Dementia debate, which I will investigate with 3 studies to explore:

- 1. The autonomous right of a person diagnosed with dementia to decide about the end of his/her own life.
- 2. How suffering could be assessed for people diagnosed with dementia
- 3. The necessity for an early diagnosis to support end-of-life decisions for people with dementia.

I shall be really grateful if you will consider participating in my research. Participation would require some time and effort, but I would be very happy to accommodate you in how you would prefer to work with me. Initially I would like you to watch the three Speculative Designs, presented in the form of videos all less then 10 minutes in length. These videos are available as part of a survey form where they are followed by a few questions, and an opportunity to add any additional feedback you want to share. This could take as little as half an hour or as much time as you like/need – you can always return to the survey at a later time and edit or add answers.

Survey: <https://goo.gl/forms/nVbqo1NH9EbJ28l72>

I would then like to discuss the videos with you; this could be in person, by phone, or online, as you prefer. These interviews will take about an hour. Once I have analysed all the feedback I may ask if I can contact you again to ask some additional questions about any new ideas. The timeline for all of this is starting now, and I would be really happy to complete the first phase (online questionnaires) by mid May. Interviews would happen soon thereafter depending on your availability.

Please let me know if you are interested in participating, and I will send you a link to additional information via the online survey. Please note that all participation will be anonymous and you may, at any point, discontinue your participation.

Thank you so much in advance, your contribution to my research is immensely valuable.

Bij voorbaat dank  
Marije



No individuals living with dementia were interviewed. This was intentional, based on an assumption that people writing euthanasia requests for dementia do not yet have dementia but base their request on their personal experience of the disease in their loved-ones. Much time was spent trying to confirm this suspicion but sadly no research has ever been conducted to see why people are indeed requesting euthanasia in dementia. In a quest for this information contact was made with Marc van Toor from the Disciplinary Court for Healthcare [Tuchtcollege voor de gezondheidszorg], who responded:

*“No research has been conducted into this phenomenon. However the RTE can conclude from the dossiers based on reports from SCEN physicians that requests often come from the fact that those requesting euthanasia have experienced the effects of dementia up-close and based their decision on this: I don’t wish to experience that.”*

Bert Keizer, the SCEN physician who participated also stated:

*“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.”*

During the recruitment process, future participants received contextual information via email about the research to help them decide whether they wanted to take part. The introduction to these emails were personalised to the participants, but the research information was as shown in Figure 5.7.

5.2.2 Ethics

The survey was developed online and all responses captured in writing. During the recruitment process, participants were informed verbally and in writing what the research was about (Figure 5.1.), and before entering the survey participants signed an informed consent form approved by the Loughborough University Ethics Committee. All interview participants were (audio) recorded and signed a paper copy of an informed consent form approved by the Loughborough University Ethics Committee (Appendix B). No ethical concerns were raised by the Loughborough University Ethics Committee, because no vulnerable parties were interviewed, all participants were cognitively competent adults. Some individuals were explicitly asked if their name could be used, for example when their professional role could add weight to an argument, if this was consented to verbally in the interview then names are used in this research (Table 5.8.).

Participant	Expertise	Experience with dementia	Age	Survey	Interview	Consent
A	Researcher	Personal	40-50	Partially: 18 Sep 2017	In person: 17 Aug 2018	Anonymous
B: Bert Keizer	SCEN + geriatric physician, author	Personal and professional	70-80	No	In person: 6 Jun 2018	Name can be used
C	Palliative carer	Personal and professional	70-80	Partially: 2 Sep 2017	No	Anonymous
D	Business owner	Personal	70-80	23 Apr 2018	No	Anonymous
E: Enzo van Steenbergen	Journalist (NRC Handelsblad)	Professional	30-40	1 May 2018	Skype: 23 May 2018	Name can be used
F	Designer / business owner	Personal	40-50	2 May 2018	No	Anonymous
G: Henk Blanken	Author, journalist (De Correspondent, The Guardian)	Personal and professional	50-60	3 Sep 2018	Skype: 3 Sep 2018	Name can be used
H	Innovatrice in healthcare	Personal and professional	30-40	14 Apr 2018	No	Anonymous
I	Artist	Personal	40-50	4 Jun 2018	No	Anonymous
J	Designer / researcher. Organiser Dementia Lab Conference	Personal and professional	30-40	No	Skype: 11 Jun 2018	Anonymous
K	Designer / researcher	Professional	20-30	3 May 2018	No	Anonymous
L	Designer / researcher	Personal	20-30	7 May 2018	In person: 17 Aug 2018	Anonymous
M	Ethicist / professor	Professional	50-60	4 Jun 2018	In person: 5 Jun 2018	Anonymous
N	Consultant	Personal	80-90	No	In person: 3 Jul 2018	Anonymous
O	Legal assistant	None	40-50	2 Jul 2018 excluded		Anonymous
P	Designer / professor	Personal	50-60	12 Apr 2018 excluded (UK)		Anonymous

Figure 5.8  
Table of participants



Conceptual framework

- **Suffering**  
Responses related to assessing suffering as well as attempts to define suffering and perceived suffering.
- **Autonomy**  
Responses related to the right to self-determination, personality and decision making on behalf of a person who made an advance euthanasia directive.
- **Timing**  
Responses related to choosing a time of death.
- **Planned death**  
Responses related to receiving a reliable diagnosis and the idea of choreographing death.
- **Design**  
Any responses related to the method used (showing videos and visuals to trigger discussion), were coded here. This would include new ideas to develop further and critiques on the ideas provided.

Open coding

- **Participants**  
Pre-determined ideas based on previous experiences.
- **Burden**  
Responses related to the idea of being a burden separated from suffering of the individual with dementia, the burden on others, and the shared burden of dementia.
- **Others decide**  
Ideas on who can play a part in the decision-making process of choosing a planned death in dementia.
- **Physician’s needs**  
Performing euthanasia is hard. When is performing euthanasia acceptable?
- **Improving the experience of living with dementia**  
If the conditions of living with dementia were better, would less people request euthanasia?
- **Good death**  
Ideas on what would be a good death in dementia.

Compare and contrast

- **Suffering vs Burden**  
Pre-determined ideas based on previous experiences.
- **Autonomy and others decide**  
Responses related to the idea of being a burden separated from suffering of the individual with dementia, the burden on others, and the shared burden of dementia.
- **Designing death**  
New ways of thinking about the process of dying.

5.3 Analysis

All survey responses and transcribed interviews were collected in Nvivo software for analysis. Responses and transcripts were first coded thematically using the conceptual framework derived from the literature and based on the objective of this research *Can design be a useful method to further the euthanasia in dementia debate?* (5.3.2). Next ‘open coding’ was applied to allow for new themes to emerge (5.3.3). Then the emerging themes and conceptual framework were linked together in a theoretical model to compare and contrast codes (5.3.4). All codes are listed in table 5.9.

5.3.1 Coding

The hierarchy between the codes can be seen on this Nvivo mindmap (Diagram 5.10). All codes can be seen through different perspectives; the patient; the carer or loved-ones, as well as the method used (design).

5.3.2 Conceptual framework findings

The questions that the participants were asked were developed through the synthesis of the systematic literature review (Chapter 2). The themes that were derived from this literature review also form the initial conceptual framework to start to interpret the data collected. A substantial amount of the data collected fits into this conceptual framework, which is no surprise as this would count for the responses to the questions that the participants were asked.

There was no consensus on what suffering was in dementia, how it should be defined and who was actually suffering (5.3.2.1). Through discussing ideas on autonomy, doubt was spread on those who felt strongly about the right to self-determination. If self-determination would not be possible, who would be best to make decisions about people living with dementia (5.3.2.2)? Who would make decisions and

Figure 5.9  
Table of the different types of coding

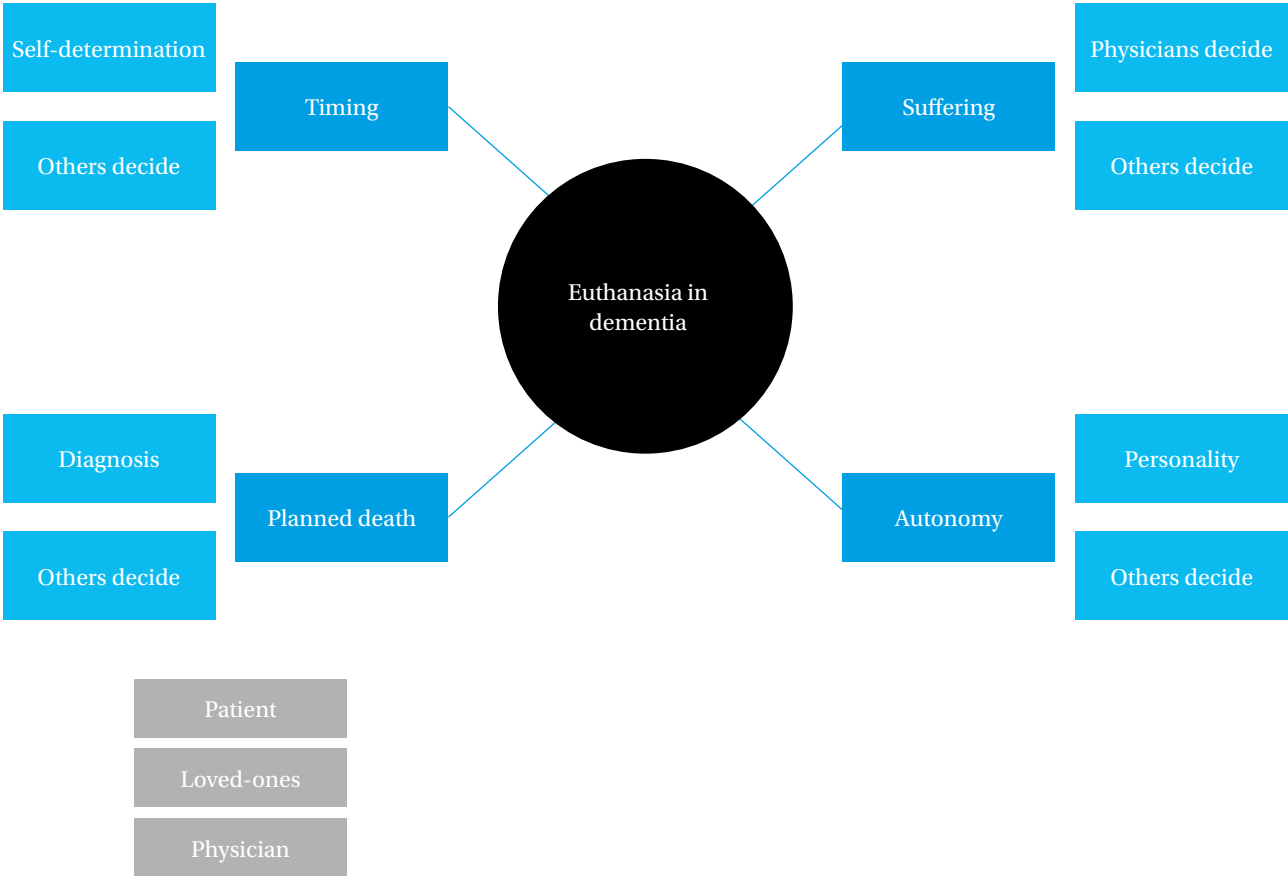


Diagram 5.10  
Nvivo mind-map visualising the conceptual coding

the timing of decisions leading to action was another point of conversation (5.3.2.3). Various ideas on planning death instead of a natural death and what this could look like were talked about (5.3.2.4). And, if this way of stimulating discussion through videos and visuals was useful is described (5.3.2.5).

5.3.2.1 Suffering

Much conversation was about suffering or quality of life in dementia. The conversations were triggered by the video about Assessing Suffering showing the story of Jan Andela, whose data were being tracked through personalised jewellery and who had assigned a ‘quality-of-life team’ assessing his physical, social, psychological, and spiritual quality of life. The video investigates ways to measure quality of life if the individual in question can not do so themselves.

5.3.2.1.1 What is suffering?

In trying to establish what is suffering is like in dementia, quite a clear picture emerges that suffering in dementia expresses itself more in an existential manner. Participants listed loss of dignity, fear and hopelessness as loss of quality of life.



D: *“Loss of decorum, no longer having a grip on things, depression, fear.”*

Some participants used themselves or their experience as an example in trying to give shape to what suffering in dementia might be:

L: *“[...] she would blackout and she would start taking off her clothes or she didn’t know what she was doing and then after half a minute she would be back and then she had no idea what happened, and my grandfather would – he got a bit annoyed with her “what are you doing, we have a guest, why were you undressing yourself?” and she would be “I didn’t undress myself!” and this was really scary, then you start to see. Because she always said, “I feel so bad inside, it’s not physical but more mental”, which could be affecting your physical wellbeing so much, she couldn’t really pinpoint it, her whole – this – [pointing at her chest] was always so painful, and she said “over time I black out, this is pain”, and then you see it.”*

5.3.2.1.2 Who is suffering?

This often leads to the question of who was actually suffering in dementia, was it the patient or the loved ones? In the case of the criteria “if I can no longer do x, or remember y” does this in fact cause suffering in the person with dementia or the loved-ones?

B: *“But we hesitate, take someone who was a really good drummer, and in his dementia he can’t play drums anymore, but he never mentions it, and the family would say “he can’t play the drums anymore,” but the drummer says “so what?” He doesn’t even know what a drumset is.”*

One participant talked about his sister and not knowing if she has any awareness at all:

N: *“She used to be a singer, she sang all sorts of music, if I sing to her, there is a response, a happy response. But other then that, nothing. You can take her for a walk, and words may be spoken, but you have completely no idea on what is going on. I have a sort of a key which I can use to touch something, and I know that is embedded deeply and that will respond. But if you are stuck in a wheelchair for 6 years, can’t move, I think it is awful. I think it probably worse for me, because she doesn’t even know.”*

Another participant relays an anecdote about two daughters he interviewed about their mother’s euthanasia in dementia:

E: *“I spoke with them at the time when the mother was still alive, so in that interview they said “for us it is getting harder, but we are not at all sure if mother is actually still suffering from the dementia.”*

This idea of suffering on behalf of the other can also express itself in where responsibilities lie as described in this anecdote by the same participant:

E: *“I had a chat with a lady, she was about 80, and her husband was quite outspoken about the fact that he wanted euthanasia if he would show any signs of dementia. But once that did happen, he never mentioned it again. And she was very unclear about whether it was now her responsibility to mention it again, to mention “right, it’s time”, or “do you remember what you requested?” She never did mention it again, because she felt that it wasn’t her role, while, maybe, she would have really liked to discuss that with him still. Some fear there too. Then the husband lived for another 6 years in a care facility, which the wife felt was terrible, he was having WW2 flashbacks and every day he was hiding under the table and was super scared because the Germans were coming. So she did often think if she should not have interfered when it was possible.”*

5.3.2.1.3 Who can decide if a person with (advanced dementia) is suffering?

In asking participants to assign people who could assess suffering answers were not clear cut.

Some listed potential people who they felt could do this:

I: *“Friends and the GP and or psychologist (I think family members might have too much of an emotional and even monetary stake).”*

F: *“Family, friends, psychologists. But this is so tricky, hard, if not impossible for those who are assigned to make such a decision.”*

But most were not sure and described a rich tapestry of complexity and interwoven lives, and made suggestions on how quality of life might be assessed:

H: *“The example in the scenario [of Jan Andela] sounded nearly too perfect to be true. If every individual would have a social network as close and stable as the fictive gentleman in this story, I would be happy to say “this sounds like a good idea”. Knowing life, and families how they really are, from both qualitative literature study and life experience, I must say that who should be involved in assessing quality of life should ideally be chosen by the individual on one hand, but on the other hand, not every person has actually people close to oneself that she can trust, and in some cases people are over-trusting in others in a way that can be harmful for their wellbeing, if based on this misjudgement life and death decisions are being made. Hence I feel that a life-training of self perceived and self-chosen values over a life time should be part of it. An assessment with the individual what matters to him/her the most in life – something which can change over time – should be part of the decision making, rather than putting it into the hands of others from the own social circle. This, in combination with objective vital signs and emotions measurement and with the judgement of an ethics committee of independent people that are trained in the area of ethics, but then chosen also based on the life values of the individual could contribute.”*

N: *“Well, if you think about it. It is about living, and thus it is also about living together. I don’t think you can say this, purely for yourself as one individual. Now the law says “unbearable suffering”, and that eliminates entire families, but if you take this route [the Assessing Suffering video], you make this choice “do I end it or not”, in a responsible manner, then you are not doing that alone.”*

Others were more certain in their response:

K: *“People who have had a lot of experiences with the individual in question, who are able to see in context how much someone is suffering. Additionally, it should be more then one person, no-one should make such difficult decisions alone. The decision of this group must be unanimous. The group must be guided by experts, to prevent loss of friendship. The person in question would never have wanted people to start fighting.”*

Participant G feels strongly that he should be able to transfer the decision to his wife, as she is the only one who can decide about his happiness:

G: *“But what it still is about, physicians say, I don’t want to do it at that stage because we do not decide about happiness, we decide about suffering, and we don’t know if that man is suffering and wants to die, which is why I want to transfer the decision to someone who can decide about happiness.”*

5.3.2.1.4 Preventing suffering

A few suggestions arose about ways that suffering in dementia could perhaps be lessened. One example was mentioned about specific therapies focussed on reducing fear:

H: *“Level of fear and anxiety, on a state and trait level of the individual should be taken into account as well. What if a dementia-fear focussed therapy, maybe driven by positive psychology instead of problem solving clinical psychology could help people to accept the unknown future – which seems to consist of suffering alone in one’s own forecast of the future to come with dementia.”*

If euthanasia should be a rational choice, then participant J feels that the first step is make sure there are no other, better options:

J: *“One can only provide euthanasia as an option, if there is a reasonable alternative: good palliative care, only if these two are balanced. [...] What if we say, what if the family says, you have earned your care, you have cared for us your entire life. Would it then be different, that is what I wonder, I actually don’t think so, but I do wonder.”*

5.3.2.1.5 Summary on suffering

Clearly there are no solutions to how suffering can be assessed and who should be doing that. What is apparent is that suffering in dementia is very real, both for the future patient (fear of suffering), and the loved-ones. Anecdotes also suggest that people with advanced dementia can be seen to suffer, though there is no obvious evidence of that. Perhaps if there was better care for advanced dementia and the negative image of this disease can somehow be lifted, a different picture could emerge.



5.3.2.2 Autonomy

Autonomy, the right to self-determination is valued in Dutch society. In principle, the right to decide about yourself seems relatively straight-forward, however discussions around the scenario of the Plug (4.3) made clear self-determination is not quite so simple.

First it was important to discuss what autonomy actually is or how it is perceived. It became apparent that true autonomy does not exist and because humans are inherently social beings, the actions of one person will affect others. One symptom of dementia that makes the right to self-determination so terribly complex is personality change. Whose right to self-determination are we actually talking about? So, who should be making the decisions when it comes to euthanasia in dementia, can it be the person themselves, should it be others, or could a non-moral entity do this? What would be the conditions for euthanasia and how could these conditions be ‘programmed’?

5.3.2.2.1 What is autonomy?

Not many participants tried to define autonomy, but the fact that it is a complex idea does become apparent. Bert Keizer writes about autonomy in his book ‘Voltooid’ [Complete] (2018) and explains in the interview the problems around the notion of autonomy:

B: *“Autonomy is the protection of your own personal space amongst others, you could never be autonomous without other people. Only on the moon there is true autonomy, but then there are no traffic rules on the moon either. So autonomy can only exist in context of others. We can give each other space, well ... so you are in the group, and you want to get out, but this is a decision you can’t make without the group, so, if you ask, do you think other things are important besides patient autonomy – absolutely, the autonomy is important, and the way the patient executes this autonomy, that is what is important.”*

The ethicist also made clear true autonomy does not exist:

M: *“A truly independent perspective on one’s (future) life with dementia is obviously an illusion. The perceived value of one’s life with dementia, is not independent of relations (of care) and how they are put into practice, organized, and maintained.”*

Most lives are not solitary and our actions have consequences. How important are these consequences, and how can they be considered?

B: *“The fun of your existence, at least if things are going well, is that you live with other people, that are aware of you being alive, and so on. Right?”*

L: *“But also, I understand, when you have a family, you cannot just ignore all the connections you have with people.”*

5.3.2.2.2 Who is autonomous: Personality change  
If autonomy is primarily about the ‘self’, and the ‘self’ being able to make decisions about the ‘self’, what happens if the ‘self’ changes?

J: *“The Plug starts from a splitting of the ‘I’ that was, before dementia set in, and the ‘I’ that I am with dementia, and the ‘I’ that I shall become as the dementia progresses. My problem with this is, if you that that splitting in three, the original ‘me’, the diagnosed ‘me’ and the demented ‘me’, when we talk about this Plug, which basically ‘turns off’ the system, shall we say, then this is from the perspective of the ‘me’ of then, the ‘me’ before the dementia, that ‘me’ is looking to the ‘me’ in the future. (...) What I find hard is this splitting the different ‘me’, then, now and into the future, and to define what should happen to the person now, or in the future, from the person in the past. Because the person that was, and the person in the future, the only question you could ask then is, does this future person not have any decision power anymore? And does the future ‘me’ have no rights to decide about the current ‘me’, or to debate the past ‘me’? The big problem is that there is no way to facilitate this debate, and we have no idea how to hold this debate, and then I keep getting stuck in my reasoning.”*

A: *“I mean, logically I would say, yes of course, of course the choices that you take before [you are sick] are more valuable, but the choices you have taken before also are taken before you have first-hand experience what it means to be sick, so that’s the tricky part.”*

E: *“It is complicated, because you can’t reason, and you end up at the question “Who am I?” And what counts? And for whom? The new person, or the one you once were?”*

One person was not so sure that personality change necessarily occurs in dementia:

M: *“Another issue is the concept of selfhood implied in this video, which suggests that a future self is necessarily disconnected from the present self, that is supposed to be gone, a body left behind. I think this view is contested. Another assumption is that someone with dementia is no longer capable of expressing their own values and appreciations. Legally that may be the case, but I think this is another matter of dispute (at least not such a black and white cut off point as suggested).”*

5.3.2.2.3 Who should make decisions about end-of-life in dementia?

Participants were divided on this issue, it was very important that the patient would have a say. Some felt this was the only thing that was important, others felt that it was not only the patient who could or should be allowed to have a say, as their death would affect others and these others therefore are also stakeholders. Additionally if the patient would be unable to make decisions, others would need to have a much clearer idea on their wishes – even though these might change.

**The patient should make decisions**  
Some were clear that it would always have to be the patient themselves making a decision about their own death.

I: *“I think euthanasia should be lot easier in general. In the case of dementia I feel the patient should be able to request (demand) it in any stage of the dementia. So also when dementia hasn’t presented itself yet. And patients should be able to determine the level to which the quality of their life has to have deteriorated in order for euthanasia to take place.”*

E: *“I think it is obvious that someone at time of death must be able to confirm their death wish, even though this is hard in dementia.”*

C: *“The patient should be cognitively sound at the time the Plug is implanted [...] ideally this would have been a well considered request that was discussed with others, but ultimately the patient does not need to ask for anyone’s permission.”*

Leaving the decision up to the patient removes the responsibility of such a decision from others. Loved-ones may feel strongly about this decision, but having a say in it is complicated as is illustrated in this anecdote by Bert Keizer:

B: *“... a few months after her death I run into one of her friends, from her social circle, she had a rich social circle. And I asked the friend “how did you feel about it”, she said “I thought it was awful”, so I ask “why?”, “well, I thought she could have waited”, you know. But this is something you are scared to say, because the person in question is suffering enough, she is asking to die, that is how bad it is, and then you can’t budge in and say “but what about me?”, there is no space for that. I have heard that several times, that people find euthanasia awful, but are afraid to say anything, because then you really break all the rules. It is hard enough for her, and then you rock up with your problems.”*

**Others should make decisions**  
If others should make the decision for euthanasia in dementia, often in the case that the patient themselves is no longer capable, who would be able to take this responsibility and how they would be able to take this responsibility is a subject of much discussion.

If the patient transfers this decision to another, do these others have a responsibility in executing this wish? Some felt that this was the case:

L: *“If my grandmother would have dementia, and she would have had this wish before she got dementia, clearly written out, “do this when I have this” then as a family, you are responsible for her death in a way, because she has asked, wrote down “when I have dementia I want to have this, so I give you the responsibility of doing it because I cannot handle it” and I think then you have, as a family, maybe the last word in when it happens.”*

**A non-moral entity making decisions**  
Decision making for end-of-life is hard. Not many people really want to take the responsibility for these kinds of decisions, besides the person themselves. What if the (future) patient can ask a machine to make this decision instead? This is the scenario of the Plug, and opinions varied on how people felt leaving the decision on ‘pulling the Plug’ up to a machine.



Some felt this could be a good solution:

I: *“We do this all the time, anyway [...] Giving your (quality of) life over to a machine or device is nothing new.”*

A: *“I am pretty sure that I would install the plug on myself. It might be easy to say, because it is a decision that looks far into the future at the moment. However, I think it is brilliant. The big fear would be that the plug activates the process too early, for mis-functioning or for mis-reading of the cues.”*

E: *“I did think it was an interesting thought. Because indeed you transfer the responsibility to a machine, and something objective. But then, isn’t that actually better than leaving this responsibility with a physician, who can be hugely affected by making such decisions?”*

H: *“While I am generally more of a nature loving person, here I believe that there are advantages in technological developments.”*

Others were not so sure:

F: *“Ethically this is not pleasant. Some sort of bomb in your body. I think people would become pre-occupied with this once they would have it implanted. It would be different if you could remove it at any time.”*

G: *“Because the thing we fear in dementia is the dehumanisation, and this Plug, or something outside of us, is the ultimate consequence of this dehumanisation. So it is fighting fire with fire.”*

L: *“The technology can become something that does not increase the autonomy of a person, but it undermines it in a way that other people start to get ownership of what you can and cannot have.”*

5.3.2.2.4 Criteria for advance euthanasia directives

In discussing if or how The Plug could work some thought went into what kind of criteria one would programme to trigger the Plug. These kinds of criteria could be useful in advance directives.

G: *“The conclusion I came to in the end was that the norms should not be medical, but besides that what would it measure? I remember sitting with my friend in Amsterdam, in a restaurant, and I was asking “Bas, what does this thing measure?” what he said was “Happiness”, “Bingo” I thought! That was of course beautiful.”*

Some participants felt it would impossible to programme the conditions to trigger The Plug:

B: *“Of course I disagree, of course you can’t specify your circumstances, that is impossible. It won’t work.”*

D: *“It would seem complicated to define the right circumstances that could determine the right time. It could happen, like in the newspaper article, that family or friends think the Plug acted too soon ... still, it is good if it acted on previously programmed criteria. This is what the person decided when they were completely healthy.”*

Participant F tried to define what kind of conditions could trigger The Plug, perhaps banal activities such as making coffee:

F: *“If it would all go according to plan, this man [referring to the BBC newspaper article], this man would be unaware when the moment would come to pass. Assuming you would programme this Plug to the moment you lose contact with the world around you and yourself. Then the question would be, how would you programme the conditions for this to work? For example, if someone can’t remember how to make coffee, or is getting lost?”*

Participant K was concerned about how certain conditions could be mis-interpreted:

K: *“I was wondering, what would happen if someone was just having a bad day? If you would just have a bad period because of different circumstances, would that also activate the implant? I also find it hard to imagine how someone would describe the conditions for activating the Plug.”*

Even without changing personality, one could change their mind, would you be able to unplug The Plug?

H: *“A person making a decision about which criteria should be in place to end one’s life when implanting The Plug could change one’s mind based on other influences, changes in life and love etc., which are not predictable in the moment of implanting it.”*

K: *“Would it be possible to change the conditions? How does it activate? Would there be a warning so there would be an option to say goodbye?”*

5.3.2.2.5 Summary on autonomy

Autonomy is a complex notion that may often be misunderstood. Some participants tried to make clear how they understood the concept of autonomy. True autonomy would be unachievable as humans are inherently social beings, and what one person does will affect others. How this affects others, and what responsibilities others have on this effect is unclear. It would seem that these others would very much like to respect patient wishes, but knowing a patient’s wish after personality change has set in is impossible.



5.3.2.3 Timing

Making a decision for euthanasia in dementia is complicated. Deciding the time euthanasia should take place can be even more complicated. Currently euthanasia in dementia occurs extremely rarely in the late stages of the disease, and more commonly in the early stages, when the patient can still confirm their euthanasia request. The timing issue arose in discussion of all the scenarios and referring to the timeline helped to direct the conversation.

Discussing the timeline graphic with SCEN physician Bert Keizer, who does make decisions on when euthanasia will take place, he suggested the ‘window of opportunity’ could be extended a little:

B: *“I think the window could be a bit bigger – I have helped people a bit later on. I would have to remind them who I was, what I came to do, but they did retain that information and are aware. Then I make them a drink, no injection.”*

5.3.2.3.1 Too early

Euthanasia in dementia is possible in the early stages of the disease when the patient can confirm their request for euthanasia. It this stage there may not be any suffering besides fear of the future. Many feel that this stage is ‘too early’.

Much discussion was about what would be ‘on time’, for Bert Keizer, the SCEN physician having to perform euthanasia, this early stage would be ‘on time’. In a comment on The Plug, feeling that if you would get The Plug, you might as well just do it yourself, the fact that this would have to be early could be overcome:

B: *“This we can solve with proper early diagnostics, and a little personal bravery. But I can completely understand that people say, I will just wait a little longer...”*

5.3.2.3.2 On time

Participants struggled to define what the right time would be and how to determine it.

D: *“Euthanasia should be possible [in dementia] because it is inhumane [dementia], but I think it is hard to decide the moment. You would probably keep postponing this moment. Especially if you already have dementia symptoms. It is probably equally hard for others (a physician, child, partner etc.) to decide the right time.”*

In this example it seemed that the conversation on deciding the ‘right’ time was ‘on’ time:

N: *“Well, you are trying to find ways for a dignified end, to say goodbye to life in a humane manner. When is the actual moment that this possibility passes? Incredibly hard to measure. You can’t possibly calculate all the different ways, but what you could say is that this person was absolutely sound of mind, and made this choice, in conjunction with family. That is important, not doing that alone. And if it happens like that, I think, this is a good decision. What happens after is what happens, you have made your choice. Our GP asked us this question, “can you please ensure that you make clear what you want, if the time comes”. And we chose palliative care, my wife was already sick, but very sound of mind.”*

This participant tried to determine a criterion:

A: *“I remember when my grandmother was ill, people around her kept on saying “she is not herself anymore”, so maybe that is the point, when you are not yourself anymore. But that is very difficult to judge, what is ‘yourself’? But then at that point I might want to have that possibility...”*

Only one participant was clear when ‘on time’ would be:

G: *“On time is when my life does not contribute to the happiness of myself and my loved-ones.”*

He was aware that he would not be able to decide this time himself in dementia, but his wife would know:

G: *“If I, in her judgement, am not aware of who I am, where I am, how happy could I be? If I am clearly confused, or scared, that would count. But if I am nothing, then maybe not, but then of course I wouldn’t care if she decides to let me live for a short time or a long time, or if she says, right, it’s been good but it is time. Depending on what she is able to and what she wants to, or what the family asks of her.”*

If one could forecast future suffering, then this would help determine a time of death:

H: *“Other aspects in here are both the reliability in forecasting perceived future suffering (how can I know how much I will suffer under dementia when?) as well as determining the timing of ending one’s life, in that very context.”*

There are times when families can work out the right time, together, as is described in this anecdote:

B: *“I know one case ... her husband has dementia ... and her brother – these are rather well educated Dutch people, and they follow this dementia process, the husband and brother in law, and the kids as well, they did manage to, in a period of three years; to figure this out, together. And it concluded in an assisted suicide. In collaboration with the GP. The GP brought the stuff ... took them three years. But they were scared ... the hour. The daughters were more strict. The wife and brother in law didn’t really want to push and say “John it is time ...”, but the daughters, cool huh, the young ones did have the courage. They managed to convince the mother and uncle to, together, tell the father, and they managed. A period of three years it took. Every month they would meet, they had a wonderful wine cellar, that kind of milieu. So they would drink wine, and discuss.”*

5.3.2.3.3 Too late

For some it was clear to know when the right time had passed:

E: *“What is hard is when that moment is, the exact timing. When is the moment that someone is suffering unbearably. What you often see with people who are dealing with this, usually the partner of a person with dementia, who knows, this is a person who would prefer euthanasia, but these people never really know when the moment is that action is required, because we do know – at some point I was interviewing a family; two children – who mentioned “our mother” she was in a care facility... and they had missed the opportunity, when the mother would have been cognitively capable to make decisions about what she would have wanted – she was in quite a late stage – and at some point is was getting more and more difficult for them [the children], but they also said to each other “for us it is getting harder, but we are not at all sure if mother is actually still suffering from the dementia” and they told me “that moment, we have been unable to pinpoint when that moment arrived, the moment when she still did, or did not, suffer from her illness.”*

5.3.2.3.4 Summary on timing

Many would like euthanasia in dementia to be possible beyond the early stages of the disease. In later stages of the disease almost all agreed that at this point the patient themselves would no longer be able to decide if the right time was there. Some ideas on what would be the right time were indicated. Happiness and quality of life could potentially be assessed by loved-ones.



5.3.2.2 4 Planned death

In order to be able to plan a death in dementia one would need a reliable diagnosis, especially if euthanasia is only possible in the early stages of the disease, it would be important to base this decision on a reliable diagnosis, because the symptoms of dementia might not be obvious yet at the stage where euthanasia is possible.

5.3.2.4.1 A reliable diagnosis

A reliable diagnosis would help to start a conversation between a patient and loved-ones about end-of-life preferences:

E: *“Right, that is another type of responsibility. I don’t think we have reached an ideal stage yet. Not only is the diagnosis late. The conversation around the issue [what if] is also starting far too late, between patient and physician as well as within the family. This can still be quite a taboo subject. You would want it to be possible to have such a conversation within your family, that you would able to tell each other “what is it that you want” and “how” and “what is the time that you don’t want to go on” and “how will you let us know?” I don’t think many people have conversations like this. At least I haven’t heard that, that people are open about this. This could certainly be improved. I think it has to do with it being a taboo.”*

Even though diagnoses often come late, there is hope, and dementia diagnostics are improving:

B: *“Early diagnosis is getting better and better. Biologically and anatomically. The diagnosis of dementia is a kind of cluster. The most important diagnostic informant is the flatmate. Same as with being deaf. They tested and measured me with an audiogram, but I am driving my wife nuts. So that is your best audiogram. In dementia it is the flatmate. (...) But flatmates want a technical diagnosis. When we are talking anatomical markers [inaudible] atrophy, that has been mapped very well, diffuse brain damage, and the other is the protein ratio, which is quite indicative for Alzheimer’s.”*

Receiving a diagnosis too late can mean that patients do not trust this diagnosis any longer because symptoms of dementia can cause paranoia:

B: *“Yes, that is typical in dementia. “I am not demented, you are all hiding my keys!”*

Participants were quite clear on what kind of information would be useful in such a diagnosis:

D: *“Objective test results on the stage of the dementia.”*

E: *“The speed of cognitive and physical decline.”*

K: *“I would like to know how much time I would have, and how much decline there would be in this period, which would allow me to also plan for fun stuff.”*

5.3.2.4.2 Who is involved in deciding if a diagnosis is needed?

People who should be involved in receiving a diagnosis were not necessarily the same people who were involved in deciding about euthanasia in dementia. The test itself was seen as a purely medical responsibility, however the consequences of receiving such a diagnosis did require a support network for most.

Most participants listed who they thought should be involved in receiving a diagnosis:

E: *“Medical specialists.”*

F: *“Loved-ones, patient.”*

H: *“The individual herself..”*

I: *“Only the patient and who they feel should be a part of it. Anyone should have a right to do the test.”*

K: *“A medical specialist should decide if a person has dementia or will develop. The person who the diagnosis is for should be able to decide if they want to receive the diagnosis.”*

A: *“Your own choice, but I would say that it is something that is supported by professionals that know how to deliver a message and know what people do, might do, attempt to do with the replies that they get, and are professionally prepared to deal with the consequences.”*

One participant was not happy about the idea that a commercial company would be involved in diagnostics (as suggested in the Planned Death video):

M: *“As soon as there is a commercial company involved in early diagnostics or even a do-it-yourself kit in this game, the discussion is on the loose because of the dangers that are inherent. For example, false positives or negatives, the interpretation of an ‘objective’ result, potential pressure of society on the need to take such a test, and so on...”*

5.3.2.4.3 Requirements for diagnosis

Some participants spoke about what should be considered for receiving such a diagnosis for the people involved. H stresses that receiving a diagnoses should be a well-informed decision.

H: *“For receiving a dementia diagnosis, considered should be education and psychological support. What does it mean for me, for my loved ones, and the rest of life. Education not only at point of care in the moment of diagnosis, but also before (to decide whether one actually wants this diagnosis and is ready with dealing with the consequences of knowledge) and also afterwards, in the weeks and months thereafter, including discussing whether end of life decisions are something that one wishes to take on, or prefers to leave it to the nature of the disease instead.”*

M argues in the same vain, what could be the unintended consequences of receiving a life-changing diagnosis:

M: *“Looking at known tests, reasons could be “at least we know for sure it will be a healthy child” as a comfort measure, but that does not consider a medicalised life, additional stress about a desired outcome or even the possibility that there might be an undesired outcome when new decisions need to be made. And for those that do not test there is such a thing as ‘anticipated decision regret.”*

K reasons that this is a decision that requires support:

K: *“I would not like to know this too far in advance, because I would live in constant dread. There also needs to be a good support system in place for receiving and post diagnosis.”*

It is also important to remember that having a diagnosis did not necessarily mean one could only plan death, but also life:

M: *“If you can diagnose dementia, then based on that diagnosis there is more then one option, not just planning a good death, but also a good life with dementia.”*

One participant had a new suggestion for how a diagnosis could play out:

J: *“If I think personally, I think I would not want to know, so I am not going to try and answer this rationally, you can not respond to this rationally, so if I look at it emotionally, I would look at myself, and I would say it would be better not to know at that time, but you could say, “give it to a physician of whom you know that they could follow you your whole life, and who decides when it is time to inform this person”, and there would be certain times, if it is early-onset ... then it could happen at any time ... perhaps we can see small signs, and that would signal the time to start discussing this with person x. So I would certainly see this responsibility with professionals, if you would give this responsibility to the family, what a weight would they have to carry, so I would do it that it is announced only when the first signs start to show, and then start the support on how to continue. Now we are in the beginning phase, and we will work together to see how we can proceed, you are still cognitively capable to help decide a path for yourself. But to say it age 35, 45 or whatever and say, “within 20 years there is a big chance”, in my case, not rationally, in my case this would cause immensely negative thoughts, and I would focus too heavily towards that moment, and I might just die in a traffic accident or something. This would be my problem with it. And a good way to announce it, I think this has everything to do with relationships, I think it can only be done by a professional with whom you have a good relationship.”*

5.3.2.4.4 Summary on planned death

A reliable diagnosis is useful for considering end-of-life options in dementia, and are becoming more likely. Receiving such a diagnosis can be problematic and support is recommended. Support could come from medical professionals with additional support from social networks. Making an informed decision about receiving a diagnosis is sensible. The best time to receive such a diagnosis was not clear.



5.3.2.5 Findings on the designs

The questions in the survey were based around the scenarios presented and in the interviews the questions asked were also in response to the videos and the timeline. Participants were asked if they felt that the scenarios and the timeline had stimulated the discussion and had helped them to formulate ideas. Participants were very happy to have the designs as a starting point for conversations, it helped them to get in the right frame of mind, and also to formulate their own opinions. The designs were set up as thought experiments, and they were recognised as such:

B: *“Well, you are talking about, in three different ways you discuss the possibility to do something, about something that we feel very uncomfortable about. What can you do with this dementia? Keep going? Suicide? And everyone is stuck there, and people find it hard to develop an opinion. But you don’t present them as a solution, but as a thought experiment.”*

Participant J describes how the design helped him by making the issues more personal:

J: *“It is much better then just describing a few ethical questions and asking how you would relate to those, yes, I think this is a much more powerful way. It definitely touches you.”*

Participant N found the contextualisation provided by the designs helpful:

N: *“In this case you are doing stuff with full consciousness and eye for the circumstances and you try to gain wisdom from this.”*

Henk Blanken was charmed by how the designs helped to make the different perspectives clear, which is why he liked to have some of the designs to support the public debates in Pakhuis De Zwijger (6.1 and 6.2):

G: *“I think it is great research you do, I was immediately intrigued by the idea, your videos, they work really well to get the discussion started. And to make different perspectives clear.”*

Participants did feel that it was important to present these scenarios in context, and they emphasized that prior knowledge of dementia and euthanasia would be required. Bert Keizer expresses some concern that some of the designs could be alienating, and would require careful introduction:

B: *“Well, you prepared me for this, and I know you are thinking about this and you want to put these concepts next to each other, and do some sort of comparative research and you are, in all sorts of different ways, trying to dig in the whole mountain of dementia, and in that context, I like watching these videos. They are thought experiments, but they are quite alienating, for someone who has no knowledge of this conversation, they would be really strange.”*

Enzo van Steenbergén feels that some of the designs could be quite provocative, though he also recognises that this provocative nature is what might stimulate the debate:

E: *“Well, personally I think they are interesting, but I am very familiar with the subject matter. I think it could scare people, but that is not by definition a bad thing though, for as long as you make clear that this is fictional, a method to trigger discussion, then actually they are really good. Because if you would discuss the issue without them, it is really hard to think beyond the situation as it stands, now, and these do make you think beyond that, so that is a really good thing. You might get some angry people, but...”*

5.3.2.5.1 Responses to the design of the Assessing Suffering scenario

Some of the feedback to the designs relates to the scenarios specifically. Here, responses to the Assessing Suffering scenario are discussed. The Assessing Suffering scenario was developed to help participants imagine other ways of measuring quality of life. The scenario presented was a rather optimistic one, and in that sense could invite criticism too. Overall this scenario helped to move beyond traditional ways of measuring suffering. Participant M, the ethicist, felt it was good that Jan Andela was supported by a variety of people:

M: *“A good idea to give Mr. Andela a voice, sensitive others that can function as antennas, picking up signals that can be expressed in care around well-being and that could*

*articulate a death wish in a legal court. The name ‘death companion’ is quite good, even though they won’t follow you. I like the relation subject; they won’t leave him alone in these dark times, but then maybe if they are there for him his suffering might not actually be so bad. Whether he is unable to experience his quality of life, as suggested, can be discussed; expression and evaluation is a different think then objective judgement.”*

Participant J found the Assessing Suffering scenario good, because he could emphathise well with the main character, the situation was familiar to him:

J: *“the video with Jan in it, the one you named Jan, I found that one the most powerful, because, I guess I could relate, my dad is old too, so that one I could relate it to the most. [...] There you see Jan sittings and the daughter, yes, I can understand ... I thought that was really good, because you could say “is it desirable for family?” but that just doesn’t relate enough, so it is really interesting to see this speculative design way. What would also be interesting, or maybe you have done this already, to make the objects, and to take this into a group discussion, and show, “this was my dad’s pocket knife”, and this could be a different way “this is what we are developing in my Lab, and so on,” I would be curious to see what kind of results that would generate, could be even more powerful, with a certain target audience, who would be really engaged, and they experience this with friends dying, so death is an important theme, even though we dare not discuss it.”*

5.3.2.5.2 Responses to the design of the The Plug scenario

The concept of The Plug was developed as a way to develop advance euthanasia directive criteria, as well as investigating alternatives to who should act upon an advance euthanasia directive. The research did not expect that the potential existence of a Plug would be taken seriously. However, on a few occasions the primary researcher was asked where one could order such a Plug (at IEA conference in Florence), more detailed information on the technology behind the Plug (also at the IEA conference), and when this technology would become available (at RtD conference in Delft). Generally speaking people who engaged with this idea of technology being part of end-of-life decision-making were of a younger generation

(<40 years), this became clear from discussing this concept at the KNMG round-table meeting (7.3).

The idea of introducing technology as an objective player sparked the imagination in participant A, who is managing director of a company that works with developing future technologies, and works with managing the ethical consequences of technologies:

A: *“I mean, I should think about it, maybe I am saying something that I would regret, but that may actually be a nice use of technology. Instead of trying to have technology have feelings, which I don’t really believe in, I mean, you are not asking technology to make a choice, you have already made a choice, the technology is just triggering an action, performing a task, it’s clicking a button, with a delay.”*

This role of technology in making end-of-life ‘decisions’ was one that sparked concern. Some participants questioned if technology could ever be neutral:

K: *“Ultimately there is always a person responsible. Even if the technology decides the time has been reached where the wearer would have requested euthanasia, there is someone behind the technology who designed it. This is why, in my opinion, these decisions can never be made by technology alone, there has to be a human aspect in the loop.”*

Participant M, who works with technological innovations points out the mediating role technologies have:

M: *“This Plug seems a highly individualizing technology as it would avoid making others around us co-responsible for such morally impossible decisions. The Plug is presented as a neutral means in the hands of a rational subject who wants to stay in charge. But the technology plays an active, mediating role, translating existing meanings and values beyond original intentions. This role of technology should also be taken into account.”*



At other times the mere idea of presenting the concept of an advance directive as technology was immediately dismissed, which happened at the first public debate at Pakhuis de Zwijger (6.1) where Karin Spaink, a publicist, shot the whole idea down by saying:

*“The classic misunderstanding about technology that it will understand and know everything about what it is to be human. It is funny as a gimmick, but at the same time I would think, right, pffff”* (Karin Spaink, time 1:46:50).

In the context of the public debate there was much less control on how to introduce the designs, which may have contributed to this unexpected result.

The Plug scenario sparked much debate and in that sense it was seen as a useful thought experiment to open up debate:

G: *“It is good for the discussion, but that is about it I think, as actual concrete solution, even if it would work, would never happen. Not the concept.”*

5.3.2.5.3 Responses to the design of the Timing scenario

The timing scenario was presented as an information graphic and as such did not actually trigger much discussion based on the design, but yielded much more responses based on content. Bert Keizer did point out some ways of improving the timeline, and felt that the ‘window of opportunity’ was bigger (4.3.4). The timeline was photographed by many during the public debate at Pakhuis de Zwijger (6.2), and requested to be used at some other occasions (6.2).

5.3.2.5.4 Responses to the design of the Planned Death scenario

The Planned Death scenario was intentionally designed as quite an emotional scenario, and introduced some concepts of commerciality that was intended to question ‘free choice’ (4.4). Participants found the scenario quite loaded:

M: *“the last one ... the collapsing buildings ... that ... a striking image.”*

A: *“Jesus Christ, Marije, pffff – sigh.”*

Some appreciated that these triggers asked for personal responses and not necessarily rational responses:

L: *“Yes, it’s good that you specifically ask to look at your own experience because then, that is something you try to make it abstract in your head, “ok, I want to get rid of that subjective stuff”, have this recipe ready, this answer ready for any situation, but you cannot always have that for these kind of things, so when you bring it back to your own experience you start to see where the problems are, and what kind of decisions people actually have to make and how difficult – the context, that is very important, so I think that is the only way to get to understand it or talk about it.”*

Participant A describes how scenarios that do not attempt to be rational can help to gain more honest responses:

A: *“It’s a way to hack the easy judgemental patterns that we might get into, we think that is politically or ethically done and should be done and could be done, and if you access people’s reaction emotionally and experientially then you get more honest replies, more relevant.”*

Participant N also stresses the importance of personal experiences, and describes creating personal experiences in way of data collection as a process of discovery:

N: *“What you must – must? – yes, you must go the way of the discoverer “what are my experiences?” it will be trial and error. Here too.”*

5.3.2.5.4 Summary on design

Presenting designed scenarios as thought experiments helped to trigger discussion. It was good that these scenarios were not presented as design solutions, allowing participants to formulate their own opinions around the concepts. Participants appreciated the non-rational nature of this way of discussing moral dilemmas and felt that by reflecting on their own personal experiences greater understanding could be generated.

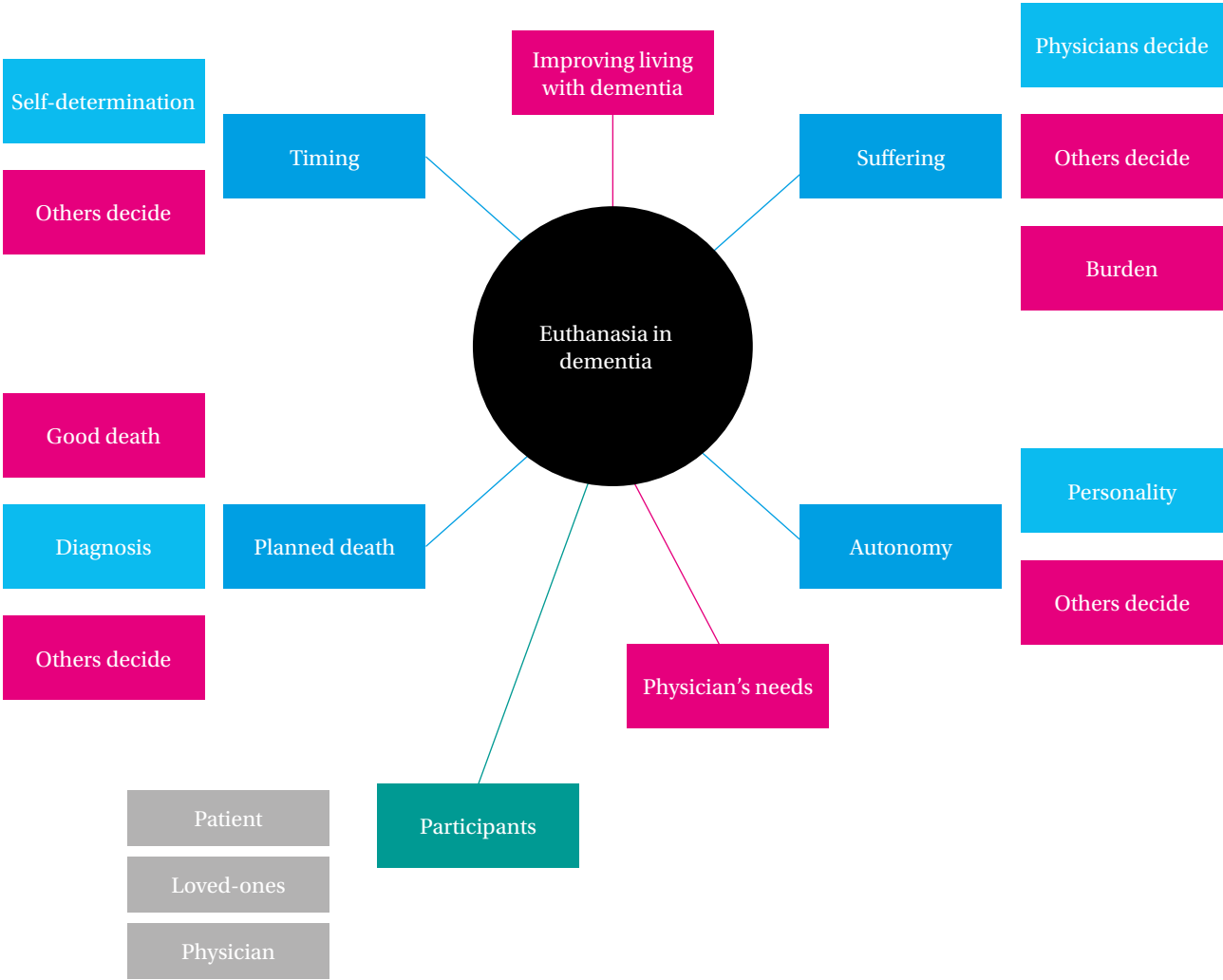


Figure 5.11 Nvivo mind-map visualising the conceptual coding in blue and the open coding in magenta.

5.3.3 Open coding

In order to avoid any preconceived ideas and to prevent influencing the data, an open coding process was applied to see what themes would emerge from the data.

Looking at the data coded into themes, and being able to analyse some of the patterns, some interesting findings emerged. It became apparent that participants already had quite strong ideas about their positions in the debate on euthanasia in dementia. This position would seem related to their previous experiences (5.3.3.1). Thoughts on suffering led to varying opinions on the theme of burden, what does this mean and how could this sense of burden be relieved outside of euthanasia (5.3.3.2). Who could decide on behalf of a person living with dementia was talked about at length (5.3.3.3). Lastly, ideas on what might be a good death in dementia are highlighted (5.3.3.4).

5.3.3.1 Participants

Through the open coding process it emerged that the participants had formulated quite strong opinions already about euthanasia based on their previous experiences. This section describes participants responses from the survey on how they felt about euthanasia in dementia before engaging in the designs. Most people felt from the outset that euthanasia in dementia should be possible, but they were aware that this was a complicated matter. Even though all participants felt that euthanasia should be an option, those who had primarily professional experience questioned the need for this option more, and the question on if we can relieve (perceived) suffering in dementia, or whether dementia patients even do suffer came up frequently. One participant often returned to the question:



E: *“to what extent do people with dementia actually suffer?”*

Another participant was wondering if better end-of-life-care would change the desire for euthanasia:

M: *“[...] and perhaps another part may have to do with lack of support, or lack of good quality care, these could be other factors that could impact the person themselves, and the surrounding as well. I think it is clear that a lot can be helped in that area.”* [...] *“Conditions are not separate from support from social surroundings, meaning that the solution need not be the individual’s choice of death. Unbearable suffering could also mean that much more effort needs to be put into making living with dementia more bearable, without thinking that is going to fix everything.”*

Yet another participant had strong feelings against the need for euthanasia on the basis of lack of palliative care:

J: *“Of course people speak from a negative perspective, because there is no option there, there isn’t enough palliative care, or the palliative care is too expensive.”*

With decent palliative care, and people still wanted euthanasia he had no objections:

J: *“One can only provide euthanasia as an option, if there is a reasonable alternative: good palliative care.”*

Additionally, people with more objective experiences were more insistent on the patients being able to decide, even if cognitive functioning was already diminished:

E: *“The best option is still that the person requesting euthanasia confirms this request at time of death, even though this is not straightforward in dementia.”*

M: *“In general, paternalism, speaking on behalf of another person, hindering someone to have control over his/her own life, should be avoided as much as possible.”*

The possibility to change your mind was important, even though this would be difficult for people living with dementia. This participant stresses the importance of being able to change you mind in case of the Plug:

K: *“Personality or an opinion can change through other factors then just dementia. Someone with dementia might want to change their mind not because of the dementia but because of other life events, the living situation or their social circumstance.”*

People with primarily personal experiences with dementia were more in favour of the option of euthanasia. Many were also clear that this should just be the individual living with dementia’s decision.

One individual felt that it should simply be done if this was requested by a cognitively competent person:

I: *“I am quite the proponent of self-determination in life and death. If you want to die in the prime of your physical life you should still be able to do so in a way that is dignified and at the burden of as few people as possible.”*

Another participant responded to the question where they were asked who should be involved in end-of-life decisions:

C: *“Ideally it would be a well-considered decision in conversation with others, but ultimately the person in question doesn’t need to ask anyone’s approval.”*

Yet another participant would have the Plug installed if this was possible:

A: *“I have been thinking about it a lot, after the video. I am pretty sure that I would install The Plug on myself. It might be easy to say, because it is a decision that looks far into the future at the moment. However, I think it is brilliant.”*

Overall, from this small group of participants, personal experiences shaped opinions. Subtle differences between reasonable personal experiences where loved-ones with dementia did not seem to suffer too much, compared to those with personal experiences where the loved-one did seem to suffer substantially, did shape opinions. Equally, those with a broader range of experience and expertise used their personal knowledge to shape their thoughts. In the next sections participant’s thoughts are discussed by theme.

5.3.3.2 Burden

The idea of ‘burden’ came up frequently. This is a complex term, in the context of these conversations meaning ‘a heavy obligation.’ This could be the worry of becoming a burden from the patient’s perspective, or the feeling that the patient was indeed a burden from the carer’s and loved-ones’ perspectives. Additionally the duty to have to perform euthanasia could be seen as a burden on physicians. Burden was often mentioned in relation to suffering (5.3.2.1). Participants were struggling with this concept of burden. The idea of burden was discussed from various angles, from the perspective of the patient, the loved ones, society and what we could do with this concept.

5.3.3.2.1 Carer burden

The effect of caring for people with dementia has been studied extensively and it is clear that this is a task that causes much stress (2.2.1.2). Participants also agree that caring for people with dementia is hard.

The SCEN physician explains how looking after a person with dementia is tough:

B: *“Two things: nightly unrest, loss of sleep, kills you after three nights, and the second is incontinence, once they start smearing poop, it stops. It causes aggression. Sadly not rarely you will find that the carer starts hitting the patient. I have seen it all.”*

Participant J describes how relatives are unable to deal with being a witness to their loved-one’s dementia:

J: *“I am thinking of certain care facilities I have visited and where I have spoken to patient’s relatives and they say “I am not sure if I am able to visit again,” not financially, but emotionally. I do understand perfectly why someone would say “I don’t want to do that anymore,” I can understand that you can say, “I have said my goodbyes, it is finished for me,” I understand that.”*

5.3.3.2.2 Physician burden

The burden having to perform euthanasia did not come up so much in these discussions but there was some mention of how hard this task must be.

E: *“That is a very interesting thought experiment, because I think that will make people reason quite differently. I couldn’t, you wouldn’t do it yourself of course, but that is exactly what you ask of a physician.”*

H: *“At the same time, I don’t like the idea of involving humans to help ending lives, that originally have their jobs to save lives. It’s unfair to put this burden on them, or to let them feel that they can ‘play god,’ where they shouldn’t be able to do so, I think.”*

5.3.3.2.3 Societal burden

Although the financial burden of providing care for people living with dementia is currently not a practical issue in the Netherlands, it is a political issue that may need consideration, and was discussed by a few participants.

F: *“The idea of not wanting to be a burden could arise from societal pressure; if everyone has euthanasia in dementia you feel you might have to as well. If a device such as The Plug would exist, would this not also trigger a commercial expectation, from insurers for example? Care does cost a lot of money after all.”*

J: *“I believe that the financial can not be a consideration for care!”*

M: *“People are often trapped between their autonomy and their co-dependency with others, between a rational decision and a more emotional drive to keep living and fear of death, between the individual experience of suffering with euthanasia as a solution and the implied criticism of society where the elderly lose their meaningfulness, so euthanasia becomes a solution.”*

Perhaps society should have more of an obligation in providing care:

J: *“I always think, in an ideal world, of course wrong, perhaps somewhat idealistic, in an ideal world you would have a very inclusive society, that would also relieve carer burden ... so that these questions would completely change. I find this really hard, because I do know that that is not the reality. But that is a question you could ask as a society. So this kind of connects what Distelmans also says; if we can find a good way, if we can care for people with dementia in a beautiful way, and I choose the word ‘beautiful’ consciously,*



*because I don't just want to say, feed them, give them shelter, but instead provide a beautiful care, and the same should apply to the primary carers, and if you do that, would the question not be completely different?*

5.3.3.2.4 Being a burden (patient burden)

Participant's personal reasoning for requesting euthanasia often included the idea of burden:

K: *"I think that if a person with dementia feels that his or her life is no longer contributing, or is causing more pain to him/herself and others around them, they should be allowed the option to end their lives."*

A: *"Maybe I will get scared when I am closer, but at the moment I am rather convinced I would prefer not to be a burden for others."*

M: *"What you can encounter, is that patients, in the beginning, worry about their loved ones, and what they may cause the others to have to go through. And of course, they themselves will experience fear, insecurity, depression, and so on... but this may pass at a certain time..."*

It was agreed that not wanting to burden loved-ones or society was a noble intention, but very complex.

The SCEN physician encounters this issue frequently in euthanasia requests:

B: *"So, you can't say "I want to die because I don't want to be a burden", but why is ... this is a part of your internal make-up, if you are nice to others this causes much joy, that is being part of being human."*

The ethicist was trying to understand the underlying social situation around this feeling:

M: *"So the balance is in the mercy, to prevent suffering of loved one, a bit sacrificial." [...]* *"That is what makes it such a weird disease. And the suffering, before dementia has set in properly, is in fact focussed on the other. A rather complicated social situation."*

This participant did not feel that this fear of becoming a burden could be a genuine feeling:

G: *"No, I think there is a lot of social pressure and grandiloquence, I say this because the whole drive towards euthanasia in the Netherlands, the idea that this a good thing,*

*that it should be allowed is full of egotistical thinking. The right to self-determination is all about the self and not others. I am not sure it's true, if people say it [I don't want to be a burden], I guess it could be true sometimes, but I think the primary concern in a euthanasia request is the fear of suffering."*

There is a huge stigma around the fear of becoming a burden or being a burden or indeed feeling that the person you are caring for is a burden. This subject is taboo and is not often discussed. Even though participants acknowledge that burden does exist, it is not clear if it can be acted upon.

B: *"Can the loved-ones decide about their own suffering that occurs in caring for a person with dementia? Right, their suffering certainly contributes badly to their own well-being."*

J: *"What would the carers have to say about their own suffering which is being caused by the person with dementia? We are a little bit stuck in a sense of guilt, of course we want to care for these people, we love them, but is incredibly hard and it makes you sick ... this is complicated one. What rights do the carers have about their 'sickness'?"*

M: *"Not causing hurt for others ... yes ... so let's think consistently about personhood, if that isn't individualistic, but is being carried by your social circle, then it would count for the whole, and not just for the positive experiences, but then the suffering is also collective ... yes ... yes ... goodness ... yes .. pffff."*

5.3.3.2.5 Summary on burden

This sense of burden that surrounds dementia is felt in different ways by the different parties involved in the disease. The patients primarily fear becoming a burden, but once they are demented it is not at all clear if they feel like they are a burden. Carers feel a strong sense of duty in caring for loved-ones with dementia, but more often than not, the burden of this caring makes them sick. Additionally physicians feel a strong sense of burden in having to perform euthanasia, which is why they only perform euthanasia if the decision for euthanasia still can be made by the patient, however the patient making a decision based on fearing becoming a burden is not a reason to perform euthanasia.

5.3.3.3 Others decide

If others should or could decide on behalf of a person with dementia to choose euthanasia was discussed in the context of autonomy in section 5.3.2.2. This section describes candidates for decision-making in a more practical sense; what would it be like if others did decide on behalf of a person with dementia to choose euthanasia, and who would perform the euthanasia?

In response to the survey question 'Currently the responsibility of making a decision about euthanasia lies with physicians. Who do you think should be involved in making end-of-life decisions?' most people listed who they felt would be qualified to make such decisions:

D: *"The GP, children, partner a good friend. The opinion of my loved ones, very close to me, should be considered as well."*

E: *"Medical specialists, family and the patient and potentially close friends."*

F: *"Loved-ones, psychiatrists, psychologists."*

H: *"An ethics committee (referring back to euthanasia in the third Reich – there physicians made the decisions, too)."*

Some anecdotes on how other people deciding if dementia should occur could play out were recounted or imagined. The SCEN physician describes how a patient's wife is trying to influence the decision:

B: *"I do think that it should be possible that the surroundings think along with the person with dementia. But I also know examples, I visit this man who has requested euthanasia – here we are again – and I talk to him, and I ask, are you happy, "yes, it's wonderful here", and his wife, she is sitting behind him, she is signing to me [kill him], wonderful. It's a comedy sketch."*

G describes an experience where care-givers could have imagined making the decision for euthanasia on their loved-one themselves in order for the euthanasia to happen later:

G: *"I know from these two women, Kea and Jannie, Jannie is Joop van Loo's wife, the main character in my book, for them [the women] it would have been completely logical if it they would have had to do it [euthanasia] in those late stages, if there hadn't been a GP. I know from Jannie that she would have loved it if*

*Joop would have been able to live a bit longer, into the stage where a GP no longer would have been able to perform euthanasia, but she could have [performed euthanasia]."*

L looks at the practical implications of euthanasia:

L: *".. but make certain conditions in which it happens, because you are the one that has to deal with it actually, also the aftermath, I mean you have to make the coffee for the physician, the guy comes to do it [euthanasia], you know. It is this kind of practical stuff."*

Bert describes what it is like to perform euthanasia:

B: *"But I don't do it alone, you need the patient, the wife, a buddy, colleagues, and then you discuss with more colleagues. If you had to do this alone, it would be terrible. One of the main characteristics of ethics is that you don't make any decisions alone. That can never be good. Absolutely unlikely that one person could."*

G can imagine why physicians may not want to perform euthanasia:

G: *"I can absolutely imagine that a physician won't do it. Someone who is completely cognitively incompetent, where you can't establish if he still wants to die, where you cannot establish if they suffer, I can imagine a physician would say, "I will not kill", but if he [the patient] catches a cold or something else and I can make sure he dies gently in a week or two, I think that is totally comprehensible from the physician's perspective."*

5.3.3.3.1 Summary on others decide

There was consensus about the idea that deciding euthanasia should not be done alone. Almost all mentioned the inclusion of loved-ones (family, friends) in this decision as well as professionals. The type of professionals varied from physicians to psychiatrists to ethicists.



5.3.3.4 Good death

A natural death is often seen as a good death (2.2.4.1). Natural deaths are very rare in the western world where about 80% of people die in some form of care (WHO, 2018). This means we are in fact in control of how we die. Are there ways we can make this ‘good’?

M: *“Nature can be cruel. Right, nature is doesn’t imply meaning.”*

Participant A and L discuss together that we can learn from our experiences now, in order to have better deaths:

L: *“Because people get older and older recently. There is only a couple of generations that have been confronted with this situation where you can make a choice, what if we think about it now and we experience this because of our grandparents, it could be that we could make different decisions now that have effect on ...”*  
A: *“... what you say is, we are more aware ...”*  
L: *“... or we could have dementia then and maybe we ...”*  
A: *“... at least we had first hand experience ...”*  
L: *“... exactly.”*

Planning for a good death might have to start much earlier in life as this participant suggests:

J: *“In Belgium you choose a GP [...] they know my wife, they know my kids, they know me, and you try to see the same GP, because they know your context. [...] based on the relationship she has with me and my family, is the best person to start this conversation. My thing would be, how do you design the way to build this relationship? That would be the starting point.”*

The relationship a physician has with their patient is important, as the SCEN physician explains:

B: *“This is the thing, in dementia, and this is the requirement that I impose, you have to have rapport with these people.”*

It is important to make sure that the planning is for the benefit of the patient and their surroundings, which might not always be so clear:

B: *“If a doctor thinks that someone should leave this life harmoniously, so that daughter who lives in America, who he [the patient] hasn’t seen for 30 years, he has to make peace with her, otherwise he can’t go. Complete*

*nonsense of course, but sometimes you have physicians who project quite a bit, their idea of a good death. However, I can’t imagine I would perform the service of euthanasia for someone whose loved ones would be against the euthanasia. I can’t imagine.”*

Different types of deaths leave different kind of scars. Suicide leaves terrible scars, sudden deaths in accidents or war are also perceived as awful by those who remain behind (Kimsma & van Leeuwen, 2007). In that respect a planned death can help provide ways to deal with loss:

B: *“The pinnacle of autonomy would be actual suicide, where you hang yourself while your wife is at the shops. Sadly this is not rare, there are about 1,500 elderly a year that do this, without discussing it with anyone, in their own despair. In contrast to this, is suicide in conversation with your loved ones, this is a much more bearable event. The true lonely suicide leaves terrible scars, people never recover from this, it is absolutely terrible. If that is your child it is one of the worst things. So the other self-killing, where we are all present, together, choose some music, and well “off you go, dad”, is also not great, the grieving, but much better than the true lonely suicide. So, besides patient autonomy, the way you deal with your loved ones, in your choice in self-dying, this could provide some form of quality.”*

L: *“I was grateful that my grandmother, who was mentally very stable, but physically unable to live for much longer, was able to make a decision in which she had ownership of her life, and where she felt supported in making the decision to end her life in the way that she wished to.”*

However, euthanasia also need not be the best solution for loved-ones:

B: *“But what rarely gets mentioned in euthanasia is that is doesn’t always give good ‘mourning’ because the bystanders think “why was this necessary? Couldn’t you wait?”*

5.3.3.4.1 Conclusion on a good death

With medical advances, death is becoming more of a ‘choice.’ Based on a few generations of experience and more awareness of the importance of thinking and planning death, not just for the individual but also for the social surroundings, we may now be at a stage where we can truly start to ‘design’ death.

5.3.4 Compare & contrast

Contrasting the themes from the Conceptual Framework (5.3.2) with the findings that emerged from the Open Coding (5.3.3), a few areas have opened up for further investigation and can make contributions to the debate on euthanasia in dementia.

The connection between ‘suffering’ and ‘burden’ is investigated in 5.3.4.1. The right to self-determination and who can decide is explored in 5.3.4.2. Lastly what would make a good end-of-life in dementia is examined in 5.3.4.3.

5.3.4.1 Suffering versus burden

Feeling like a burden could be seen as suffering (Dening et al., 2012). Carer burden is a real phenomenon, the health of carers is affected by the ‘burden’ of looking after their loved-ones with dementia (Chiao et al., 2015). Additionally, the financial cost of dementia care can have a big effect on society (Bilchik, 1996).

5.3.4.1.1 Suffering burden

The suffering that happens in dementia is largely existential for the person living with dementia but the burden on the carers could also be seen as suffering and has an impact in the quality of life of both the patient and the carer (Chiao et al., 2015; Bailes et al., 2016). Most euthanasia requests come from people who have cared for people with dementia themselves (5.1.1). This may mean that the experience of living with dementia is perceived as so bad, that people would prefer to die. Some participants suggested as much:

J: *“If we can find a good way, if we can care for people with dementia in a beautiful way, and I choose the word ‘beautiful’ consciously, because I don’t just want to say, feed them, give them shelter, but instead provide a beautiful care, and the same should apply to the primary carers, and if you do that, would the question [in response to talking about the burden of carers] not be completely different?”*

5.3.4.1.2 Financial and societal burden

In the Netherlands healthcare is provided, therefore decisions for euthanasia are not borne out of financial need, but in other countries the cost of receiving end-of-life care is expensive and can be a reason for patients to request assisted dying (Bilchik, 1996). There is growing concern 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). A current estimate is that the cost for care is about £32.250 per person with dementia per year (Dementia Tax, 2019). The financial implications of healthcare planning can have huge societal impact (Eley, 2018). In the financial context of the euthanasia debate, it is worth mentioning the QALY; Quality Adjusted Life Year, used in economic evaluation to assess the value for money of medical interventions. One QALY equates to one year in perfect health. To be dead is associated with 0 QALYs, and in some circumstances it is possible to accrue negative QALYs to reflect health states deemed ‘worse than dead’ (Barrie, 2014). Money in relation to death is a taboo subject. Quantifying death through financial means is unacceptable:

J: *“It should not be allowed to make this a financial consideration, and as a society we must look out for the other and also for the carers, who are burdened by this, stuck with it, and unable to fulfil this task.”*

This societal burden need not be expressed financially, but can still have effect on individual decision-making as participant F expresses when asked what other factors one should consider besides patient autonomy:

F: *“Pressure from society. If you don’t want to burden people with your dementia. If everyone has euthanasia in case of dementia, you might feel you should do the same.”*

Efforts are being made to change the discourse of dementia into a more positive and inclusive view of aging (McParland et al., 2017). Institutions globally are collaborating on “reducing the worldwide burden of dementia” in an initiative launched at the Global Action Against Dementia Conference in March, 2015 (Shah et al., 2016).



5.3.4.1.3 Concluding suffering versus burden

The sense of ‘burden’ that is felt by both the person with dementia as well as the carers seems to extend what can be defined as ‘suffering’. Looking at ways to relieve the feeling of burden in both carers and patients may change the perception of the disease on dementia, which in turn could change the amount of euthanasia requests in dementia. Financially, with raising levels of dementia, caring for people with dementia will remain expensive. Priorities in societal spending must be made.

J: *“I think it is a shame that we should live in a society where we should make a financial consideration in decisions about ... where we need to take this into account, because we can’t afford it anymore – this in contrast to a debate about whether they should finance new fighter jets. And the government struggles with this, how can you ask us (citizens) to make budget cuts in healthcare if you are going to spend tens of billions for new planes?”*

5.3.4.2 Autonomy and others

Autonomy only exists in context to others (Keizer, 2018). Including loved-ones in a decision-making process about end-of-life in dementia is helpful for the patient as well as the loved-ones (Kimsma & van Leeuwen, 2007). Once cognitive decline is so large that it is no longer possible to ask the person what they want, we can only really know what they said they would have wanted, but it is not possible to factor in any ‘response shift’ or changing your mind (Jongsma et al., 2016). Often personality change does occur, and this ‘new’ person should have rights too, but it is hard to know who can defend those rights.

5.3.4.2.1 Changing one’s mind

Being able to change one’s mind is something that was brought up frequently. Participants were not just talking about the so-called ‘response shift’ (Jongsma et al., 2016), where patients adapt to their new situation, described here by participant Henk Blanken in an essay for The Correspondent (2019):

*“You can get used to a lot. You get used to the pain, the tremors in your head, the cramp in your hands, the poor handwriting, the incontinence and sleeplessness. [...] We can’t know how unbearable the suffering will be, which is the most complicated criteria [for euthanasia]. You get used to more than you think, and the will to live is so strong that you can put up with more and more suffering – I could not have imagined ten years ago I would find living with Parkinsons ‘quite bearable”* (Blanken, 2019).

Participants could also imagine other reasons you might want to change your mind, a change in circumstances for example:

H: *“A person making a decision about which criteria should be in place to end one’s life when implanting ‘The Plug’ could change one’s mind based on outer influences, changes in life and love etc., which are not predictable in the moment of implanting it. An analogy: In the Netherlands, people can put together a cohabitation contract, that fixes some parameters of how two romantic partners wish to live together, what they want to do if one dies or if they break up. Oftentimes, they change the settings of such a contract in case a child is born, which is also recommended by notaries to do – to rethink whether the conditions put together in one moment of the relationship still apply without any changes,*

*in case fundamental aspects in a relationship change (such as becoming parents). While it might seem reasonable to make adjustments to such a contract then, as life happens, there are also couples that get so absorbed with life that they forget going to the notary to adjust the contract and they might reach points in their relationship when they regret not having done so. So – in case of euthanasia in dementia – what if a person sets certain conditions for death, but then in her life certain aspects change that change her view on things in life as well, but she is too busy to go to The Plug-adviser and update the settings?”*

Participant A also mentions how your context may change, which could call for a change in your advance directive, or indeed for others to make a decision on your behalf. Our identity and personalities may not be as static as we think, but be defined by the connections that we make (Deleuze & Guattari, 1987).

A: *“However, it is very difficult, if you have to take a decision when you are not sick yet, or if you were just diagnosed, the situation around you, the social context around you when the Plug is triggered might be completely different, your husband/wife might have died in the meantime or might have also gotten dementia or ... anything can happen ... if you have to make it into a policy, I think it’s quite clear that if you haven’t taken any decision before for yourself about whether you want to have euthanasia or not, then maybe your closest relatives or the people closest to you can take that decision for you, but of course your own decision should always overrule.”*

5.3.4.2.2 Rights of ‘new’ person

As personality change occurs, it is totally unclear what rights this new person has (Davis, 2014). Often people who wrote clear advance euthanasia directives when cognitively competent will deny the existence of this directive, or simply state they do not wish to die now. Many debates are centered around the question if the original person’s wishes should be respected or the new person’s wishes.

J: *“... but the problem is there is no way that these people as they were then, and how they are now, we can’t let them debate together. If only we could do that, then we’d have a good way, but I find it hard to leave this decision only with the person ‘then.”*

The due care criteria make sure that the person requesting euthanasia must be able to confirm this request at time of death. In many cases this means that a person with an advance euthanasia directive doesn’t ultimately receive euthanasia. The person with advanced euthanasia is not well known by ‘family’ and ‘friends’ and it is hard to be responsible for a person you don’t really know, therefore the social circle surrounding a dementia patient will mostly try to defend the case of the patient’s previous personality.

Participant G, who has written many public essays about this specific conundrum, feels strongly that he should be able to transfer his right to self-determination to his wife, who knows him (the original ‘him’) best:

*“If I can determine my own end-of-life, then I also want to be able to delegate this right to my loved-one. I want to be able to ask my loved-one to represent me in deciding when it is the right time to die. She already does this when she instructs a physician to stop treating me – this is something that can be done legally.”* (Blanken, 2019)

The legal possibility to have more control via the Do Not Treat agreement is also discussed in Chapter 7.2. The Do Not Treat agreement is legally binding, other than the advance euthanasia directive, which is just a ‘request’ and not a ‘right’. Looking at how ethical dilemmas have been resolved in a Do Not Treat agreement may help us formulate better advance directives.

5.3.4.2.3 Who decides on behalf of the person of dementia?

The problem of not being able to speak for yourself in dementia calls for the need to involve others who can speak on your behalf. This is made more complicated because of the change in personality that occurs in dementia. The ones you may have involved to speak on your behalf, may not be able to speak on the new person’s behalf.

However, involving loved-ones in discussions about end-of-life in general (not just dementia), is seen as beneficial:

*“Besides problems, the option of euthanasia has also uncovered a presence of positive emotional involvement, commitment at the end-of-life, and the strengthening of relations in the face of death”* (Kimsma & van Leeuwen, 2007, p372)



When loved-ones have a greater understanding of reasons why people choose death over a life with less quality also helps manage the bereaved deal with grief. In a study comparing grief management in the bereaved of people who died of cancer naturally or by euthanasia, it was found there were less grief symptoms and post-traumatic stress reactions in the loved-ones of those who died by euthanasia (Swarte, 2003).

Blanken argues for more involvement from the loved-ones in his article ‘When I no longer know I am alive, I want to die. This is my directive.’ in the Correspondent, May 2019. Many people have in their advance directive the clause ‘I want to die when I can no longer recognise my children’, Blanken says what this really means is ‘I want to die when my children no longer recognise me’ (Blanken, 2019). This would require a much more active involvement from the children. However, dilemmas might arise in children having to admit no longer recognising their parent and that then being an incentive for euthanasia.

5.3.4.2.4 Who helps the physician to perform euthanasia?

All decision making around end-of-life is hard, and it is recommended that no part of this decision-making is done alone. A very important voice in this decision-making process is the physician. A great deal of the responsibility lies with them, and ultimately they are the ones having to perform euthanasia. Physicians could help themselves by initiating earlier conversations with their patients about end-of-life:

J: *“In Belgium you choose a GP, and you stick with this person or GP group, and this should prevent a bit of ‘GP shopping,’ but I can see, they know my wife, they know my kids, they know me, and you try to see the same individual, because they know the context. [...] I think that that person, based on the relationship she has with me and my family, is the best to start this conversation. My thing would then be, how do you design the way to build this relationship? That would be the starting point.”*

E: *“You could say, you’d have to develop a ‘conversation method,’ which would allow you a low threshold start to such a conversation. Though I could imagine, you would need the authority of a physician, to start such a conversation. If such a person gathers the family together and says, such-and-such is getting old, it is time to discuss this, how do you all feel about end-of-life, how do you feel about the last years. A good point to include lots of stuff, and put down, who this person will talk to later, if the time is there. Who wants to help deciding what stage we are at. I think this could work, under guidance of someone with a natural authority, because people themselves would never initiate this.”*

5.3.4.2.5 Concluding autonomy and who decides

Decision making about euthanasia in dementia should not be done alone. Equally, performing euthanasia in dementia should also not be done alone. It would seem that clearer guidelines on how to go about working together making these decisions would be helpful. Suggestions were made that the physician would be the obvious person to at least introduce the subject of end-of-life in dementia, and many do so already, however physicians are not required to do this, and have no formal training in supporting end-of-life decision-making. Physicians need education and support in starting conversations about end-of-life options with people with an early diagnosis of dementia and their social circle. Additionally clearer guidelines for writing do not treat statements as well as advance euthanasia directives would help all parties involved.



Figure 5.12  
Euthanasia Coaster  
by Julijonas Urbonas  
(2010), <http://julijonasurbonas.lt/euthanasia-coaster/>

5.3.4.3 Designing death

It was concluded in 5.3.3.4.1. that, with death becoming more of a ‘choice’, we may have arrived a stage where we can start to ‘design’ death. Artists and designers have been imagining different ways to die such as the controversial ‘Euthanasia Coaster’ by Julijonas Urbonas (2010), who designed and engineered a “hypothetic death machine in the form of a roller coaster, engineered to humanely – with elegance and euphoria – take the life of a human being” for his PhD at the Royal College of Art (Urbonas, 2010).

Natsuki Hayashi, a student at the ‘Products of Design’ Master course at the School of Visual Arts in New York (USA), explored a contemporary design of assisted suicide in her project ‘Sincerely’. She imagines different ways for assisted dying, and for people to be able to be in control of their deaths, but also different ways to ask for help, and rituals to say goodbye (Hayashi, 2016).

The need to discuss dying more openly together is becoming more apparent and events are popping up to do exactly that, like a Design Council initiative ‘Reinventing Death for the 21st Century’ in 2015, where the process of dying was discussed and (re) imagined.

Other initiatives of various qualities exist such as the Death Café movement where people gather to discuss their mortality (<https://deathcafe.com/>), or a German community ‘Re.Designing Death’ of people who want to build and nurture new opportunities for innovation around death and dying, and research initiatives such as the ‘Death and Dying Discussions mini-symposium’ at OCAD University in Toronto 2019 and 2020.

5.3.4.3.1 Conclusion on designing death

Dying is something that will happen to all. Instead of passively waiting for ‘nature’ to happen, better ways of dying could be imagined and designed for all those affected by this process.





The products shown in this image are not real. They are speculative designs created as part of an academic Masters thesis project. The work is a prototype only, constructed to investigate the potential role of design in the context of end-of-life issues. The persons shown in this image are hired professional actors.

5.4 Reflection

In tackling a morally complex issue such as the debate on euthanasia in dementia it was felt really important to ask people relevant to this debate questions. A well-rounded group of participants was found with one type of participant missing; those strongly against euthanasia in dementia. It is expected that those strongly against euthanasia in dementia could have added different kind of responses than the ones gathered now. Because not all participants took part in both the survey and the interview, some discrepancies in responses arose. In general, survey responses were shorter in nature (with the exception of survey participants H, K and M), and interviews were richer in the data they yielded. In cases where participants took part in the survey and the interviews it was interesting to receive more elaborate and contextualised explanations to their responses which was really clear in participant L who told many anecdotes.

The suffering theme was discussed extensively and here new nuances were brought to the foreground on the experience of suffering with the patient, but also their connections. This gave rise to the ‘burden’ concept where the burden of

dementia could be seen to lie with the patient, the carers, physicians and society at large. The Assessing Suffering video was appreciated by participants as it was a scenario that was easy to relate to, and many participants could place themselves in this scenario, even though the scenario was also deemed a bit idealistic.

The autonomy theme (The Plug), raised the most discussion (Figure 5.14). Whether this was because if the fact that this video was the most provocative, or if the concept of autonomy or self-determination was something that concerned people most is unclear. It could be that this theme was discussed more intensively because this was always the first one to be discussed, it is possible participants became tired after a while and thus discussed further themes less extensively. Consensus was more or less reached on the fact that true autonomy did not really exist and that others must also play a role when it comes to planning euthanasia in dementia (except with participant I). However, there was no real consensus on which other parties should also play a part in making decisions on euthanasia in dementia, though most suggested physicians would have a very important role.

Figure 5.13 Couple Hood, Natsuki Hayashi (2016). <https://productsofdesign.sva.edu/blog/masters-thesis-sincerely>

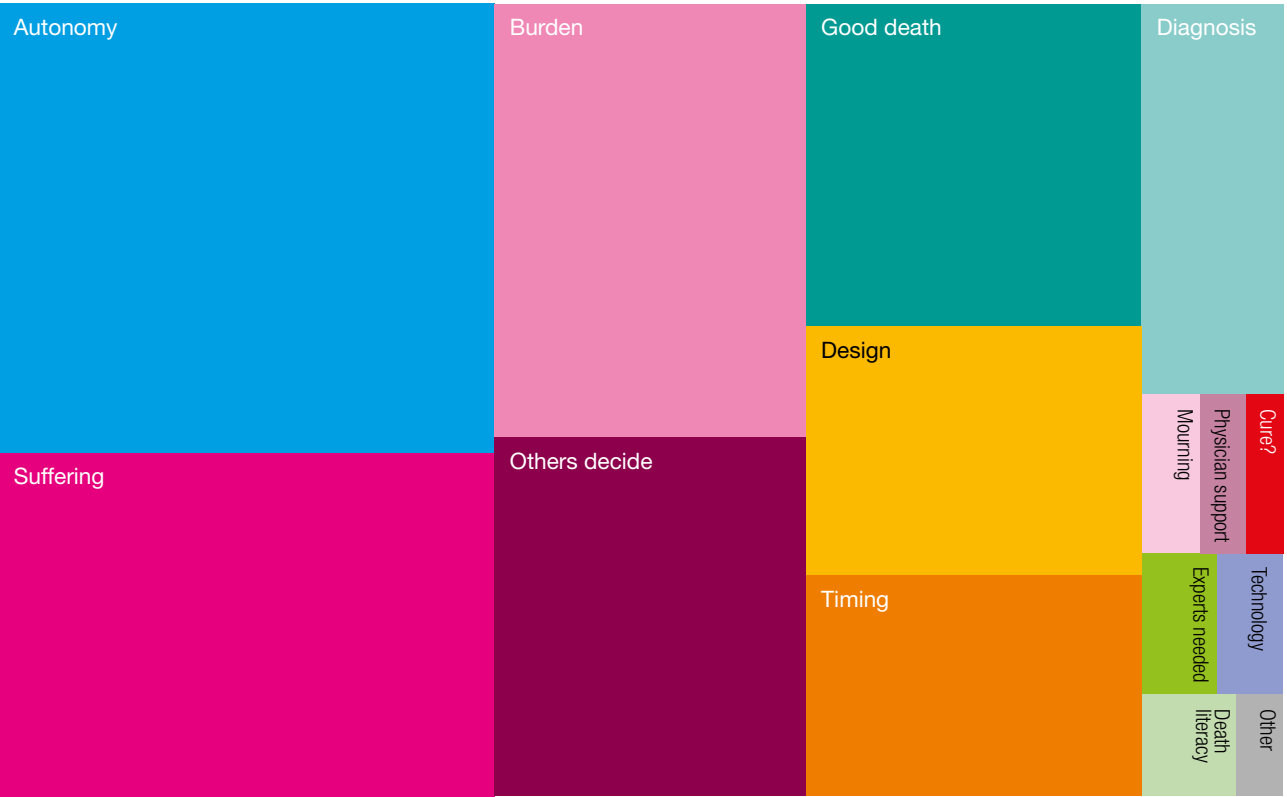


Figure 5.14 Hierarchy chart from extrapolated from Nvivo.

Who should make decisions at what times was not consistent throughout the progress of dementia. Different people were important at varying stages but in general a physician would need to be involved in diagnosis, planning, helping with writing an advance euthanasia directive and/or a do not treat agreement, helping with discussions in social circles and potentially finally the execution of the advance directive. Loved-ones (family or friends) were certainly important, in some cases in a supporting role, in some cases taking responsibility for decision-making in case the patient would not be competent to do so themselves.

The timing issue arose throughout all the themes and the timeline was a helpful tool to help participants formulate their ideas and give them a place on this timeline. It was unfortunate that the timeline could not be investigated with participants that only took part in the survey. It was clear that there is a difference between theoretically discussing a ‘good’ time to die and actually pinpointing the moment of death. Pinpointing the exact ‘right’ time is hard.

The idea of planning death was less controversial than expected, considering this is a fairly new occurrence in our society. The video was seen as quite emotional but many could empathise with the person portrayed through the euthanasia note. Interesting ideas on how planning death could be improved were suggested and these would be worthy of further investigation. This might be a good time to start thinking about how we might design a good death in dementia.

New ideas that emerged were:

- ‘Being a burden’ should be seen as a genuine issue in end-of-life planning.
- Others are important in decision making about end-of-life.
- Physicians should play a (more) important role in initiating conversations about end-of-life. A good and long relationship between patient and physician would be preferable in this case.
- Re-imagining the dying process could help stimulate ‘death literacy’.



## Part 5

# Applications

Some of the research presented in this thesis has found some real-world applications. It would seem that new ways to address the debate on euthanasia in dementia are welcome. Taking these design provocations out of the research context has some implications. The designs were created for expert stakeholders where the designs could be carefully introduced. How the designs created for this research were applied in a real-world scenario are described in this segment. Beyond the research implications, this also illustrates the gap between academic research and design practice.

Applications used in cultural platform Pakhuis de Zwijger in Amsterdam are shown in Chapter 6. First the use of an edited version of The Plug video in a public debate organised by Pakhuis de Zwijger is described in section 6.1, next the use of the timeline as well as additional executions of the overall research are discussed in section 6.2. Chapter 7 outlines the use of The Plug video as a tool to trigger discussion for The Royal Dutch Medical Association (KNMG).



# Chapter 6

## Pakhuis de Zwijger



Pakhuis de Zwijger is a cultural organisation and an independent platform for and by the city of Amsterdam and its inhabitants. Pakhuis de Zwijger functions as a debate centre, putting dialogue before debate and connection before opposition. It stimulates collaboration, puts urgent matters on the agenda, and links them to the creative industry. It is about connecting domains and disciplines, sharing knowledge and experiences, and designing and imagineering the future of everyday living. It has a community of around 100,000 members following de Zwijger live and online (<https://dezwijger.nl/over-ons/about-us/>).

Through the connection with one of the original research participants, Henk Blanken, it was discovered that Pakhuis de Zwijger was hosting an evening around Henk’s statement “*my death is not my own*” (Guardian, 2018) on 22 October 2018.

Considering the nature of Pakhuis de Zwijger and their general interest in “*connecting domain and disciplines*” contact was made via email with the event organiser, Femke Awater. Femke was quite charmed by this research’s approach to this debate, which resulted in a collaboration:

“*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 addition to our programme.*”  
(Femke Awater, Pakhuis de Zwijger)

This collaboration will be described in this section. First the event on 22 October will be discussed from planning to actual and followed by the responses to this event. This event’s success led to a follow-up event on 10 December 2018, which will be outlined in section 6.2.

Figure 6.1. Screenshot of the event.



Figure 6.2 Hugo Borst speaking about his mother. Photographs by Margi Geerlinks

### 6.1 Public debate

#### “My death is not my own”

This evening was an initiative of author and journalist Henk Blanken, a Parkinson’s patient who will likely develop dementia. Henk wants to die ‘on time’, which for him is “*when I can no longer contribute to my own and others’ happiness*”, at this time Henk would no longer be cognitively competent to confirm his death wish, so he proposes that his wife should be able to make this decision for him, which currently is legally not possible. This is why he wants to open up discussion with the general public, other patients, researchers, doctors and loved-ones on this evening.

“*Annually thousands die deeply demented, even though they were clear they wanted to avoid this undignified process, their advance directive stated “if I need to go into a home, I’d rather die”, however only about a hundred people were granted their wish, because the demented lose autonomy. For those who don’t wish to die too late, have to die too early, and this is what this evening will discuss*” (Blanken, 2018).

#### 6.1.1 Evening set-up and execution

Initial contact with event organiser, Femke Awater, was made quite late in the process. A lot of the programme planning was already set, and speakers were invited. This meant that there was little time to schedule a speculative design, therefore Femke asked if the original video could be reduced to 2 minutes. After a few edits to try and shorten the existing Plug video, it was decided together with Femke and Henk to create a new video, an ‘advertisement’ for The Plug. The advertisement would play after a segment where Govert den Hartogh (a Dutch moral, legal and political philosopher) would describe the problem of personality change: “*the discussion about end-of-life in dementia, unlike in other chronic terminal diseases, is not so much about quality of life, but it’s more of an ethical discussion, in dementia your personality changes, who can make decisions for this new person?*” (den Hartogh, 2018).

Henk and Femke approved the advertisement version of The Plug (Figure 6.3) and it was scheduled for broadcasting on the evening of 22 October 2018. The schedule was discussed to try and establish the best flow between concepts and speakers.



<b>TIMETABLE ‘My death is not my own’ 22 October</b> <i>20.00-22.00, Setting: Chairs set up in U-shape: ‘living room style’.</i>	
18.30 - 19.30	Speakers dinner
19.45 - 20.00	Doors open
20.00 – 20.01	Pay As You Like trailer PDZ
20.01 - 20.05	Welcome by Frénk van der Linden (publicist who has published about his own experience in dementia).
20.05- 20.20	Henk Blanken reads his wish to be able to delegate the right to self-determination to a loved-one.
20.20 – 20.30	Frénk van der Linden addresses misconceptions about euthanansia in dementia and engages the audience in discussion.
20.30 – 20.45	Hans van Dam (physician) and Heleen Weyers (legal consultant) analyse the current situation: how does the euthanasia law function now and what are its shortcomings?
20.45 – 21.00	Hugo Borst (writer) speaks about his mother, illustrating the perspective of the one left behind.
21.00 – 21.06	Govert den Hartogh explains how we are focussing on the wrong thing in this debate, in dementia it is not about quality of life like in other chronic diseases, but the question is an ethical one: in dementia you become a new person, who can decide about this new individual?
21.06 – 21.10	Short video (1 min) by Marije de Haas about a future scenario. What if you can programme an implant which can decide when it is the best time to die for you?
21.10 – 21.30	Group discussion with Karin Spaink (publicist), Miriam de Bontridder (legal consultant for Stichting De einder – consultaion in end-of-life) and Govert den Hartogh. Can Henk ask his loved-one to make decisions about his end-of-life? And if not, why could you ask a physician?
21.30 – 21.40	Frénk van der Linden checks if the audience feels differently now.
21.40 – 21.55	Henk Blanken explains his solution and discusses this with Bert Keizer (physician, philosopher and writer) and Hugo Borst. Is it possible, do they agree?
21.55 – 22.00	Frénk van der Linden concludes the evening and announces a follow-up event for 23rd of November to continue the conversation.

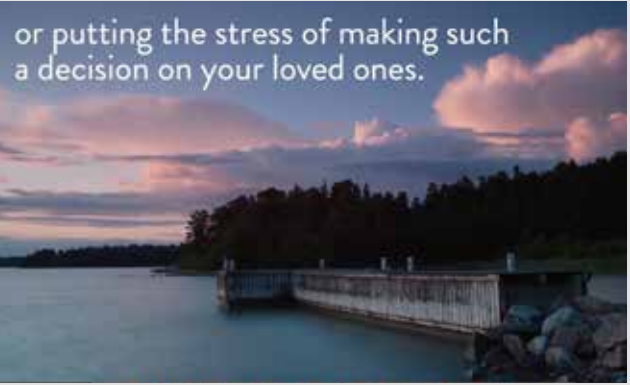
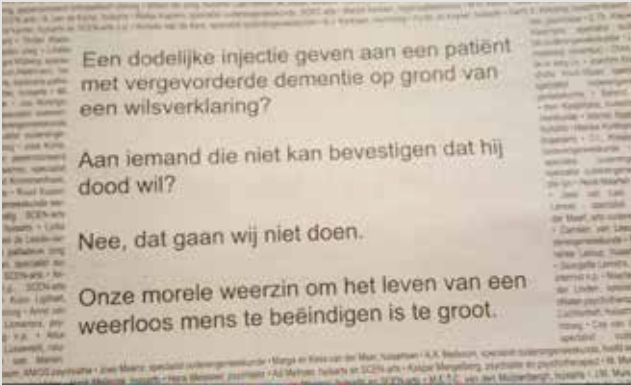
6.1.2 Use

The public debate would take place on 18 October 2018 at Pakhuis de Zwijger in Amsterdam, in the ‘big room’ seating 300 people. The event was sold out. The event was also live streamed and the video is still available for viewing on the website of Pakhuis De Zwijger: <https://dezwijger.nl/programma/mijn-dood-is-niet-van-mij> (Figure 6.1). In table 6.1 the programme is outlined (translated from Dutch)

The audience was asked to document their thoughts on cards that were handed out at the beginning of the evening and that they handed back in at the end. These thoughts would inform the next event and are described in the next section (6.1.3).

Table 6.1  
Programme

Figure 6.3  
The Plug  
advert,  
developed for  
Pakhuis De  
Zwijger, 22  
October 2018





6.1.2.3 Outcomes

With regards to The Plug video the outcomes were minimal. The video was intended to follow Govert den Hartogh’s story about the complexities of autonomy especially in dementia where there is personality change. However, Govert went ‘off-script’ and spoke about his own advance directive and his reasoning (1:16:15). The Plug was later asked about in conversation between Govert den Hartogh, Karin Spaink and Miriam de Bontridder, but this conversation was cut short by the response of Karin Spaink:

“The classic misunderstanding about technology that it will understand and know everything about what it is to be human. It is funny as a gimmick, but at the same time I would think, right, pfff” (Karin Spaink, 1:46:50)

The evening was well received and many of the complexities inherent in the debate on euthanasia were made clear. No actual solutions were found, but it was a useful way to engage in conversation. Karin Spaink says this when asked to think from Henk’s perspective:

“I think he already uses all the right arguments, and the best one is, as he says, that this is a way to trigger the debate, to engage in conversation [...] with his wife and children” (Karin Spaink, 1:44:50)

The audience consisted of many stakeholders who had a chance to have their say:

“The thought that we would be able to die exactly on time, and that we have to try to adjust the system in order to allow this, this thought is of course, the Greeks called it hubris, aimed incredibly high, if not too high” (Audience member working at the review committee for euthanasia 1:29:42).

One particularly poignant remark was made in the audience by Mieke Visser, GP and SCEN physician:

“We are talking about it how difficult it is to decide on euthanasia for someone with an advanced form of dementia, but on the flip-side we then do decide that someone should continue living in miserable conditions, sometimes for years to come. And this is what I don’t understand, that it is easier to decide to keep people alive, but that it is really hard to make the other decision [to decide for euthanasia]” (Mieke Visser, 1:55:27)

At the conclusion of the evening Frenk asked the audience if anyone had changed their mind in hearing the different arguments during this evening. Some people raised their hands and felt they had a better understanding about what it would mean to ask their loved-ones such a question, and would now think twice about doing so.

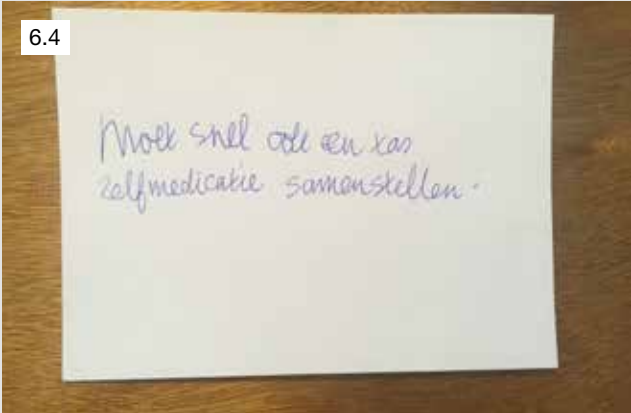
At the end of the evening 73 audience members handed in cards with their thoughts. These were documented in a Google spreadsheet (<https://docs.google.com/spreadsheets/d/1zrSEF-d6vFRG1I9JSIVCFd7eUp0hbVtPIbNfJhyWlns/edit#gid=0>). These can be roughly classified into four categories:

- People feel that talking about end-of-life will be essential  
17 cards –figure 6.6-6.7,
- People feel that they should take control over end-of-life themselves  
13 cards – figure 6.4-6.5,
- Most cards expressed that the issue is complicated  
34 cards – figure 6.10-6.11,
- and a few other remarks mostly considering alternatives to euthanasia in dementia  
7 cards – figure 6.8-6.9.

6.1.2.4 Discussion

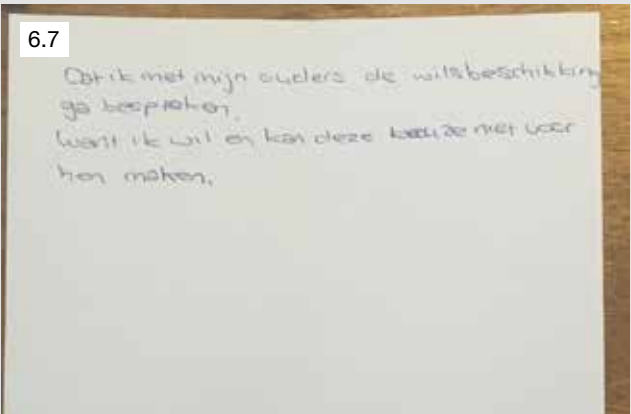
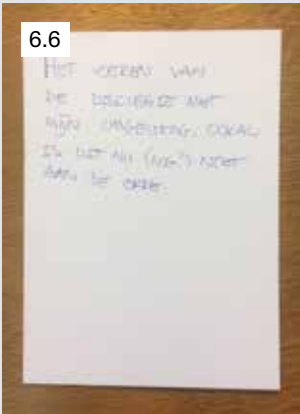
After this evening, it was clear that the issue of euthanasia in dementia had not been resolved, but that having this conversation was valuable. Basing the conversation on Henk’s statement had seemed to open up the conversation in a different way, and allowed people to discuss the problem in a more experiential way, with the focus on the role of the loved-ones. Essential here is that the loved-ones as well as the patients have a real thorough understanding of the problem of requesting euthanasia on someone’s behalf.

Participating in this event was very interesting and an excellent way to reach out to a larger audience, additionally it was also a great opportunity to network with stakeholders. Due to delayed flights, the speaker’s dinner was missed, which was unfortunate, however this was rectified with some after-event drinks. New plans were formed with Femke, the event organiser, for the next edition of the programme and beyond.



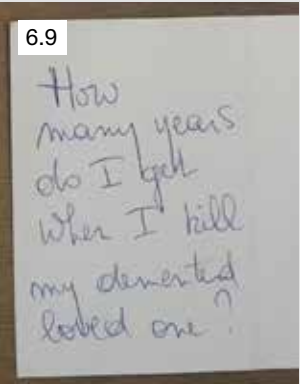
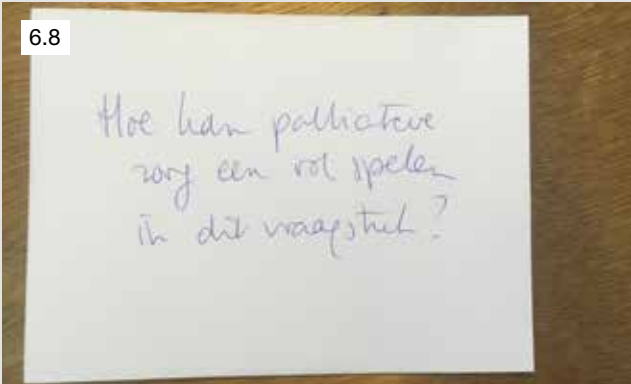
“Should put together a bag of self-medication soon” (Figure 6.4).

“Even more convinced that I need to sort out means myself” (Figure 6.5).



“The need to discuss this with my [social] surroundings, even if there is no immediate need (yet?)” (Figure 6.6).

“I will discuss the advance directive with my parents, because I do not want to be the one to make this decision for them” (Figure 6.7).



“How can palliative care play a role in this issue?” (Figure 6.8).

“How many years do I get when I kill my demented loved-one?” (Figure 6.9).



“We have been talking about this for years, you think to get closer, but the closer you get, the harder it is” (Figure 6.10).

“I am still confused, but on a much higher level” (Figure 6.11).



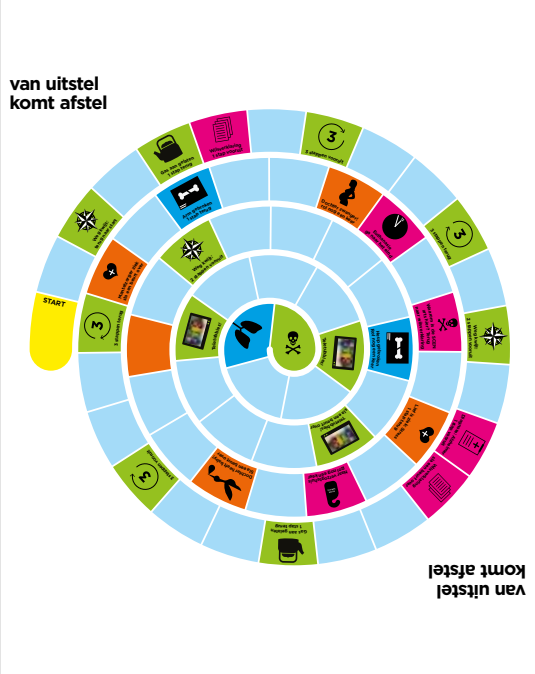


Figure 6.12  
Draft proposal  
of ‘game-  
of-life’ style  
game as  
conversation  
starter for  
end-of-life  
discussions in  
dementia.



Figure 6.13  
Draft proposal  
of using  
a strong  
statement  
to initiate  
discussion.

### 6.2 Public Debate “My death is not my own II”

The second installment of the debate ‘My death is not my own’ at Pakhuis de Zwijger was to take place on 10 December 2018. This was planned as a smaller event, with much more audience engagement, through various roundtable discussions with introductions by specialists working in the field. Patients, loved-ones, professional carers and specialists were asked to participate to investigate what might be required to enhance the process around euthanasia in dementia. Questions are based around what changes can we introduce ourselves, and what changed need to be made more systematically?

#### 6.2.1 Evening set-up and execution

This second event was still based around Henk’s statement ‘My death is not my own’. His statement had gotten a bit more nuanced after the previous event where it became clear that it would not be so simple to delegate end-of-life decision making to a loved one, and also that it would perhaps not be a nice decision to have to make, as a loved-one.

In setting up the event many iterations were made between Femke, Henk and the primary researcher of this thesis. The set up would be 80 participants, all collaborating on 8 round-tables. Initially it was planned to have four themes, two tables per theme, the themes would follow this research; suffering, autonomy, timing and planning death. This was then altered to have more focus on the

time issue with the primary question: What is dying on time? In order to guide the discussion, a game was developed, based on ‘the game of life’ and with a working title ‘van uitstel komt afstel’ which is a Dutch saying for ‘from postponement comes cancellation’ which seemed apt for the debate, but perhaps a bit too confrontational. The game was designed in the same way as ‘the game of life’ but events in the game were based on the experience of living with dementia. The various ‘type’ of events were colour coded (figure 6.12), with green being events caused by the disease, orange are events happening in the social surroundings, pink are events related to end-of-life planning and blue are health-related events that would affect the lived experience. In developing the game we came across many problems, namely that the gameplay would not work out between ten people, and that the game might be too complex for the timeframe (20 minutes per roundtable discussion) and might not address the issues Henk wanted to be discussed. With this game not working, it was decided that it was likely that no game would work that could be played quickly with 8-10 persons with 20 minutes and get the desired result.

The next proposal was developed in conversation with Marieke Sonneveld from the End Of Life Design Lab at TU/Delft. The proposal centered around making a strong statement and participants would argue a position in favor or against from the perspectives of the patients, loved-one or physician.



Figure 6.14  
Table design with scenario  
instructions. People sitting in  
the blue section would argue  
from the perspective of the  
physician, people seated in the  
yellow are would argue from  
the perspective of the loved-  
ones and people seated in the  
magenta section would take the  
position of the patient, all based  
on the provided scenario.

**Patiënt**

Hier **geen** euthanasie, ...

**Naaste**

Hier **wel** euthanasie, ...

**Arts**

Hier **geen** euthanasie, ...

Figure 6.15  
Bespoke cards to write down  
arguments in favor or against  
euthanasia in a specific scenario.



**Scenario 1:**  
**Harry and Elke**  
My love will know the best time

Harry and Elke visit their GP when Harry (71) has been living with Alzheimers for a few years already. Two months prior Harry had made an Advance Euthanasia Directive, in which he declares in plain English, which Elke has written down for him, that he does not want to live any longer. Elke does everything for her husband, and Harry can at times appear psychotic, disoriented, but also occasionally completely lucid. “If this is how it has to be, I want to die – but not yet, if that is not necessary.” In response to asking Elke if she is coaching her husband she says she helps him with everything, so this too “otherwise he forgets”. In a lucid moment Harry asks his GP: “If I am too far gone, Elke has to decide the time, will you help me with it?”

**Scenario 3:**  
**Jan and Jan Jr.**  
He never would have wanted this

Jan arrived at the care facility four weeks ago, an 82-year-old former entrepreneur with advance dementia. He was cared for at home for many years, he could afford the care, but has recently started to display more extreme behavior, aggression alternated with crying and hiding. Once Jan started to smear his feaces on the wall, Jan jr. asked the care-facility physician if he couldn’t end it “he never would have wanted this, he always told me in the way he transferred everything to me. I wish he would get pneumonia, but my dad is as strong as an ox.”

**Scenario 2:**  
**Jet**  
Nothing is up – yet

The GP has known Jet for twenty years, even if he didn’t see her much; she was always healthy. Now she is 78 years old. Recently the GP told her she has Alzheimers disease; he suspected this already for a year, but never told her, our of compassion. There was nothing he could do to help her anyway. Until recently Jet held numerous positions as an ex-politician. Outwardly there seems to be nothing wrong with her. But her husband died last year. She can’t handle the emptiness at home. Her best friends are also dead, she is lonely. She rarely sees her only daughter. Jet and her husband had a busy and rich life, that appears meaningless now. Jet is worried about her decline and wants to die.

**Scenario 4:**  
**Theo**  
A different person

Theo, an 83-year-old former lawyer has always been completely clear. The doctor has known him for a long time, and has – when Theo was diagnosed with Alzheimer’s disease – talked to him about his advance directive. If he no longer recognises his children, Theo said, if he has no idea of time, if he is deeply demented, then he wants to die – even if he then says he does not want to die. He is aware of the risks, and accepts this, being a lawyer. Theo thought he could stay ahead of the game, but dementia caught up with him. Suddenly he was lost, a different person. If he wants to die? Certainly not.

Figure 6.16  
Scenarios  
written by  
Henk Blanken



Figure 6.17  
Initial set up for timeline activity,  
with a much more basic timeline  
simply stating diagnosis,  
biographical death, biological  
death.

After this experiment Henk decided he wanted the participants to discuss specific scenarios (figure 6.16). Some statements and scenarios were tested among colleagues at Umeå Institute of Design and De Zwijger. People who had experience with dementia responded well to the scenarios, so therefore the scenarios were developed further. After some back and forth discussion about complexity, it was decided to have scenarios and design the tables in such a way that the participants would discuss a scenario from a particular perspective; the patient, the loved-one or the physician (Figure 6.14). Cards were made where participants could write down their thoughts (Figure 6.15). Four scenarios were imagined, in different stages of dementia with varying levels of complexity (translated from Dutch).

Additionally it was agreed to add a different exercise using the timeline graphic. Initially this was planned as a round-table activity as well (Figure 6.17), but practically this would not work because we would have to swap table coverings. Also it was seen as a good moment for the audience to stretch their legs and walk-about, hence the timeline was made as a huge print that everyone could interact with (Figure 6.18). Participants would think from the perspective of patient, loved-one and/or physician and pick the best time to die from those perspectives. Cards were made where reasoning could be noted down, if wanted (Figure 6.20).



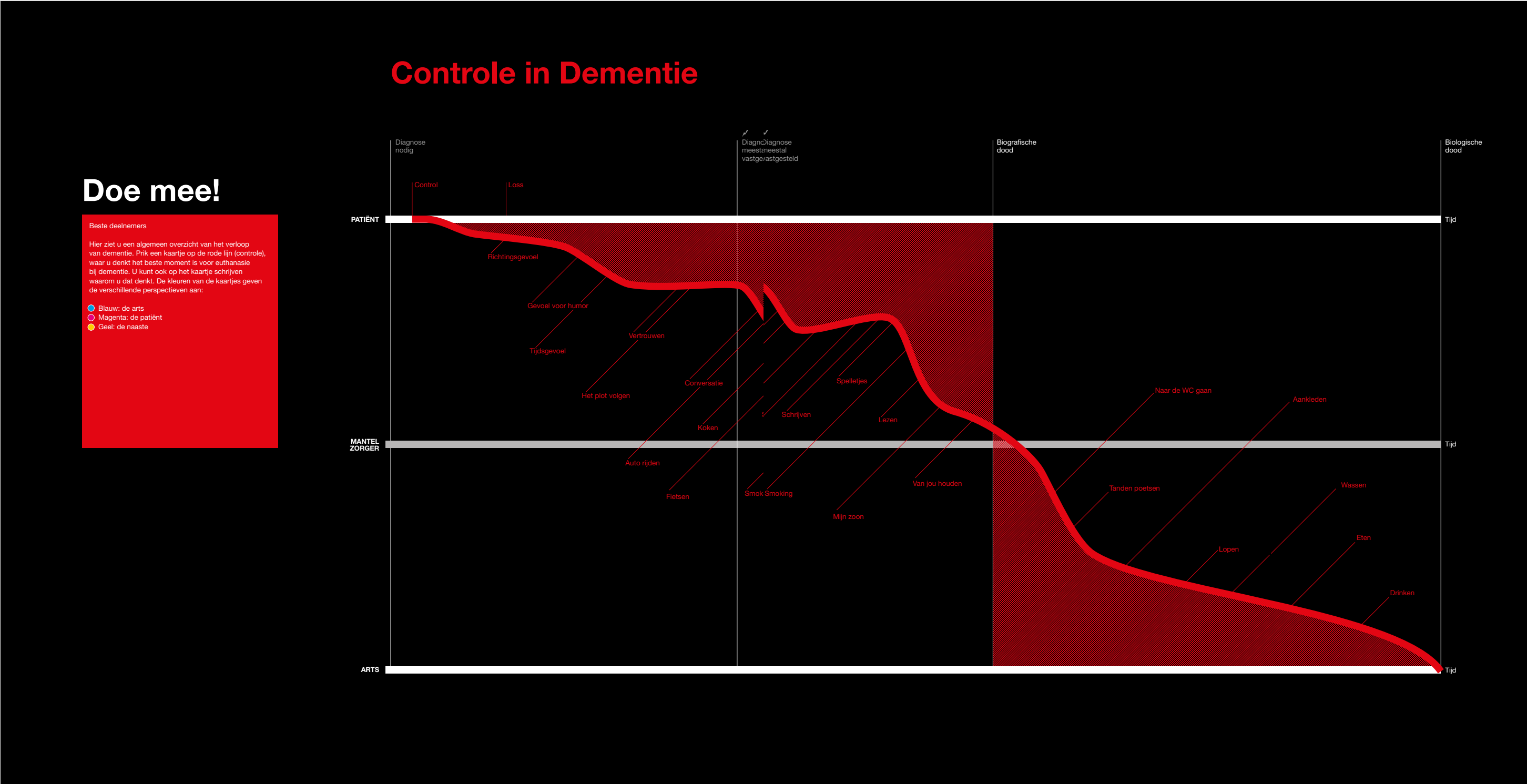


Figure 6.18  
Actual timeline used 'Control in dementia.' Graphic used for participant interaction, pinpointing the best time to die in dementia from the perspectives of patient, loved-one and physician.



**TIMETABLE ‘My death is not my own II’ 10 December 2018**

20.00-22.00 *Setting: 8 round tables with 8 chairs.*

18.30 - 19.30	Speakers dinner
19.45 - 20.00	Doors open
20.00 - 20.05	Play fragment of Henk’s TEDX talk
20.05 - 20.15	Welcome by Tanja van Bergen. Tanja reads some cards that were left at the previous event (figures 6.3-6.10), and asks some introduction questions to find out who is in the audience and how they relate to the subject being discussed.

**Round 1: The review committee and the physician**

20.15 - 20.30	Henk Blanken introduces the conversation. Jakob Kohnstamm introduces his expertise (chairman of the regional review committe for euthanasia). Tanja asks questions.
20.30 - 20.50	First round of round-table discussions. Each table needs to consent. Two scenarios being discussed (Jet and Jan & Jan jr.).
20.50 - 21.05	Summary (Tanja) Tanja asks each tables most important findings* – *make sure to ask Agnes Wolbert, director of NVVE

**Round 2: Patients and loved-ones**

21.05 - 21.20	Introduction by Constance de Vries (SCEN physician) and Aleid Truijens (journalist for De Volkskrant). Tanja asks questions about how the loved-ones fit in. What can you expect from a patient or the children? Is death the only solution?
21.20 - 21.40	Second set of round-table discussions. Each table needs to consent. Two scenarios being discussed (Theo and Harry & Elke).
21.40 - 21.55	Summary (Tanja) Tanja asks each tables most important findings.
21.55 - 22.00	Closing words. Tanja asks everyone to pin a card to the timeline; when is the best time for euthanasia in dementia?

Figure 6.19  
Timetable

Figure 6.20  
IJ-zaal at  
Pakhuis de  
Zwijger



**6.2.2 Use**

The public debate took place on 10 December 2018 at Pakhuis de Zwijger in Amsterdam, in the 'IJ Zaal' seating 80 people (figure 6.18). The event was sold out. The event was also live streamed and the video is still available for viewing on the website of Pakhuis De Zwijger: <https://dezwijger.nl/programma/mijn-dood-is-niet-van-mij-2>. The programme is outlined in figure 6.19 (translated from Dutch).

Some last minute changes were made to the schedule and the timeline activity was moved to the end of Round 1, as a leg stretcher. People would also be encouraged at the end of the evening to engage with the timeline again, if they had changed their mind of wanted to add anything.

Upon entering the room, people who arrived in groups were split up, so they would not sit together in order to encourage conversation. Additionally an attempt was made to spread well-known figures in the debate across different tables (such as Bert Keizer – SCEN physician and author, Gerrit Kimsma – physician and associate professor of medical ethics, Henk Blanken – author, Jakob Kohnstamm – ex-politician and chairman NVVE, Jan den Biggelaar – physician).

In the round-table discussions participants were encouraged to find consensus between patient, loved-one and physician. This was hard, and it was also hard for people to speak outside of their speciality, for example if a physician was seated at the ‘patient’ side of the table, they would have trouble to not let their professional knowledge take over in discussion (figure 6.21).

The scheduling had been somewhat optimistic, and it was quickly discovered the discussions took a lot longer then planned. The second round of scenarios was revised to just one scenario (Harry and Elke). The timetable exercise also took more time then planned and sparked lively conversation amongst the audience.





Figure 6.21  
Lively  
discussion  
about the  
scenario Jan  
and Jan Jr.

6.2.3 Outcomes

The evening was filmed for live streaming and is still available online (<https://dezwijger.nl/programma/mijn-dood-is-niet-van-mij-2>). The audio has been transcribed and analysed in Nvivo software. Coding in nodes was not applicable here, as there is no comparative data. However coding was used to highlight important sections and coded by themes derived from the literature (suffering, autonomy, timing and planned death). First the evening kick-off will be transcribed, this would set the tone for the event. Second, the responses to the scenarios will be discussed. Third, speakers insights will be relayed per theme, and lastly, a concluding summary of the event.

The evening was kicked off with a fragment of Henk’s TEDx talk, a beautiful and very personal way of framing the problem:

“We, Dutch people, are very proud of our right to self-determination. Just like we are proud of our liberal drugs policies. It is part of our national identity. Just like windmills and the red light district. But this right to self-determination we are so proud of – it doesn’t exist. The euthanasia law isn’t quite as liberal as everybody thinks. And if we are talking about dementia, the law is a ‘dead

letter’; a physician can help you, but he doesn’t have to. Euthanasia is not a right. The decision is not with the patients, not with the relatives, not your loved-one, but the physician and the physician only. The paradox is excruciating, your whole life you live in fear that you will be chasing nurses in your underwear. Chasing shadows. Chasing yourself. And you think “never that”, but once you are as confused as you never wanted to be, you are unable to request death. And then consequently, nothing will happen. Because physicians don’t kill people that can’t request this themselves, that can’t comprehend what is happening. Every year about 10,000 demented people die in the Netherlands. About half of those had documented they did not want to die this way. That they wanted to die with dignity. How many people succeed? A hundred. On average about 100 people escape that fate, but only because they request euthanasia in the first phase of dementia. Imagine. Your symptoms don’t show, you don’t behave badly, it could take years before you are sent to a care facility, and yet you decide to die already now. The courage that would be required. But what else can you do? There is no choice. Who doesn’t want to die too late has to die too soon. Because ‘on time’ is too hard.”

The evening was set-up for substantial audience participation, and the audience contributions will be relayed first, per scenario. Only three scenarios were discussed due to time limitations, and during the progress of the evening more emphasis was put on finding solutions per scenario, asking the audience to find what could work in these vignettes.

The first scenarios discussed was the story of Jet: The GP has known Jet for twenty years, even if he didn’t see her much; she was always healthy. Now she is 78 years old. Recently the GP told her she has Alzheimer’s disease; he suspected this already for a year, but never told her, out of compassion. There was nothing he could do to help her anyway. Until recently Jet held numerous positions as an ex-politician. Outwardly there seems to be nothing wrong with her. But her husband died last year. She can’t handle the emptiness at home. Her best friends are also dead, she is lonely. She rarely sees her only daughter. Jet and her husband had a busy and rich life, that appears meaningless now. Jet is worried about her decline and wants to die.

The audience felt it was important to make sure that Jet was not depressed. They found it odd that the doctor had not informed Jet earlier, maybe there was some important history there that was not clear? People thought euthanasia would not be quite an option yet, the suffering did not seem hopeless, but one thing they felt could be an option was a thorough ‘do not treat’ agreement.

The second scenario that was investigated was that of Jan and Jan jr.: Jan arrived at the care facility four weeks ago, an 82-year-old former entrepreneur with advanced dementia. He was cared for at home for many years, he could afford the care, but has recently started to display more extreme behavior, aggression alternated with crying and hiding. Once Jan started to smear his feaces on the wall, Jan jr. asked the care-facility physician if he couldn’t end it “he never would have wanted this, he always told me in the way he transferred everything to me. I wish he would get pneumonia, but my dad is as strong as an ox.”

The audience thought it was important to know more information from Jan senior’s GP. It was agreed that euthanasia was not possible, unless Jan would be able to express this himself, but solely the son’s request was not enough. Also the audience hoped that the suffering might not be hopeless, Jan had only been in his new home for a short period, and good care might help him. Here too a good and clear ‘do not treat’ agreement seemed an option, even if Jan jr. was worried his father would not get sick.

The last scenario that the audience discussed was that of Harry and Elke: Harry and Elke visit their GP when Harry (71) has been living with Alzheimers for a few years already. Two months prior Harry had made an Advance Euthanasia Directive, in which he declares in plain English, which Elke has written down for him, that he does not want to live any longer. Elke does everything for her husband, and Harry can at times appear psychotic, disoriented, but also occasionally completely lucid. “If this is how it has to be, I want to die – but not yet, if that is not necessary.” In response to asking Elke if she is coaching her husband she says she helps him with everything, so this too “otherwise he forgets”. In a lucid moment Harry asks his GP: “If I am too far gone, Elke has to decide the time, will you help me with it?”

A learning from the first round-table discussion was to ask the audience more specifically to search for possible solutions to the problem, so responses here were more focussed around what would be possible in this case. The audience felt that the physicians could play a bigger role here. The SCEN physician could be part of discussions earlier in the process, and the GP could make sure the request came from Harry and not Elke. Another suggestion to do this was by documenting the conversations between Harry and Elke on video. Additionally the reason why Harry wanted to postpone euthanasia was seen as significant, what was it that gave his life quality still?

The speakers of the evening were representing the legal angle (Jakob Kohnstamm), the SCEN physician’s perspective (Constance de Vries) and the loved-one’s experience (Aleid Truijens).

Suffering

The need to be able to establish unbearable and hopeless suffering was very clear. Not only is this a requirement of the law as Jakob Kohnstahm explains:

*“The curious thing is ... if I were to receive a diagnosis now, Alzheimer, and I would see my GP and mention, the fear for loss of dignity, then the GP could perform euthanasia now, because that fear for the future can cause unbearable suffering now. And the curious thing is, if you can’t express this, then the unbearable suffering needs to be confirmed in another way.”*

But, establishing unbearable and hopeless suffering is also important for the person having to perform euthanasia as Constance de Vries clarifies:



“We do need to be able to see – and how you assess this we can discuss – but I do need to see that someone is suffering unbearably, because that is the law. That is our safety net. Someone who has always said, “if I am demented I want to die, if I pee my pants, rub poo on the walls, crawl under tables, and have to cry all the time, hit and bite my neighbours, then I want to die”. But if this person doesn't seem unhappy at all, then it becomes really difficult. The more extreme the behavior, the more likely it is for me to think, “he must be unhappy”, if there is a lady who very contentedly sits hugging with a doll, or stroking a robot seal, and smiling friendly at all the people, then I can't see any unbearable suffering and thus we protect them. Even if she had said she would never want that. That is the law.”

The advance euthanasia directive is often seen as a great relief, having it might prevent needless suffering. However, as Aleid Truijens describes, it can also be seen as a threat:

“My mother did have an advance euthanasia directive [...], she always said “if I show signs of dementia, then you must help me to die” and then the time was there and she couldn't get rid of it [the AED] quick enough. Every time we visited she would ask “can I live a bit longer please?” So for her the AED was a huge threat. “I am a burden to you, I am a burden to the care-facility, why am I still alive, I don't have a purpose”.”

Suffering in dementia is not only with the patient as Aleid Truijens points out:

“Those who did suffer unbearably – that was clear – that were the four children and grand children who witnessed that once so wonderful and intelligent woman turned into something else. But euthanasia is not for the family.”

Autonomy

One way of expressing autonomy is writing an advance directive (Burlá et al., 2014). SCEN physician Constance de Vries stresses that AEDs could be improved upon as well as being much more specific like in ‘do not treat’ agreements:

“I think you could prevent some of the problems by being very detailed in your AED, and you need to find a GP who wants to help you. [...] And you can also be much more clear and detailed in your treatment ban, not just if “I get pneumonia I don't want antibiotics”, but you could also say “if I become diabetic, don't give me insulin”, or “if I can't eat or drink independently, don't feed

me, then I will die, but I do want you to keep me comfortable”. You can't just let somebody dry out. But you can say, “if I can't eat, then you guys have to make sure to allow me to leave, comfortably”.

Transferring this autonomy to another remains complicated, as Jakob Kohnstamm illustrates:

“There have been cases that I have witnessed as chairman where the loved ones expressly notify the physician “this is the moment where my loved one has said, this is what I do not want”, the question is then, does the physician have the duty to to fulfil this wish? I think what you [Henk Blanken] intended to say, that it would be nice if that was the case, that your right to self-determination would be respected completely. But this is not the case in the law. Yes, the loved ones can indeed specify the time of the original desired euthanasia, but then the physician will still have to establish – and I'll get back to this – that there is unbearable suffering.”

Timing

It was confirmed that if one wants to perform their autonomy, they have to be cognitively competent and thus – in dementia – this is only possible early in the disease. Jakob Kohnstamm explains:

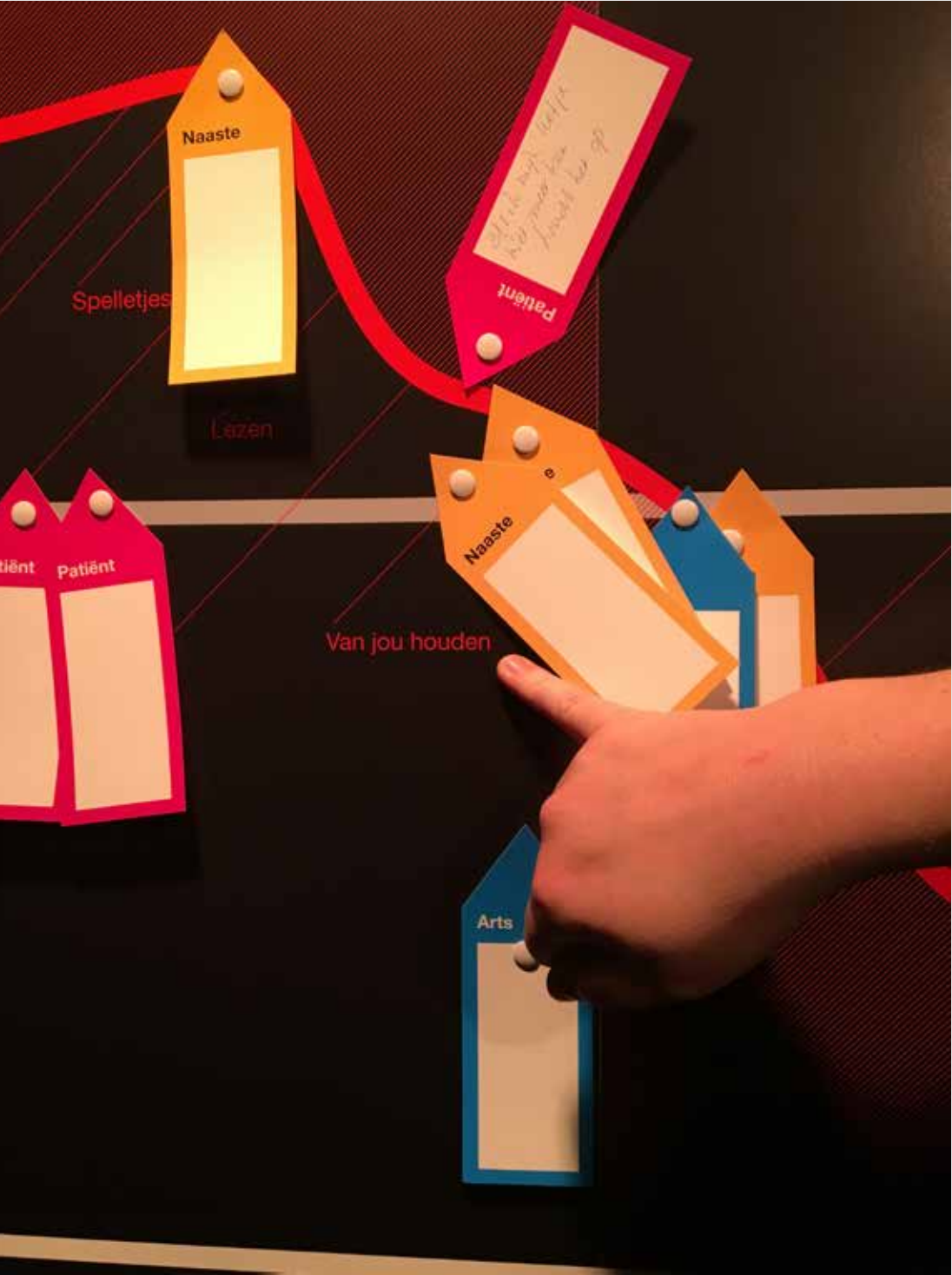
“I hear this from friends and physicians, this is a big hurdle; if the person in question is unable to communicate, unable to confirm “this is what I want”, and if you have never even known the person in question when normal communication was possible, or at least minimal communication, then that makes the situation very complex for the physician, to perform this act. And so, the conclusion, [...] be early! Discuss, at length, with your GP. Several times, every time you see your GP if possible. This will help smooth the decision making process of the GP, and then it isn't even dealing with autonomy that Henk was talking about, but they are two decisions that could meet in an eventual euthanasia.”

It is important for the individual to take action, if an early diagnosis is in place, one has to start planning for their end-of-life if they want to remain in control as Constance quite clearly states:

“It also means head out of the sand, if I want stuff to happen, I have to take action. Don't postpone it and just get on with it.”

Aleid Truijens was quite charmed with reducing complexity and taking control herself, if need be:

Figure 6.22  
Forgetting  
“loving you”  
was the most  
often chosen  
time to die by  
loved-ones.



“The pill of Drion [a fictional end-of-life pill] I shall call it, seems much more plausible to me than leaving it to others. And how to sort that with family and such – some people don't have a loving family. It is complicated, so I don't have answers, but it could be beautiful.”

The timeline exercise triggered much conversation. Different types of suffering would seem to be worse than others, and the most desired time to die, from a loved-ones perspective was when patients were unable to remember their loved ones (Figure 6.22).





Figure 6.23  
Physician’s best times to die varies greatly (blue cards).

Physicians actually chose widely varying points which did not confirm findings from the literature, that physicians prefer to perform euthanasia 'early' (figure 6.23).

The timeline was much discussed and photographed (figure 6.24), but not so many people pinned a specific time on the timeline. From some audience feedback it would seem that this was because it is really hard to choose the best time to die.

Tanja concluded the evening by asking an audience member, Agnes Wolbert, who is the director of the NVVE (Dutch Association for voluntary end-of-life) to summarise her main findings of this evening. Agnes states that each case is unique and it would be folly to try and define guidelines on “how it should be done”. She stresses the importance of having the discussion between patient, physicians and loved-ones “every case you meet is unique, and it means that close contact with a GP, patient and loved-ones is essential”. Loved-ones do have an important role to play is what she felt became clear this evening “maybe not in making the final decision, but primarily in supporting; making appointments on time, sending patients to the GP, initiating the conversation(s), having the conversation together”. What she missed in this evening was the important roles she thinks physicians should play:

*“The third thing I noticed that we concentrated a lot on patients and their loved ones, but the physicians only come up when there is the question of the actual performing of euthanasia. But how much more important would it be to have these conversations with your patients, instead of waiting for the patient to initiate this, and then saying “well, when the time comes” – I hope you will never say this – “then we will help”, that is possibly the worst thing you can do, to have this conversation at the very end, and then to not give any clear information “we will see”, this is what we, at the NVVE, hear a lot, and everything we do is focussed on preventing exactly that! We aim at keeping people well informed, to have them have these conversations well informed, with their GP. It would be super valuable if the GP would take the initiative to start this type of conversations at an early stage. “Do you ever think about your end-of-life?” So what would it look like if physicians started these conversations?” (Agnes Wolbert)*

Henk Blanken’s final insight of the evening was:

*“The focus must be on the conversation between the patient, the loved-one and the physician. It will have to be meaningful for the physician, the physician will need to be able to act upon this, and how we can do that – no idea – yet.”*

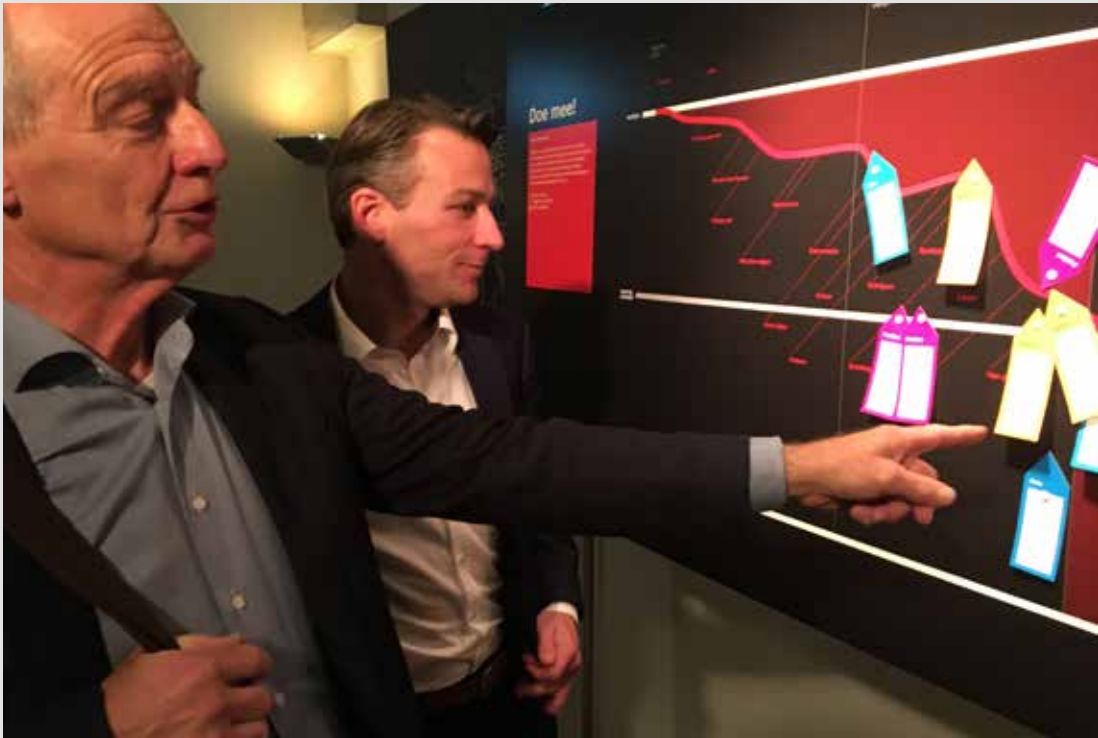


Figure 6.24  
Two GPs discussing (and later documenting) points on the timeline.

6.2.4 Discussion

After this evening the issue had also not been resolved, but it felt like some progress was made. Various voices were heard and some of the complexity was unfolded. For example the importance of a crystal clear advance euthanasia directive and some ideas on how to go about doing that, using various media – one need not be restricted by words on paper. Additionally knowing that it is crucial to have a detailed ‘do not treat’ agreement was an important finding. Also it was clear that physicians would need to be educated further in being able to handle, and even initiate end-of-life conversations with their patients.

Additionally very interesting conversations were held at the speaker’s dinner and during the after-event drinks. At the speaker’s dinner Constance and Henk discussed more practical ways for him to be able to have euthanasia if he would develop dementia. Constance had some great examples of advance euthanasia directives, which were – interestingly – based on exactly the same quality of life criteria as outlined in Chapter 4.2.2. Her recommendation was to track what would give his life quality and how he would adapt to his situation. This would help her greatly inform decisions about performing euthanasia. After the event a conversation between two SCEN physicians (Bert Keizer and his colleague) was also of a more practical nature. They were comparing stories on what ‘procedure’ they followed when they were performing euthanasia. What did

they say as they entered the house? What would they say to the patient as they administered the medicine? And how did they leave the family after the deed was done? Bert asked if there were no rituals that could be designed for this?

Following the event some new contacts were made. Some people requested the timeline for personal use, but also a request to use the timeline was received from Anke van Beckhoven from Together Against Loneliness [één tegen eenzaamheid], an initiative from the Ministry of Health, Wellbeing and Sport, who wanted to use the timeline as a tool for communication in a conversation about the burden primary carers carry and personal values for a dignified life (<https://www.eentegeneenzaamheid.nl>). A connection was also made with the Royal Dutch Medical Association (KNMG) who were interested in collaborating in a workshop to help KNMG formulate a stance on the debate on euthanasia in dementia. How this unfolded is described in detail in the next Chapter (7).

Shortly after this event Henk wrote his manifesto (Blanken, 2018), which was published in De Correspondent [Dutch independent online news platform]. His opinion from first writing in 2017, speaking with me in 2018 and publishing this has become more nuanced. He still wants to die ‘on time’ but is a bit more careful in how to transfer the responsibility of decision making to a proxy.



# Chapter 7

## Royal Dutch Medical Association (KNMG)

The Royal Dutch Medical Association (KNMG) is the professional organisation for physicians of the Netherlands with its main objectives to improve the quality of medical care and healthcare in general, and to improve public health. They achieve this by proactively responding to developments in health care and society, through developing guidelines and policies, lobbying, and providing services to their members.

The KNMG works in close collaboration with other stakeholders such as government, politics, health care insurance companies, patient organisations, and other organisations in healthcare, to achieve high quality healthcare. KNMG policies cover the full range from public health issues, medical ethics, science, health law to medical education. In order to address the debate on euthanasia in dementia and to provide support for physicians in the Netherlands, the KNMG is undertaking a series of workshops to help them formulate their stance on the debate and to develop a handhold for physicians being actively involved in euthanasia requests in dementia.

Representatives of the KNMG were present at the public debate at Pakhuis de Zwijger on 10 December 2018, which resulted in them seeking contact with the primary researcher of this thesis with a request to collaborate in setting up round-table discussions about euthanasia in dementia.

In this section first the intentions and set-up of the round-table discussion with be explained (7.1). Next, the round-table discussion itself will be described with its outcomes (7.2). And lastly the use of a design application in a real-life setting will be reflection upon (7.3).

### 7.1 Roundtable discussion

The Royal Federation of Physicians (KNMG) is an organisation that supports physicians in the Netherlands. In order for the KNMG to formulate their vision and recommendations for physician support with euthanasia requests in dementia, the KNMG has set up a series of activities. The KNMG want to show stakeholders that they consider a wide variety of viewpoints beyond the medical profession. KNMG’s Ethics Policy Advisor contacted this research’s primary investigator to ask for ideas on how to collect some of these viewpoints. A proposal was submitted and after some internal deliberation at KNMG it was decided to run two roundtable discussions using The Plug video as a conversation starter. Additionally it was requested that the primary investigator of this research would moderate one of the roundtable discussions together with another independent moderator, Hans van Santen, a General Practitioner and ex-editor of the magazine Medisch Contact. These moderators would be independent from the KNMG, to avoid KNMG bias.

The first roundtable discussion was planned for 14 March where the KNMG had invited academics, ethicists and authors to take part. The second roundtable discussion was planned for 20 March 2019, where sixteen representatives of nine different social organisations gathered to discuss together the complexities around euthanasia in dementia. Here the second roundtable discussion is described because this meeting was attended by the primary investigator of this research.

Roundtable euthanasia and dementia	
Participating patient and carer organisations	
ANBO	A mayor Dutch advocate for senior citizens
V&VN	Nursing & Caring Netherlands
NPV	Christian Dutch Patient Association
VGZ	Professional Association of spiritual caregivers
NIP	Dutch Institute of Psychologists
PCOB	Christian Elderly Association
KBO	Catholic Elderly Association
NVVE:	Dutch Association for a voluntary End of Life
Alzheimer Nederland	Alzheimer Association of the Netherlands
Humanistisch verbond	Humanistic Union

Table 7.1  
List of participating organisations

#### 7.1.1 Participants

The KNMG has set up a series of events to research their position in the debate on euthanasia in dementia. This particular event would look at the perspective of patients and carers. Therefore they invited representatives of all important patient and carer organisations in the Netherlands; ANBO, V & VN, NPV, VGZ, NIP, KBO/PCOB, NVVE, Levenseindekliniek, Alzheimer Nederland and Humanistisch verbond (Table 7.1 for translation and expansion on participating organisations)

All participants listed wrote position papers about their viewpoint on the debate, which were carefully studied by both moderators and taken into consideration by the KNMG. These position papers were written specifically for KNMG consideration and thus will not be disclosed here.

Roundtable euthanasia and dementia	
Wednesday 20 March 2019	
Timetable	
18.00	Welcome invited parties. Bread meal.
18.30	Opening words by René Héman, Chairman KNMG
18.35	Introduction to the programme by moderator Hans van Santen
18.40	Meet and greet
18.50	Showing The Plug
18.55	Discussion
19.10	Diving group in two subgroups according to list.
19.15	Discussion of first vignet
19.45	Discussion of second vignet
20.15	Groups reconvene
20.20	Reflection
20.30	Closing words by Hans van Santen

Table 7.2  
Programme of Roundtable euthanasia and dementia Wednesday 20 March 2019

#### 7.1.2 Set-up

The intention of the roundtable discussion was for the participants to engage in conversation with each other, no debate: no winners or losers. First a plenary discussion with all 16 participants was held in response to The Plug video. After this conversation the participants were divided into two groups, one who would be moderated by Hans van Santen and one by Marije de Haas. Each group discussed two specific case studies, 30 minutes for each case. The process was documented by five KNMG employees per group, who were not allowed to participate in the conversation. Additionally a professional journalist was present to record the process and who will write a full report (to be published summer 2019). This research was not allowed to make independent recordings of the evening, though permission was granted to write about the experience.



7.2 Conversations

The initial plenary discussion was limited. The Plug video yielded few responses. Hans van Santen asked the audience if they “would be up for one [the Plug]”, here there was some discussion, some felt this would be scary. Participants did feel that the arguments of Sabrina Naldi in the video were strong, but a representative from one of the patient organisations was clear that it was not quite that simple; what would be rights of this new person that emerges in dementia? Additionally there was some unease about a ‘robot’ making these decisions “you can’t replace a person’s needs with data based decisions” and that it would not be possible to programme the parameters.

After this initial discussion, the group was divided in two, and each group discussed the same two case studies. For each case study the group was divided into smaller groups who were asked to speak only from an assigned perspective; physician, loved-one or patient. Gert van Dijk has carefully assigned perspectives so that participants were forced to look at the case studies from another perspective than that of their own speciality.

The vignettes are translated in figures 7.1 and 7.2 and the responses to these vignettes are discussed.

From the conversation about Vignette 1 (Figure 7.1) emerged the need for an Advance Directive to be much clearer. We discussed what that would mean, practically, and here we referred back to The Plug video to see what kind of criteria you would need to ‘program’. Participants felt empathetic towards Mr. van Dam, but also agreed that euthanasia at this stage would not be possible. There was talk about how to enhance Mr. van Dam’s quality of life, and the importance of a do not treat agreement. This would be the only way that Mr. van Dam could have an ‘early death’. The do not treat agreements were discussed in some detail in what could be included and excluded, but also the need for these to be extremely clear.

In response to Vignette 2 (Figure 7.2), the role of the loved-ones was discussed in-depth; sometimes the feeling of being a burden would trigger people to write an advance euthanasia directive, in order to prevent suffering in their loved-ones, however, if euthanasia would fail in this case, it could actually cause more suffering in the loved-ones. This idea was a bit of a revelation to some participants, and likely will be much food for thought. For now, no resolutions were proposed in this regard. Participants could empathise strongly with the loved-ones in this scenario, but could equally see

Vignette 1: Mr. van Dam

Mr. van Dam is 84 years old and has had Alzheimer’s disease for the last four years. His disease is progressing and he has been moved to a care facility, because the care he needs can no longer be provided at home. However, in his Advance Euthanasia Directive that he had written a few year prior he was clear, he did not want to go to a care facility. At the time he told his GP “If I need to go into a home I want euthanasia Doctor, for me that will be unbearable suffering”. Now he often doesn’t recognise his wife when she visits. Sometimes he is sad and angry with his wife because she has ‘let him down’. Often he is agitated at night and starts wandering through the facility. At those times he seems unhappy and confused. At those times he sometimes tells the geriatric specialist that he wants to die. At other time he seems content with his life in the care facility and denies his death wish. “Dead, who me? Oh no doctor!”

What factors do you consider from the perspective of physician, loved-ones and patient? What factors are communal, which ones are different from the three perspectives?

that performing euthanasia in this case would be out of the question, it was too late and the same would apply to Mrs. Ter Steeg as discussed earlier about Mr. van Dam, that a clear and well-written ‘do not treat’ statement would be the best option.

Overall, reflecting on both vignettes, it was seen as very important for the physician to be involved in discussions with their patients very early on, preferably even before a diagnosis. In these end-of-life conversations between GP and patient it would be essential for the GP to not steer the conversation to euthanasia, but discuss quality in end-of-life. All did agree there would be much power in the do not treat agreement, which is a patient’s right, and the euthanasia request can only ever be a wish. The distinction between ‘no treatment’ being a right and ‘active euthanasia’ being a request was fiercely discussed, because some participants felt there was no rational distinction between those two options.

Additionally there was some discussion about how much in ‘control’ you could be in end-of-life, with the religious associations feeling not so much, and the other parties feeling you could be in control quite a lot.

Figure 7.1  
Vignette 1,  
translated  
from Dutch.

Figure 7.2  
Vignette 2,  
translated  
from Dutch.

Vignette 2: Mrs. Ter Steeg

Mrs. Ter Steeg is 62 years old and has been living with vascular dementia for the last 7 years. She is completely care-dependent and is limited to chair with integrated table to avoid falls. She is incontinent for urine. Shortly after receiving her dementia diagnosis she made an advance euthanasia directive where she would want euthanasia as soon as she was unable to recognise her children. “I don’t want that doctor”. Now she no longer recognises her husband and children, she no longer requests food or drink, but will eat and drink if she gets offered sustenance. She is living in a care facility, but shows no signs of unhappiness and seems content with her situation. However, her husband and children find her situation undignified and insist on euthanasia “mother would not have wanted this”. When the geriatric specialist addresses this with Mrs. Ter Steeg she does not seem to comprehend what the doctor is asking.

What factors do you consider from the perspective of physician, loved-ones and patient? What factors are communal, which ones are different from the three perspectives?

7.3 Reflection

It was interesting that an association such as the KNMG was interested in using the material created for this research for their purposes. In conversation with Gert van Dijk (KNMG’s Ethics Policy Advisor) to plan these round-table discussions a lot of different options were discussed and the roles the scenarios made for this thesis could play. They were interested in this different way of looking at this ongoing debate that has reached a certain ‘staleness’ in the Netherlands. For the KNMG it is very important to develop their own point of view on the debate and the triggers developed for this research could potentially spark some renewed interest.

Meeting the roundtable participants informally during the meal served for this evening as introduction it was clear that most participants were a little confused about the role a designer could play in this debate. It was important to convince the participants that being a designer did not mean that there was no in-depth knowledge about the debate. Perhaps a coincidence but two of the younger KNMG employees seemed certainly more open to the idea of a designer being involved, and one of these was quite charmed by the idea of a Plug, and

the use of technology in euthanasia. After some discussion, participants felt more at ease once they realised the video was based on ‘serious’ research.

Reflecting on the evening with some participants after the event was finished, it was clear that The Plug scenario does need some time to sink in. Participants felt they would have a lot more to say about The Plug now. Some felt that it was a rather absurd thought experiment, where others felt that it was a good conversation starter. Initially the participants had felt too uncomfortable at the start of the evening with so many new faces and representatives of parties that they were likely to have conflicting ideas with to express their own opinions on such a provocative scenario. Moreover, Gert van Dijk, the organiser of both events said that The Plug video had yielded a rather engaging discussion in the first roundtable discussion which had been attended by a different type of participant group.



## Part 6

### Learnings





# Chapter 8

## Discussion

This thesis has explored how design approaches can be used to further the debate on euthanasia in dementia by designing prompts addressing four themes;

- suffering,
- autonomy,
- timing,
- planning death.

This chapter reviews and contextualises the findings to firstly consider how dying with dementia can be improved by looking in detail at these four themes (8.1). Secondly the use of design to prompt discussion is examined (8.2); and finally, the limitations of this research are summarised (8.3).

### 8.1 Dying with dementia

The research questions (1.1) have been investigated through a systematic literature review (Chapter 2), survey and interviews (Chapter 5), and real-world applications (Chapters 6 and 7), and will be discussed by theme below.

#### 8.1.1 Suffering

Previous literature (2.2.1) suggests that suffering is individualistic and difficult to assess. The empirical research from the survey, interviews (5.3.2.1.3) and real-life applications (7) found that the perceived suffering and actual suffering are interlinked, meaning that carer-burden is influenced by personal interpretations of whether the patient is suffering. The experience of being a carer and finding caring burdensome can influence the fear of becoming a burden. This new data makes clear that the ‘burden’ issue is much more complex then previously found. Perhaps this is because of the stigma around the idea of burden. Additionally it would seem that care-giver burden, physician burden, societal burden and patient burden have been looked at separately before, but have not yet been linked together in this way.

As summarised in Chapter 2.2.1, the literature found that the fear of living with dementia is driving people to request euthanasia (Gastmans & De Lepeleire, 2010). Assessing suffering in dementia is complicated because it is nearly impossible to have a meaningful two-way conversation with people with (advanced) dementia (Hertogh, 2009; Smith & Amella, 2014; Buiting et al., 2009; Buiting et al., 2008). It is difficult to assess if people with dementia are able to adapt to their new situation (Jongsma et al., 2016). Additionally, it is hard for the assessor to not project their own feelings on assessing suffering in others (Rietjens et al.,2009b).

#### 8.1.1.1 What is suffering?

Participants felt that suffering could best be assessed by the patient (5.3.2.1). Where there is loss of cognitive function, it was found that the best people to assess suffering in a patient would be loved-ones or physicians. However, loved-ones could have a biased view:

I: “[...] *I think family members might have too much of an emotional and even monetary stake.*” [survey]

F: “*But this is so tricky, hard, if not impossible for those who are assigned to make such a decision.*” [survey]

B: “[...] *see, if you as a doctor thinks that someone should leave this life harmoniously, so that daughter who lives in America, who he [the hypothetical patient] hasn’t seen for 30 years, he has to make peace with her, otherwise he can’t go. Complete nonsense of course, but sometimes you have physicians who project quite a bit, their idea of a good death.*” [interview]

It is unclear if people with dementia are able to judge and adapt to their own changing condition (Jongsma et al., 2016). What does seem apparent is that people with dementia live in the moment, which is perhaps the best way to accept their predicament:

B: “*But we hesitate, take someone who was a really good drummer, and in his dementia he can’t play drums anymore, but he never mentions it, and the family would say “he can’t play the drums anymore”, but the drummer says “so what?” He doesn’t even know what a drumset is.*” [interview]



8.1.1.2 Who is suffering?

In dementia suffering occurs in the care-giver, the physician, society and the patient (Hiel et al., 2015; Sercu et al., 2012; Cantarero-Prieto et al., 2019). Suffering did not only happen with the patient; loved-ones also suffer, and perhaps even more then the patient (5.3.2.1)

Aleid Truijens: *“Those who did suffer unbearably – that was clear – that were the four children and grand children who witnessed that once so wonderful and intelligent woman turned into something else. But euthanasia is not for the family.”* [real-life application, 6.2]

These four categories of suffering are expanded in the following sections. The findings from this research have added to knowledge in assessing quality of life in dementia, understanding where euthanasia requests come from in dementia, and additionally arguing for ways to lessen suffering and accepting ‘the feeling of being a burden’ as a legit symptom of suffering.

8.1.1.2.1 Care-giver burden

The carer-burden has been investigated thoroughly and it is found that care-giving may be beneficial for people living with dementia, but not the care-givers themselves (Hiel et al., 2015). Some research indicates that carer-burden can be caused by lack of time (Luchetti et al., 2009), or that care-giver burden is caused by the characteristics of the care-giver (Schoenmakers et al., 2010). The severity of the patient’s symptoms are linked to the burden care-givers feel (Mohamed et al., 2010). However, other research concluded that more research was needed to determine why informal care-givers for people with dementia have a diminished quality of life (Farina et al., 2017). It is also recommended that care-giver burden should be included as a criteria in policy making and clinical practise (Bastawrous, 2013). Holey and Mast (2009) investigate the relation of anticipatory grief with carer-burden in dementia, and found that these are strongly linked. Anticipatory grief *“encompasses grief in anticipation of the future loss of a loved one, in addition to previously experienced and current losses as a result of the terminal illness”* In dementia, care-givers already experience loss even if the patient has not yet died, however this loss is not considered in defining carer-burden (Holley & Mast, 2009, p388). Defining loss, suffering and burden for care-giver, physician and patient in more detail would help

to understand the ‘being a burden’ that people with dementia like to avoid.

Chapter 5.3.2.1 reported findings from case study 4.1 in which participants gave accounts that agreed that being a care-giver is hard:.

B: *“Ma is caring, it is killing her, kids visit, and then it doesn’t seem all that bad.”*

8.1.1.2.2 Physician burden

Chapter 2.2.4.4 reports that physicians don’t enjoy performing euthanasia. Many physicians can understand the request for euthanasia and want to help relieve the patient’s suffering, but still find performing euthanasia an unpleasant experience (Sercu et al., 2012; Stevens, 2006; Georges et al., 2008). A recent study found that physicians often feel pressured by euthanasia requests. This pressure comes in a variety of forms; the relationship between patient and physician, the relationship between loved-ones and the physician, the interpretation of advance directives and the inability to accurately assess suffering, as well as time pressure and other organisational factors (de Boer et al., 2019).

Chapter 5.3.3.2.2 and Chapter 6.2 reported findings from case study 4.1 and 4.3 in which participants gave accounts that comment on the burden that physicians may feel in being asked to perform euthanasia:

Jakob Kohnstamm: *“I hear this from friends and physicians, this is a big hurdle; if the person in question is unable to communicate, unable to confirm “this is what I want”, and if you have never even known the person in question when normal communication was possible, or at least minimal communication, then that makes the situation very complex for the physician, to perform this act.”* [6.2, public debate]

8.1.1.2.3 Societal burden

Even though healthcare in the Netherlands is free, the media talks frequently about the cost of dementia, and the concern of supporting a growing group of people living with dementia (volksgezondheidzorg, 2015). People with dementia might be feeling societal pressure, as participant F explains:

F: *“The idea of not wanting to be a burden could arise from societal pressure; if everyone has euthanasia in dementia you feel you might have to as well. If a device such as The Plug would exist, would this not also trigger*

*a commercial expectation, from insurers for example? Care does cost a lot of money after all.”* [survey]

The economic burden from a societal perspective refers to the costs of all resources consumed or lost due to dementia (Xu & Qiu, 2018). The economic cost for dementia per patient, per year, *“is on average €32,506.73”* in Europe (Cantarero-Prieto et al., 2019, p1). The World Health Organisation has recognised dementia as a global public health priority (WHO, 2012).

8.1.1.2.4 Being a burden (patient burden)

Although no statistical data are available to confirm whether euthanasia requests in dementia come only from people who have experienced dementia in a loved-one, anecdotal evidence would strongly suggest that this is the case, as described by Marc van Toor from the Disciplinary Court for Healthcare [Tuchtcollege voor de gezondheidszorg] in email communication with the primary researcher:

*“No research has been conducted into this phenomenon. However the RTE can conclude from the dossiers based on reports from SCEN physicians that requests often come from the fact that those requesting euthanasia have experienced the effects of dementia up-close and based their decision on this: I don’t wish to experience that.”* (Tuchtcollege, van Toor, 2019)

Those who had witnessed dementia in their loved-ones were indeed the most likely to request euthanasia according to Bert Keizer (5.3.2.1):

B: *“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.”*

This would suggest that the experience of caring for loved-ones with dementia is driving euthanasia requests. It seems logical that people diagnosed with dementia worry about becoming a burden, after all, they themselves have experienced carer-burden. However, worries about becoming a burden are not recognised as ‘unbearable suffering’ and therefore do not carry any weight in an euthanasia request (Brock, 2000; Dening et al., 2012).

The SCEN physician confirms this:

B: *“The funny thing is that, with a euthanasia conversation, people say, I just feel bad for my children, and then you always say “you can’t say that, I believe you feel it this way, but you can’t say that, because then I can’t help you.”* [interview]

The feeling of ‘being a burden’ came up during interviews and the applications (Chapter 5, 6, 7) and was found to be more complex then the literature concludes (2.2.1.2). New literature found certainly acknowledges that carer-burden exists, but tends to investigate this feeling of burden in a clinical way, linking it to depression and patient behavior (Mohamed et al., 2010; Schoenmakers et al., 2010). If the fear of dementia drives people to sign advance euthanasia directives, this could mean that the fear of being a burden triggers people to write advance euthanasia directives in order to prevent suffering in their loved-ones.

A: *“Maybe I will get scared when I am closer, but at the moment I am rather convinced I would prefer not to be a burden for others.”* [interview]

8.1.1.3 Methods to assess suffering

Measuring quality of life is complex. Diversity in knowledge between patient, loved-ones and physicians is hard to compound in one ‘tool’ (Sawatzky et al., 2018). Perception of quality can vary between patient, loved-one and physician, and is also determined by cultural heritage, life goals and definitions of autonomy (Winzelberg et al., 2005; Carr, 2001). When the patient is unable to speak for themselves this capacity needs to be transferred to a ‘surrogate’, not all ‘surrogates’ are comfortable about speaking on behalf of the patient (Johnson et al., 2015). The role of the carer as advocate on behalf of the patient as well as proxy decision-maker may conflict with the carer’s own interests (Keywood, 2003). Informal caregivers were more reliable proxies when quality-of-life assessments on palliative patients were tested between patient, carer and nurses, however carers and nurses alike overestimated psychological symptoms, confirming the complexity of assessing quality-of-life in cognitively incapable people (Dawber et al., 2016).

Suggestions emerged from the research, particularly in the real-world application (6.2), on how to better assess suffering, for example, communicating the need for the advance



directive. Constance de Vries, a SCEN physician, gave a story about a dementia patient in her care where they found a solution to support this patient confirming her euthanasia wish, even if (verbal) communication was not possible (6.2.3). They wrote a detailed advance directive and put it in a large red envelope, which had a prominent place in the bookshelf. The advance directive was discussed regularly with Constance and the husband, and it became a signpost for a euthanasia wish:

“At the time euthanasia became more relevant, her husband would say, “Margriet it is here” [pointing at red envelope], “it is here on the bookshelf, and if you want it, you just go and get it.” Margriet had a typical Parkinson walk, and she would walk to the bookshelf, but she would just pass it – she did not want the envelope. [...] But having it gave here a secure feeling; “I can always escape when I want,” this was very important for her.”

One participant (L) described an anecdote of a semi-objective carer who could have a clearer view about whether a patient was suffering. The important factors were that the carer was not related to the patient, didn’t have any particular expectations from the patient, and was there full-time to observe the patient’s behavior in a more holistic way:

L: “So then at a certain point they had this very good friend, caretaker, that could live on their – they have a farm – for free, and she would take care of them. And she, because she was a bit outside, but still part of the family, she was always there, she could really assess, really see when it was going fine and when not, because she was constantly there, and I think that’s ... so yeah ... the question if children of these people, if they are enough to assess this ... “well, you know they are doing fine, we had cake last week,” but that is not how ... you should really be there.” [interview]

Another participant suggested that suffering should not be measured, but instead happiness should be assessed. In his opinion the person best equipped to decide about his happiness would be his wife:

G: “We decide about suffering, and we don’t know if that man is suffering and wants to die, which is why I want to transfer the decision to someone who can decide about happiness.”

Many widely used quality-of-life measures are not patient centred because of the limitations in the design of questionnaires or weighting systems (Carr, 2001). Suffering is an individual experience (2.2.1), a few quality-of-life assessment tools take this into account such as the schedule for the evaluation of individualised quality of life (SEIQOL), but are deemed not applicable for patients with loss of cognitive functioning, and take a long time to perform (O’Boyle et al., 1993). Further research into creating tools to measure quality-of-life, suffering and/or happiness in dementia would be extremely useful.

**8.1.1.5 Improving care to relieve suffering**  
Improving the condition of living with dementia may enhance the experience of loved-ones, which, in turn, could reduce euthanasia requests. Chapter 5.3.3.2.3 discusses the need for better care in dementia in order to be able to make more rational decisions on euthanasia. Much other research is dedicated to improving care for people living with dementia and their carers, for example, in palliative care there is a push for communicating that dementia is a terminal disease and must be treated as such with careful end-of-life planning, although opinions on ‘good’ end-of-life planning in dementia differ and more research is needed to be able to define better care (Poole et al., 2018).

Aleid Truijens illustrates the need for better care with an anecdote at Pakhuis de Zwijger (10 December 2018):

“How many euthanasia requests are left if people had it better in care-facilities? [...] I noticed is that people [patients] are sad about small things. For months, my mother only had one armrest on her wheelchair, which caused her wrist to get stuck, and no-one fixed this. My mother hated certain foods, and hey presto, she gets served Brussel’s sprouts three times a week. It sounds so futile, but it could help to ...” [real-world application, Chapter 6.2]

Efforts are being made to improve care. Designers are trying to create solutions that improve the experience of dementia for patients and carers (Brankaert, 2016). Many of these solutions are very successfully aimed at individual experiences, but seem hard to scale up (Wilkinson et al., 2018; Branco et al., 2017). Some designs offered provide ways to create better quality moments, which may help the overall experience of dementia (van Rijn et al, 2010). Solutions such as the ‘dementia

village,’ for example the Hogeweyk village in the Netherlands, are care facilities designed to be more like a community and less like a hospital (Hurley et al., 2000). Extensive ethnographic research at a similar German village ‘Tönebön am See’ concludes that the construction of different ways of care relies on idealistic views of what care can mean. Care is a complex cultural phenomenon and needs to work for patient, loved-one and carer alike. The dementia village is an example to illustrate the complexities of care (Haeusermann, 2017). Since the inception of the Hogeweyck dementia village in 2009, euthanasia request have not been reduced. Hogeweyck can only serve 152 patients, and is very expensive to run (Saner, 2018), so perhaps conclusions about a link between better care and euthanasia requests cannot (yet) be drawn. Participants touch on the need for better care, although they do also question how successful this might be to reduce euthanasia requests:

J: “ What if we say, what if the family says, you have earned you care, you have cared for us your entire life. Would it then be different, that is what I wonder, I actually don’t think so, but I do wonder.” [interview]

Further research is recommended to investigate the link between quality of care and euthanasia requests in dementia.

**8.1.2 Autonomy**  
The literature review (2.2.2) revealed that some people like to feel in control over their end-of-life (Schroepfer et al., 2009). People can be in control over their end-of-life by writing advance euthanasia directives (Burlá et al., 2014; Flew, 1999; Gastmans & De Lepeleire, 2010). Advance euthanasia directives can provide peace of mind for terminally ill people (Rosenfeld, 2000; Brock, 2000). However, advance euthanasia directives are largely ignored in advanced dementia because the disease presents with personality change (Davis, 2014), and assessing suffering is difficult (Rurup et al., 2005b). Deciding on behalf of a cognitively incompetent person in life-and-death situations puts strain on physicians and loved-ones (Buiting et al., 2008; Rietjens et al., 2009b; Bernheim et al., 2014).

**8.1.2.1 What is autonomy?**  
The results found some different perspectives on autonomy that did not seem to have been previously explored (systematic literature review; 2.2.2). First it was important to establish what is really meant by autonomy. One of the participants, Bert Keizer, who wrote extensively about autonomy in his book Voltooïd [Complete, 2017], explains what should be considered when talking about autonomy:

B: “First we need to say a few words about autonomy. It is a paradox, it is constantly in discussion, especially in the Netherlands, but no-one actually pauses to consider what it is that we are actually discussing. Autonomy is the protection of your own personal space amongst others, you could never be autonomous without other people.” [interview]

Winzelberg et al. (2005) found that interpretations on the definition of autonomy vary, and often autonomy is interpreted as a way to be in control, though this control need not be only about the ‘self’. Autonomy needs context of others and ethnic backgrounds are also important in defining what autonomy means (Winzelberg et al., 2005). With this in mind it would be important to establish patient’s interpretations of their right to self-determination first to be able to interpret their advance directives accurately.

**8.1.2.2 Who is autonomous: personality change**  
In 5.3.2.2.2 it was reported that the advance directive completely ignores the rights of the new person who may come into being due to the dementia. It was unclear how new person should be acknowledged.

E: “It is complicated, because you can’t reason, and you end up at the question “Who am I?” And what counts? And for whom? The new person, or the one you once were?”

L: “This relates to questions that are about ownership and autonomy in these situations: Are the choices you make before you have dementia more important than the decisions you make while you suffer from dementia? This is something that I think is very interesting and important to discuss.”



Personality change has been discussed as a diagnostic measure (Rankin et al., 2005), or as a symptom that increased care-giver burden (Welleford et al. 1995). However, no published literature was found on the rights of the new person in personality change.

8.1.2.3 Advance euthanasia directives should work

Advance euthanasia directives are based on the principle of autonomy (2.2.2.1). Autonomy is not uniformly understood by patients, some see it as a way to exert control (Burlá et al., 2014). Some patients express their autonomy by wanting to be in control of the effect their illness could have on loved-ones, additionally autonomy is understood differently in varying ethnic backgrounds (Winzelberg et al., 2005).

The use of the design prompts in the survey and interviews (5.3.2.2.4) elicited responses which confirmed previous research (2.2.2.1) with respect to advance euthanasia directives. It was suggested that these should work, but that this was complex; an advance directive was not clear enough on when and who should perform euthanasia. One suggested way to tackle this problem was with the help of others, as participant N explains:

N: “Yes, you must not, you can not do this alone. That is now crystal clear to me, by witnessing all these deaths in a short period of time. I have not just witnessed it, but I have fully experienced it.” [interview]

It was suggested by participants that clearer guidelines on how to make end-of-life decisions together would be helpful (5.3.2.2.4). Participants who had professional experience with dementia, felt that physicians could be a good person to introduce the subject of end-of-life in dementia, because they are the go-to authority in matters of care.

E: “You could say, you’d have to develop a ‘conversation method,’ which would allow you a low threshold start to such a conversation. Though I could imagine, you would need the authority of a physician, to start such a conversation. [...] I think this could work, under guidance of someone with a natural authority, because people themselves would never initiate this.” [interview]

Hillebregt et al. (2019) report other cases of proxy decision making, such as the Family

Group Decision-making Model (FGDM), used in childcare welfare, there is a system in place where loved-ones are helped by a professional in their decision-making process. The decision-making responsibility is then slowly transferred from professional to family. Similar systems are sometimes used in decision-making about adults, to help communication between a multi-disciplinary team and family members, however the transition of responsibility does not often take place here. A systematic literature review on the effectiveness of family group decision-making interventions in adult healthcare and welfare concluded that assessing these systems is difficult, because a lack of literature (Hillebregt et al., 2019). There are no systems in place for proxy decision making in dementia, but inspiration may be found by looking at proxy decision making in other situations where the person in question is incapable of speaking for themselves.

8.1.2.4 Importance of others

If “autonomy only exists in context of others” (B, 8.1.2.1), then it becomes apparent that others are important. Participants concluded that amongst ‘others’ should be various healthcare professionals and loved-ones (family, friends). How much these ‘others’ have to say was inconclusive, a majority of participants , and all of those who had personal experience with dementia, agreed that this was something the patient should make clear in their advance directive. It can happen that physicians become more important towards the later stages of the disease, where loved-ones are more crucial in the beginning stages. These changing conditions should be considered when assigning various responsibilities in relation to a person living with dementia.

A: “However, it is very difficult, if you have to take a decision when you are not sick yet, or if you were just diagnosed, the situation around you, the social context around you when The Plug is triggered might be completely different, your husband/wife might have died in the meantime or might have also gotten dementia or ... anything can happen ...” [interview]

Transferring responsibility from patient to others in cases outside of dementia are also complicated and inspiration can be gained by looking at palliative care. Palliative carers are seen to be good negotiators between physicians and families in intensive care (Bienvenu, 2018). Palliative care nurses are trained in end-of-life conversations (Head et al., 2018)

and could provide support in drawing up advance directives and negotiating between all stakeholders.

8.1.2.5 Changing one’s mind

The importance of being able to change one’s mind on an advance euthanasia directive was brought up frequently, and one of the main reasons people felt The Plug implant would be a bad idea. Changing lives and contexts were the reason minds could change:

K: “The fact that personalities can change from causes other than dementia. I can imagine that a person living with dementia may wish to change their mind on their euthanasia decision, not just because symptoms of dementia, but because of other life-events.” [survey]

When people are no longer cognitively competent to make decisions, they are also no longer capable of changing their mind. Changing conditions would have to be interpreted by loved-ones in order to make decisions on ignoring advance directives. This would link to making any decisions based on an advance direction, taking into account personality change, quality of life and any other aspect the patient may have considered as interpreted by proxies (Hillebregt et al., 2019).

8.1.3 Timing

In section 2.2.3 it was concluded from previous literature that deciding the moment of death is difficult. In dementia there is a small window of opportunity, after a diagnosis and before cognitive decline sets in, because this is when the patient themselves can confirm their death wish and take control (Hertogh, 2009). After this moment others would need to decide on behalf of the patient which brings a lot of responsibility that most feel they can or should not carry (Rurup et al., 2005b).

Some findings agreed with the literature (2.2.3), for example, understanding that euthanasia in dementia needs to take place before cognitive decline sets in (Hertogh, 2008).

Jakob Kohnstamm: “And so, the conclusion, [comparing two euthanasia cases] be early!” [real-world application, 6.2]

However, many would like euthanasia in dementia to be possible beyond the early stages of the disease. In later stages of the disease, all

participants agreed when this came up in the interviews or the open questions in the survey, that at this point the patient themselves would no longer be able to decide if the right time was there.

D: “Euthanasia should be possible [in dementia] because it is inhumane [dementia], but I think it is hard to decide the moment. You would probably keep postponing this moment. Especially if you already have dementia symptoms. It is probably equally hard for others (a physician, child, partner etc.) to decide the right time.” [survey]

The interviews discussed when participants thought would be the best time to die in dementia. Different descriptions were given but it can be summed up by saying that all felt that the right time would be when they were no longer ‘themselves.’ Happiness and quality of life could potentially be assessed by loved-ones, in case the person in question would no longer be able to do so themselves. The majority of the participants agreed that this would be a difficult task, but one participant was confident that his wife would be able to make this decision on his behalf.

G: “If I, in her judgement, am not aware of who I am, where I am, how happy could I be? If I am clearly confused, or scared, that would count. But if I am nothing, then maybe not, but then of course I wouldn’t care if she decides to let me live for a short time or a long time, or if she says, right, it’s been good but it is time. Depending on what she is able to and what she wants to, or what the family asks of her.” [interview]

The results (5.3.2.3.2) suggest that people really want to be able to postpone the moment of death, but still have the option of euthanasia. This could be done by transferring this decision to loved-ones, believes Henk Blanken. He describes this in his living will, published in de Correspondent, 2019:

“If I can determine my own end-of-life, then I also want to be able to delegate this right to my loved-one. I want to be able to ask my loved-one to represent me in deciding when it is the right time to die. She already does this when she instructs a physician to stop treating me – this is something that can be done legally.” (Blanken, 2019)

In this quote he mentions that his loved-one can make decisions on his behalf when it



comes to a do not treat agreement. Do not treat agreements are legally binding as apposed to advance euthanasia directives which are simply a recommendation (Behandelverbod, n.d.). Do not treat agreements are legally binding documents that do not need to be consented to by the patient when a situation occurs described in the do not treat agreement where the patient is unable to communicate. It may be beneficial to investigate deeper how do not treat agreements look and function and compare this to Advance Directives.

8.1.4 Planning death in dementia

It is important to address ethical issues in planning death in a society where dying is becoming a medicalised decision; 80% of people die in care facilities (WHO, 2018). Modern medicine allows us to live beyond our capacity to look after ourselves, or even to be ourselves. The literature review (2.2.4) found that this could be a reason to consider euthanasia or suicide (Hardwig, 1997; Davis, 2014; Bilchik, 1996). A reliable diagnosis is needed in order to plan death (Davis, 2014). What is seen as a ‘good’ death varies between individuals and cultures. Many view a ‘natural’ death as a good death (Raus et al., 2012). A natural death takes the responsibility of the death away (Rachels, 1998). Rational reasoning may be hard to establish in euthanasia for dementia (Farrenkopf & Bryan, 1999; Galbraith & Dobson, 2000). Performing euthanasia is hard (Sercu et al., 2012; Stevens, 2006; Georges et al., 2008) .

8.1.4.1 Natural death

Among the participants there was not such a strong need for a ‘natural death’ in the case of dementia, and there didn’t seem as much respect for a ‘natural death’ as described in the literature (2.2.4.1):

M: “Nature can be cruel. Right, nature is doesn’t imply meaning.” [interview]

B: “Yes, Nature, a fun concept. One of the least natural concepts is the word ‘nature.’ [...] People often tell me, “Doctor, shall we let nature take its course?” Delightful. If she would really want that we should undress her and put her in the forest. No, no, that’s not what we mean!” [interview]

H: “While I am generally more of a nature loving person, here I believe that the advantages of technology developments (e.g. advanced patient monitoring devices,

injections made patient triggered as well as based on semi-automated vital signs measurements and other parameters that the person with dementia should choose be triggered by).” [survey]

8.1.4.2 Rational death

Most research findings on a rational death agreed with previous literature (2.2.4.2), in that euthanasia in dementia has to be a rational, well thought through, decision. A reliable diagnosis was found to be important in order to plan for end-of-life. All participants that took the survey (5.3.2.4.1) wanted to know conclusively if they would have dementia, what stage and how fast the decline would be.

D: “Objective test results on the stage of the dementia.” [survey]

If death could ever be rational was debated. Societal and social pressure, conscious or not, could play a role in making a decision for euthanasia in dementia.

M: “People are often trapped between their autonomy and their co-dependency with others, between a rational decision and a more emotional drive to keep living and fear of death, between the individual experience of suffering with euthanasia as a solution and the implied criticism of society where the elderly lose their meaningfulness, so euthanasia becomes a solution.” [interview]

Some suggested improvement to the care for people living with dementia, which may relieve the stigma of having dementia, and this in turn could make decision making about end-of-life more rational:

J: “If we can find a good way, if we can care for people with dementia in a beautiful way, and I choose the word ‘beautiful’ consciously, because I don’t just want to say, feed them, give them shelter, but instead provide a beautiful care, and the same should apply to the primary carers, and if you do that, would the question [in response to talking about the burden of carers] not be completely different?” [interview]

Ways of improving care are discussed in 8.1.1.4.

8.1.4.3 Performing euthanasia

Physicians could play a much more important role in planning end-of-life care. Agnes Wolbert (NVVE) states, at the end of ‘My death is not my own II’ Pakhuis de Zwijger in December (2018), that, in her opinion, physicians should play a more important role especially in initiating end-of-life conversation early.

Physicians need education and support in starting conversations about end-of-life options with people with an early diagnosis of dementia and their social circle (5.3.2.4). This would help their decision-making process in performing euthanasia. A study on advance care planning in the preoperative period concluded that physicians have little support in initiating end-of-life conversations (Blackwood et al., 2018). Junior doctors find it hard to initiate conversations about end-of-life. New frameworks for young doctors to enact end-of-life conversation will help to build confidence in an educational setting with supervisor support, role-modelling, feedback and debrief techniques (Thomas & Eastley, 2018). Even though doctors do understand the importance of having end-of-life conversations, many do not have these because of the emotional load (Soodalter et al., 2018).

8.1.5 Unexpected and opportunistic outcomes

This thesis did not plan for the designs to be used in real-world applications. However, there were opportunities during the PhD study to share the designs (Chapters 6 and 7). The responses to The Plug scenario and the Timeline graphic in public debates and roundtable discussions provide possible examples for the use of design for complex moral dilemmas, and are a good illustration how the designer/ researcher is not always able to have 100% control in real-life situations. Considerations such as time and budget become real constraints that must be considered as well as internal politics and agendas.

8.2. Using design to further the debate on euthanasia in dementia?

Moral dilemmas are a good candidate for a design approach because of the desire to ‘create a significant transition from a current state to a (desired) future state’ (Simon, 1996). The moral dilemma of euthanasia in dementia is a wicked problem, a problem that has inherent social complexity and no apparent solution (Tonkinwise, 2016; Zimmerman et al., 2007). To address this problem, design can be used to create relatable applied thought experiments to help formulate issues beyond abstract thought (Auger, 2013).

The designs were mostly successful as thought experiments and stimulated discussion.

B: “Well, you are talking about, in three different ways you discuss the possibility to do something, about something that we feel very uncomfortable about. What can you do with this dementia? Keep going? Suicide? And everyone is stuck there, and people find it hard to develop an opinion. But you don’t present them as a solution, but as a thought experiment.” [interview]

All participants who were interviewed (5.3.2.5) were positive about this way of discussing the debate on euthanasia in dementia. Most could empathise well with the scenarios presented and it helped them develop their own personal thoughts on the issue.

J: “I think this is the only way you can do it, it is a typical speculative design idea, presenting it as realistically as possible, but I think that that is the way you’d have to do it, otherwise it just wouldn’t touch you.” [interview]

L: “Yes, it’s good that you specifically ask to look at your own experience [...] when you bring it back to your own experience you start to see where the problems are, and what kind of decisions people actually have to make and how difficult – the context, that is very important, so I think that is the only way to get to understand it or talk about it.” [interview]

Literature found in the field of [speculative] design discusses ways of creating designs, but does not discuss ways on how to assess if a design prompt was successful (3.2). Sengers and Gaver (2006) agree that designs can be open to multiple interpretations. They suggest that designers should consider levels



of interpretations in their designs in order to evaluate the designs (Sengers & Gaver, 2006). Artifacts that are knowingly designed to provide users with specific user experiences, should provide means for discussing implications (Fallman, 2011). With visual methods becoming more popular for qualitative research it would be important for non-visual specialists to recognise that a greater understanding of the best available visualisation tools and the most effective ways of employing them in the interview process will be an asset (Glegg, 2019).

Presenting designed scenarios as applied thought experiments helps to trigger discussion. It is important to present designs not as solutions, allowing participants to formulate their own opinions around the concepts presented. Investigating moral dilemmas or complex ethical issues with design can be useful to help people to formulate their opinions, which may not be purely rational. Exploring and acknowledging personal opinion and experiences beyond the rational may help to develop a more holistic picture around issues that involve complex social, cultural, legal and scientific aspects. It is very important however to be aware of inherent bias and to present the designs not as truth, but as a means and angle of investigating a wicked problem.

8.3 Limitations

In researching the moral dilemma of euthanasia in dementia, using design, it is important to acknowledge the limitations this will inherently bring. Although there was no formal evaluation of the success of the designs, the successful stimulation of debate suggests that the designs were meaningful and communicated the key messages effectively.

8.3.1 Method

This is an exploratory thesis with as a main query seeing if design could be a useful method to further the debate on euthanasia in dementia. This was investigated by researching if the debate would be furthered on four more specific themes inherent in the debate on euthanasia in dementia (1.1). There was no formal testing on the successfulness of the design used, other then investigating if the debate had indeed progressed. It must be acknowledged that any designs created will be subjective and will carry with them the personal prejudice of the designer. In this research much care was taken for the designs created to be informed by rigorous research. Each step of the design process was carefully documented in order to be open about the decisions made during the design and data collection process, as part of the reflective practice inherent in grounded theory (Engward & Davis, 2015). The process of designing prompts itself provided the main researcher with a thorough in-depth knowledge of the subject matter, which may have allowed for asking better questions.

8.3.2 Data quality

The research was conducted with a small group of expert participants representing only people who are not principally against the practise of euthanasia. Some of the participant were not necessarily in favour of euthanasia but were willing to consider it as a possibility. The participants were selected carefully, and chosen because of their expertise in dementia (5.1). As such the participants could provide rich and well-informed data that contributed to the debate on euthanasia in dementia. It is important to be aware of each participant’s context to understand how they may interpret the debate on euthanasia in dementia (table 5.1.1). Each participant provided information based on personal experiences.

It is important to note the some of the participant were more familiar with the method of using design as a tool to aid discussion which is likely have influenced their responses in this research. It has been investigated that people who have prior experience with a certain task or product, participating in user-tests for such products, are seen to provide more consistent and valuable results (de Bont & Schoormans, 1995). As such, participants who where both experts in the content as well as the method would have been ideal.

Keeping in mind the participants varying expertise and context, this research found a rich variation in responses and has managed to contribute new knowledge.

8.3.3 Context

This research was developed specifically for the context of the Netherlands and therefore any interpretation or application outside the Netherlands must take this into account, and may need to be adapted to the new context.



# Chapter 9

## Conclusions

At the start of this thesis the primary researcher had hoped to find solutions to the moral dilemmas inherent in the debate on euthanasia in dementia by using design prompts. A personal drive to find out why euthanasia had not been possible for her mother was the motivation to start this research, as well as a selfish incentive to not fall into that same trap with a likely early-onset Alzheimer’s diagnosis for herself. The literature review provided an answer: euthanasia in dementia is possible, for as long as it is done early in the disease. The literature review also revealed that this was not a satisfactory answer, it was clear that it would be desirable to be able to postpone the moment of death with euthanasia in dementia, both for patients as well as loved-ones. With this in mind, this research has addressed areas that could be explored further by using [speculative] design:

- nuances in the requirement of ‘untreatable and unbearable suffering’,
- autonomy and proxy decision-making
- pinpointing the best time to die in dementia
- better ways to plan death in dementia

Particular attention has been paid on how to these areas were explored using design. This research has found that using design as applied thought experiments can help address complex moral dilemmas. It will illustrate this by describing how the dilemmas were further explored and examined.

This chapter starts by outlining answers to the research questions (9.1) and elaborating how design was useful in the particular dilemma of euthanasia in dementia by summarising the findings according to the themes (9.2), followed by recommendations to improve the process of dying with dementia (9.3), suggestions for further research in the debate on euthanasia in dementia (9.4) and concludes by summarising the contributions of this research to the debate on euthanasia in dementia and speculative design (9.5).

### 9.1 Answering the research questions

This thesis investigates if and how design can be used in complex ethical dilemmas. Design is moving beyond a purely problem solving practice and is starting to be used in addressing more complex issues. In this thesis design is used to create prompts to encourage conversation. The conversation these designs are facilitating is based on the debate on euthanasia in dementia according to the legal guidelines in the Netherlands.

The main questions this thesis addresses are:

1. How does (speculative) design support debates?
2. How can design support debate in the case of euthanasia in dementia?
3. What can we learn from applying speculative design to support conversation about euthanasia in dementia as done in this thesis?

#### How does (speculative) design support debates?

Design can support debate by creating applied thought experiments that stimulate participants to look at the issue at hand through different lenses (8.2). The designed ‘lens’ can help to highlight (unintended) consequences in any dilemma by thoroughly investigating ‘what if’ scenarios. These ‘what if’ scenarios are given shape through artefacts and storytelling, which help to envision possible futures, much like science fiction does (3.3). Speculative design typically grounds its designs in research in order to tell credible stories that need further investigation. It is important to present these type of designs as concepts and not solutions, which helps participants to formulate their own opinions around the dilemma presented. When using speculative design to encourage debate, you are also tapping into participant’s emotions and thus creating a rich and experiential responses that may be less rational, but more realistic to real-world scenarios.

#### How can design support debate in the case of euthanasia in dementia?

The debate on euthanasia in dementia as based on the Dutch legal system is centred around a few ethical dilemmas (9.2). Design can help to stimulate guided conversation on this debate by highlighting one dilemma at the time and illustrating the more practical complexities present in this dilemma. For example in the prompt of The Plug (4.2), the design has imagined an implant that can be programmed to euthanise a patient when the circumstances they would have programmed come to pass. This design helps to highlight that current advance euthanasia directives could never be precise enough for a physician to act upon if the patient is no longer able to consent. It also makes clear that writing a very accurate advance directive is nearly impossible, because it is hard to know what circumstances will become unacceptable when dementia sets in. Having these problems highlighted in a fictional design helps to guide the conversation in a specific direction without being clouded by other dilemmas such as suffering (4.1), timing (4.3) or the overall issue of planning death (4.4). In brief, applied thought experiments can highlight and filter out specific dilemmas and direct the conversation to get more precise input and responses.



**What can we learn from applying speculative design to support conversation about euthanasia in dementia as done in this thesis?**

Investigating moral dilemmas or complex ethical issues with design is useful to help people to formulate their own opinions, which may not be purely rational. Acknowledging personal opinion and experiences beyond the purely rational can contribute to a more holistic picture around issues that involve complex social, cultural, legal and scientific aspects. This thesis has presented four designs based on themes that are present in the debate on euthanasia in dementia. In the following section each of these themes are described and the conversations the designs triggered as well as potential paths to investigate further, based on these conversations (9.2, 9.3). Considering these outcomes, it can be said that using speculative designs to base conversations around has been fruitful and has yielded results.

**9.2 How have the design prompts informed the debate on euthanasia in dementia?**

In order to find out if design was able to support debate it is important to look at how the debate has advanced using the presented design prompts. The design prompts were used to explore four research themes:

- Suffering: What is unbearable suffering in dementia, and can it be assessed?
- Autonomy: Why is it difficult to make a decision for euthanasia based on patient autonomy in dementia?
- Timing: When is the best time to die in dementia?
- Planned death: What are the complexities around planning a death in dementia?

This section will discuss what conversation were held around these themes based on the design prompts (4). In this section, the findings are summarised based on the literature review (2), the design process (4), data collection/analysis (5, 6, 7), and the discussion (8).

**What is unbearable suffering in dementia, and can it be assessed?**

Unbearable suffering is individualistic and can only be assessed in the context of an individual’s life and experiences (2.2.1). It may be possible to assess suffering by looking at what defines an individual’s quality of life. People tend to adapt to new physical and social circumstances, but it is not clear whether this adaptation happens in dementia (2.2.1.3). This research has found through conducting interviews that it would be possible to track what gives quality of life to a certain extent in dementia and it would be important to do so (8.1.1.3). Additionally, loved-ones, who know an individual well might be able to provide input on the quality of life of their loved-ones (8.1.2.4).

**Why is it difficult to make a decision for euthanasia based on patient autonomy in dementia?**

One symptom of dementia is personality change, which makes patient autonomy very difficult to respect (2.2.2.3). Personality change causes a conflict between the person before dementia and the person with dementia (5.3.2.2.2). In general it can be said that loved-ones will respect the patient’s wishes before the dementia-related personality change occurred and physicians will respect the wishes when they would need to respond to a euthanasia request (8.1.2.2). Finding ways to track this personality change and respecting the new person’s (with dementia) wishes will be important, and there may be ways this can be done with improved advance directives and more rigorous updating of details in the advance directive (8.1.2.3). Loved-ones may also be important in the context of autonomy and could play a part in providing detail and nuance to advance directives as well as document changing circumstances (8.1.2.4).

**When is the best time to die in dementia?**

For physicians, the best time to perform euthanasia on dementia patients would be when the patients themselves can still confirm their desire to die (2.2.3.1). For patients, the best time to die is when they are no longer themselves (8.1.3). In the latter case the dementia patient may not recall their wish to die and perhaps their quality of life can be improved by providing better care (8.1.1.5). When it can be observed that suffering remains hopeless, regardless of the personality of the patient, then this may be the occasion where both loved-ones and physicians agree it to be the best time to die. If the opportunity for euthanasia has passed, care may be needed for the loved-ones who find it hard to observe personality change in the patient (8.1.1.2.1).

**What are the complexities around planning a death in dementia?**

Planning a death will need to be done together with loved-ones and physicians (8.1.2.4). Physicians are seen as the preferred person to initiate conversations about end-of-life with patients and their families (8.1.2.3). Dying does not only affect the person who is ill, but has a huge impact on those who are left behind once death has occurred (2.2.4.2). This is why planning death is complex, but can help everyone involved in the death to accept the implications. Understanding the symptoms of the disease and what problems they will cause in planning euthanasia will help to write better agreements, assign responsibilities and to make sure everyone understands the situation (8.1.2.3). With advancing medical care, dying is becoming a choice – at least in the way dying happens. Instead of passively waiting for ‘nature’ to happen, or rather, for ways of keeping a person alive to diminish, better ways of dying could be imagined for all those affected by the process of dying (5.3.4.3).



9.3 How can dying with dementia be improved?

The findings reported here shed new light on some practical improvements that could be made in the process of euthanasia in dementia. First, more comprehensive advance directives that assess quality of life should be created. Second, the role of physicians in initiating end-of-life conversations should be formalised and supported in healthcare education. Third, the stigma of talking about dying (or dying differently) should be relieved so that death literacy and death planning can be improved.

9.3.1 Burden / improving care

The feeling of being a burden as a person with dementia is currently not a valid reason to request euthanasia (2.2.1.2), and section 8.1.1.2 has shown that this is an issue that needs to be discussed. Alleviating this feeling of burden for the patient, and alleviating the carer-burden could make a considerable difference for the health and well-being of both the patient and the carer. Suggestions on how to reduce the burden were made, and would primarily rely on improving professional care for people living with dementia (8.1.1.5). However, the current trend in health care of trying to keep people living with dementia in their own homes for longer (Alzheimer Nederland, 2018) is certainly not something that would be recommended (5.3.5.1).

9.3.2 Better Advance Euthanasia Directives

Most current advance euthanasia directives are too vague. Criteria such as “if I don’t recognise my children” or “if I am no longer myself”, are not actionable upon. Advance euthanasia directives will need to improve. Ways of doing this were discussed in section (8.1.1.3) with the recommendation that advance directives should be more detailed and quality of life should be tracked continuously in detail and adjusted as the disease progresses. The important thing is to track changing personal and contextual conditions and record how the patient is adapting to their new context.

9.3.3 GPs to initiate end-of-life conversations

The role of the GP was found to be very important and it is recommended that the GP initiates end-of-life discussions early, both with the patient and their loved-ones. GPs may need support in developing a formal role in this process; and this may be an opportunity for future design communication and support input.

9.3.4 Designing death

With improving health care, more and more people will die in care (WHO, 2018). In order to plan for a good death, it is suggested that people will need to start talking about death earlier and develop a level of death-literacy. With death losing its stigma status death could be discussed more widely and it might therefore become acceptable to plan for better deaths.

9.4 Further research

This thesis investigated if and how design can be used to support debates in complex ethical issues with as subject matter the debate on euthanasia in dementia. This research has found ways that design can indeed be used to support complex issues with examples on the subject matter, but it has also identified a few areas for further study. First, to look ways how current design principles should be adapted to allow design to move beyond being a problem solving practice (9.4.1). Second, to study how the quality of design can be assessed in these settings (9.4.2). Additionally, this research has found areas that warrant further study on the subject matter. First, it was found to be important to establish why do not treat agreements work and advance directives do not (9.4.3). Second, to establish who requests euthanasia in dementia which might help to find out if care could be improved in order to reduce dying wishes (9.4.4).

9.4.1 Design beyond problem solving

Design methods and education should be updated to a new standard where design is geared to work with consequences rather than results. The materials to design with are ever more complex, pushing the boundaries of ethics and requiring designers to be more responsible. Designed materials now have the capability to change dynamically over time and in response to context. Making sense of these changing things and their consequences presents a challenge that requires thorough investigation (Redström & Wiltse, 2018).

9.4.2 Assessing quality of design when used as a tool

In more traditional design settings the quality of a design would be measured in its functionality through iterative prototyping and user testing. When design is used as an applied thought experiment the way to measure its quality becomes more complex. How can the quality of applied thought experiments be tested? It is recommended that design practice looks at other disciplines to investigate further how to assess quality and impact.

9.4.3 Difference between Do Not Treat Directives and Euthanasia Directives

A question that was raised in the public debate at Pakhuis de Zwijger (6.1) by audience member Mieke Visser, GP and SCEN physician, has resonated:

“We are talking about it how difficult it is to decide on euthanasia for someone with an advanced form of dementia, but on the flip-side we then do decide that someone should continue living in miserable conditions, sometimes for years to come. And this is what I don’t understand, that it is easier to decide to keep people alive, but that it is really hard to make the other decision [to decide for euthanasia]” (1:55:27)

The literature discusses the difference between palliative sedation and active killing (2.2.4.1); palliative sedation is preferable because it resembles a natural death (Raus et al., 2012). A similar situation may be the case between ignoring advance directives in dementia and the popularity of do not treat agreements. At the KNMG round-table discussions the do not treat agreement was discussed (7.2), and the question ‘why we feel comfortable not to treat people based on a do not treat agreement which can’t be confirmed by the patient’ was raised. SCEN physician Constance de Vries at the second public debate at Pakhuis de Zwijger (6.2.3), also confirms that much more specific do not treat agreements could solve many of these moral dilemmas:

“I think you could prevent some of the problems by being very detailed in your AED, and you need to find a GP who wants to help you. [...] And you can also be much more clear and detailed in your treatment ban, not just if “I get pneumonia I don’t want antibiotics”, but you could also say “if I become diabetic, don’t give me insulin,” or “if I can’t eat or drink independently, don’t feed me, then I will die, but I do want you to keep me comfortable”. You can’t just let somebody dry out. But you can say, “if I can’t eat, then you guys have to make sure to allow me to leave, comfortably”.

It is suggested that further research is needed to investigate why do not treat agreements work well and advance directives do not; for example by looking at the legal structures of these two types of agreements as well as the practical applications of these agreements. It would also be interesting to assess how loved-ones respond differently to these agreements and how they accept decisions made based on these agreements.



9.4.4 Who writes advance euthanasia directives for dementia?

From anecdotal evidence (8.1.1.2.4) it seems that people who have experienced dementia in a loved-one are more likely to request euthanasia if they are starting to develop dementia themselves. It would be good to explore this further, for example with a large population survey. If people who have experienced dementia in a loved one are the ones requesting euthanasia, then this could emphasise the need for changes to be made for the experience of caring for dementia as well as strategies to improve the image of living with dementia.

9.5 Contributions

This research primarily contributes to the field of speculative design by showing ways to use design as a tool to aid conversation in complex ethical dilemmas. This research does not present a ‘one size fits all’ guide on how to create designs as a tool to aid conversation, but illustrates that by creating well researched artefacts and stories, conversations on complex ethical issues can be furthered in a holistic way. For the quality of these artefacts and stories, this research recommends a critical approach to design and to always acknowledge inherent bias in any creative work to allow the context and content to be transparent.

Presenting designed scenarios as applied thought experiments has helped to stimulate discussion (8.2). Using scenarios and prototypes supported the participants to formulate their opinions and map their experiences. It has also assisted in imagining other people’s viewpoints and responsibilities (5.3.2.5). The prompts have succeeded in highlighting social, cultural, legal and scientific aspects that may not be immediately apparent in personal experiences (8.2).

The contributions of this research based on the subject of euthanasia in dementia include identifying these new areas of research such as the complex feelings of ‘burden’ both for the patient and carers. Additionally the role that ‘others’ play in this debate was found to be really important (loved-ones, physicians).



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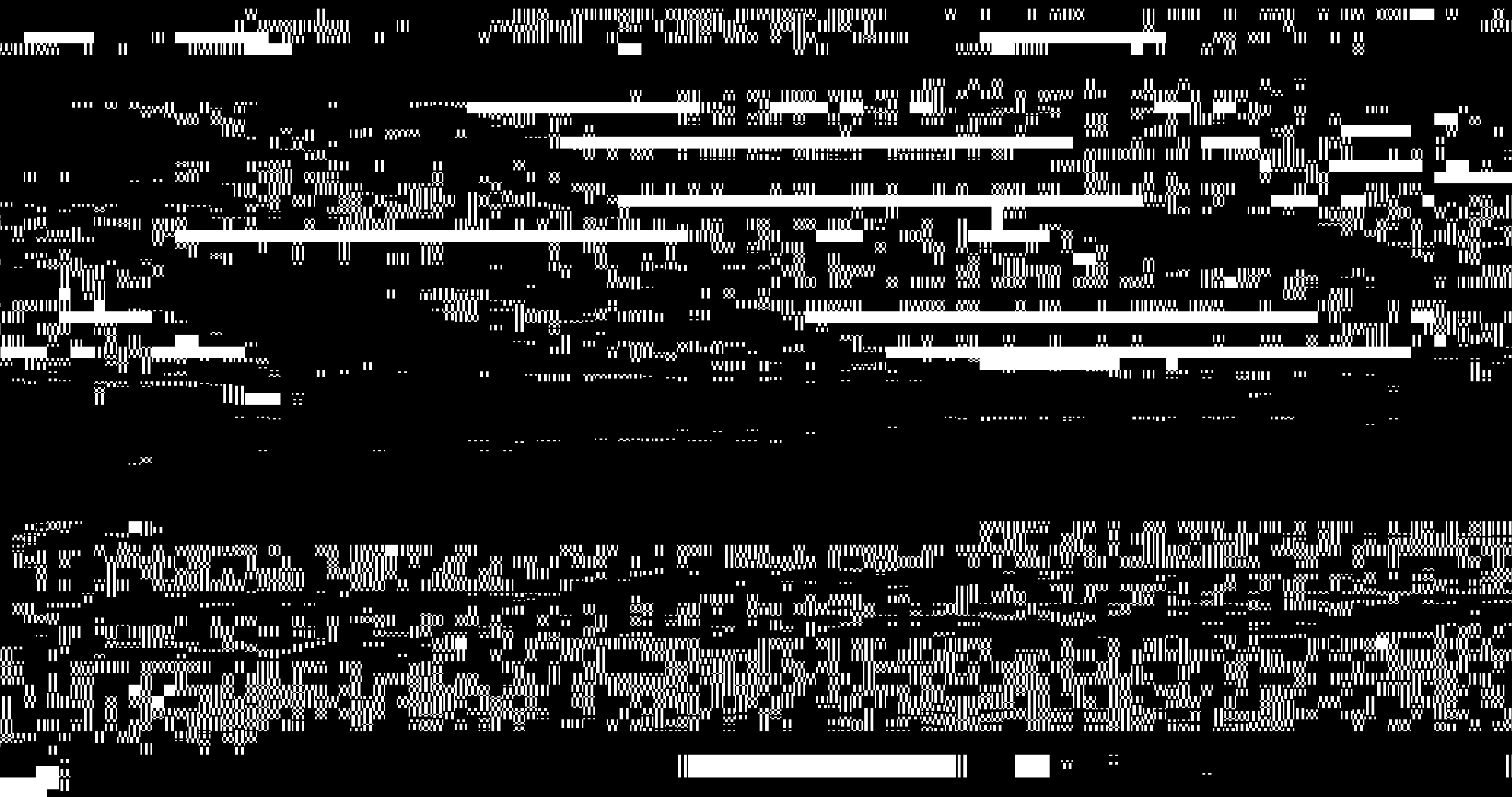
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Appendices





# Appendix A

## Literature table

### Systematic Literature Review synthesis

Themes that emerged are divided into the following subjects and discussed below;

<b>2.2.1. Suffering</b> <i>What is suffering and how can you assess suffering in dementia?</i>	<b>2.2.2. Autonomy</b> <i>Dementia presents with loss of cognitive functioning, meaning that you lose your right to self-determination; what does this mean for your right to die?</i>	<b>2.2.3. Timing</b> <i>When is a good time to plan death in dementia?</i>	<b>2.2.4. Planned Death</b> <i>What is a good death in dementia?</i>
2.2.1.1. Unbearable suffering 2.2.1.2. Burden 2.2.1.3. Assessing suffering	2.2.2.1. Control 2.2.2.2. Advance directives 2.2.2.3. Personality change	2.2.3.1. Too early 2.2.3.2. On time 2.2.3.3. Too late	2.2.4.1. Natural death 2.2.4.2. Rational death 2.2.4.3. A duty to die 2.2.4.4. Performing euthanasia
Bernheim, Distelmans, Mullie, & Ashby, 2014; Berry, 2000; Dixon, 1998; Eva E. Bolt et al., 2016; Eva Elizabeth Bolt et al., 2015; H. Buiting et al., 2009; Gjerdingen, Neff, Wang, & Chaloner, 1999; Hendin, 2002; The, Pasman, Onwuteaka-Philipsen, Ribbe, & van der Wal, 2002; Chapple, Ziebland, McPherson, & Herxheimer, 2006; Dees, Vernooij-Dassen, Dekkers, Vissers, & van Weel, 2011; Gastmans & De Lepeleire, 2010; C M P M Hertogh, 2009; Kerkhof, 2000; Martyn & Bourguignon, 2000; J A C Rietjens, van Tol, Schermer, & van der Heide, 2009; Rurup, Onwuteaka-Philipsen, Van Der Heide, Van Der Wal, & Van Der Maas, 2005; Wijsbek, 2012.	Batavia, 2000; Bernheim et al., 2014; Berry, 2000; Billings, 2011; De Boer et al., 2011; Dan W Brock, 1999; H. M. Buiting et al., 2012; Burlá et al., 2014; Carlson & Ong, 2014; Cicirelli, 1998; Davis, 2014; Deyaert, Chambaere, Cohen, Roelands, & Deliens, 2014; Dening, Jones, & Sampson, 2012; Emanuel, 1999; Garand, Dew, Lingler, & DeKosky, 2011; Gastmans & De Lepeleire, 2010; Gunderson, 1997; Rachels, 2005; Van Wijmen, Rurup, Pasman, Kaspers, & Onwuteaka-Philipsen, 2010; Wolf, S M., 2004.	De Boer, M E., Dröes, R M., Jonker, C., Eefsting, J A., Hertogh, C M P M., 2011; Bolt, E E., Pasman, H R W., Deeg, D J H., Onwuteaka-Philipsen, B D., 2016; Burlá, C., Rego, G., Nunes, R., 2014; Cohen-Almagor, R., 2003; Davis, D S., 2013; Gastmans, C., De Lepeleire, J., 2010; Hertogh, C M P M., 2009; Hertogh, C M P M., de Boer, M., Dröes, R M., Eefsting, J A., 2007; Stoyles & Costreie, 2013	Abeles & Barlev, 1999; Barrie, 2014; Bilchik, 1996; Eva Elizabeth Bolt et al., 2015; Bosshard et al., 2008; D W Brock, 2000; H. M. Buiting et al., 2010; Cooley, 2007; Daly, 2015; Davis, 2014; van Delden, 2004; Dening et al., 2012; Dieterle, 2007; Dunham & Cannon, 2008; Farrenkopf & Bryan, 1999; Fenn & Ganzini, 1999; Galbraith & Dobson, 2000; Gessert, Forbes, & Bern-Klug, 2000; Georges, The, Onwuteaka-Philipsen, & van der Wal, 2008; Hardwig, 1997; Hendin, 2002; C M P M Hertogh, 2009; Holm, 2015; Huddle, 2013; Huxtable, 2014; Kerkhof, 2000; Leget, 2006; Lowe, 1997; Muller, Kimsma, & Van Der Wal, 1998; Nicholson, L., 2013; Onwuteaka-Philipsen et al, 1997; Ravenscroft & Bell, 2000; Judith A C Rietjens, van der Maas, Onwuteaka-Philipsen, van Delden, & van der Heide, 2009; Onwuteaka-Phlipsen et al., 2003; Rachels, 2005; Raus, Sterckx, & Mortier, 2012; Rosenfeld, 2000; Sercu et al., 2012; Shaw, 2002; Short, 2003; Singer, 2003; Stauch, 2000; Steel & Kulbe, 2003; Stevens, 2006; Sullivan, 1999; Thomson, 1999; Vink, 2016; Voorhees, Rietjens, Van Der Heide, & Drickamer, 2014; Watts et al, 1992.



Systematic Literature Review: Table of included papers

Where appropriate papers were assessed with the Mixed Methods Appraisal Tool, papers with a low MMAT score (50% or less) were excluded. Various other reasons for exclusion have been noted in the table. In total 11 papers were excluded in the research.

Author, date, title	Study type	Aim	Study population	Study design	Key findings	Theme
Abeles, N., Barlev, A., 1999, <b>End of Life Ethics: Euthanasia and Assisted Suicide</b> MMAT: n/a	Bioethics	Reviews the assisted dying debate, in response to dignity in dying act, Oregon, 1997 and illustrating pro and con situations from a moral/ethical perspective.	Good selection of reviewed material; big study population.	Articles in medical journals, legislative investigations and the public press were obtained and reviewed.	Interesting presentation of cases for and against. Useful presentation of criteria for a “rational suicide”: Gallagher-Thompson and Osgood (1997) define rational suicide as “ <i>a sane, well-thought-out decision by an individual who is mentally competent, and who is capable of reasoning and choosing the best alternative among the many available.</i> ”	Rationality
Barrie, S., 2014, <b>QALYs, euthanasia and the puzzle of death</b> MMAT: n/a	Medical ethics	This paper attempts to express through numerical and quasi-economic measures such as the QALY, the degree to which someone’s life can be considered a burden to that individual. This paper presents a new kind of problem for the QALY. As it stands, the QALY provides confused and unreliable information when it reports zero or negative values, and faces further problems when it appears to recommend death.			There is a deep underlying confusion as to whether death, dying, being dead and ‘worst possible health’ are equivalent. The difficulties associated with trying to put a value on one’s own death cause serious problems for the meaning and application of the QALY.	Economy
Batavia, A J., 2000, <b>The relevance of data on physicians and disability on the right to assisted suicide: Can empirical studies resolve the issue?</b> MMAT: n/a	Psychology, Public Policy, and Law	This commentary concludes that values, not empirical data, must ultimately determine the legality of assisted suicide. Studies cannot resolve the fundamental issue.			Although respect for life is also a very important value in our culture, this is not translated as a desire to preserve and extend life at any cost to the individual. Americans with disabilities, similar to Americans generally, wish to be able to control their lives. They do not believe the government should deny them that control at the end of their lives. The value central to those of us who support a right to assisted suicide is autonomy.	Autonomy in disability
Bernheim, J L., Distelmans, W., Mullie, A., Ashby, M A., 2014, <b>Questions and Answers on the Belgian Model of Integral End-of-Life Care: Experiment? Prototype?</b> MMAT: n/a	Bioethics	This article analyses domestic and foreign reactions to a 2008 report in the British Medical Journal on the complementary and, as argued, synergistic relationship between palliative care and euthanasia in Belgium.	An interview with a doctor involved in the early development of the Belgian end-of-life model and two of his successors.	Interview	The Belgian model may be heresy for current mainstream palliative care doctrine, but it is a well-functioning experiment and probably a prototype of things to come elsewhere.	Rationality Autonomy Quality of life
Berry, P., 2000, <b>Euthanasia — a dialogue</b> MMAT: n/a	Medical ethics	Highlighting ethical and moral issues that arise in the euthanasia debate, from the people closest to it.	A dialogue between patient wishing to die, and physician who is supposed to make it so.	Dialogue	First person perspectives on the debate.	Autonomy Suffering
Bilchik, G S., (1996), <b>Dollars &amp; death</b> MMAT: n/a	Geriatrics	Highlighting a potential link between economical situations and assisted dying.		Research based on various quoted experts institutions	In countries where assisted dying is legal, but healthcare isn’t free (ie. Oregon, US) there could very well be a link between being a financial burden, and a wish to hasten death.	Economy
Billings, J A., 2011, <b>Double effect: a useful rule that alone cannot justify hastening death</b> MMAT: n/a	Medical ethics	Discussing the ethical and moral implications of the Double Effect.			The rules for the Double Effect are sensible, if applied correctly.	Autonomy



Author, date, title	Study type	Aim	Study population	Study design	Key findings	Theme
Bishop, J P., 2006, <b>Euthanasia, efficiency, and the historical distinction between killing a patient and allowing a patient to die</b> MMAT: n/a	Medical ethics	Voluntary active euthanasia and physician assisted suicide should not be legalised because too much that is important about living and dying will be lost. The author lays out the historical philosophical roots of the distinction between killing a patient and allowing a patient to die. This essay will help to delineate the framing questions that should be acknowledged when thinking of legalising either PAS and/ or VAE.			In short, I am saying that, by accepting mere efficiency in the physician’s action, one is precluding something altogether more spiritual. One precludes that dimension often referred to as the therapeutic relationship. That is to say, sometimes healing occurs in empathically accompanying the patient through the most terrible of times.	Moral dilemmas
De Boer, M E., Dröes, R M., Jonker, C., Eefsting, J A., Hertogh, C M P M., 2011, <b>Advance directives for euthanasia in dementia: How do they affect resident care in dutch nursing homes? Experiences of physicians and relatives</b> MMAT: 100%	Geriatrics	To gain insight into how advance directives for euthanasia affect resident care in Dutch nursing homes.	344 physicians completed questionnaire, 110 physicians provided case studies, interviews with 11 physicians and 8 relatives.	Survey of elderly care physicians and additional qualitative interviews with a selection of elderly care physicians and relatives of people with dementia who had an advance directive for euthanasia.	Advance directives for euthanasia are never adhered to in the Netherlands in the case of people with advanced dementia, and their role in advance care planning and end-of-life care of people with advanced dementia is limited. Communication with the patient is essential for elderly care physicians to consider adherence to an advance directive for euthanasia of a person with dementia.	Timing
Bok, S., 1994, <b>Voluntary euthanasia: private and public imperatives</b> MMAT: n/a	Medical ethics	To highlight societal changes in the debate for euthanasia.			Making a case for alleviating inequality on how people are treated at the end of their lives.	Economy
Bolt, E E., Pasman, H R W., Deeg, D J H., Onwuteaka-Philipsen, B D., 2016, <b>From Advance Euthanasia Directive to Euthanasia: Stable Preference in Older People?</b> MMAT: 100%	Geriatrics	To determine whether older people with advance directive for euthanasia (ADEs) are stable in their advance desire for euthanasia in the last years of life, how frequently older people with an ADE eventually request euthanasia, and what factors determine this.	Proxies of deceased members of a cohort representative of Dutch older people (n = 168) and a cohort of people with advance directives (n = 154).	Data from cohort members (possession of ADE) combined with after-death proxy information on cohort members’ last 3 months of life. Multiple logistic regression analysis was performed on determinants of a euthanasia request in individuals with an ADE.	Response rate was 65%. 142 cohort members had an ADE at baseline. Three months before death, 87% remained stable in their desire for euthanasia; 47% eventually requested euthanasia (vs 6% without an ADE), and 16% died after euthanasia. People with an ADE were more likely to request euthanasia if they worried about loss of dignity. Writing an ADE may reflect a person’s need for reassurance that they can request euthanasia in the future.	Timing Suffering Dignity
Bolt, E E., Snijdewind, M C., Willems, D L., van der Heide, A., Onwuteaka-Philipsen, B D., 2015, <b>Can physicians conceive of performing euthanasia in case of psychiatric disease, dementia or being tired of living?</b> MMAT: 100%	Medical ethics	To determine whether physicians can conceive of granting requests for EAS in patients with cancer, another physical disease, psychiatric disease, dementia or patients who are tired of living, and to evaluate whether physician characteristics are associated with conceivability.	2269 Dutch general practitioners, elderly care physicians and clinical specialists.	Cross-sectional study	Most physicians found it conceivable that they would grant a request for EAS in a patient with cancer or another physical disease. Less than half of the physicians found this conceivable in patients with psychiatric disease, early-stage dementia, advanced dementia or tired of living. General practitioners were most likely to find it conceivable that they would perform EAS. For physicians who find EAS inconceivable in these cases, legal arguments and personal moral objections both probably play a role.	Suffering
Bosshard, G., Broeckaert, B., Clark, D., Materstvedt, L J., Gordijn, B., Müller-Busch, H C., 2008, <b>A role for doctors in assisted dying? An analysis of legal regulations and medical professional positions in six European countries</b> MMAT: n/a	Medical ethics	To analyse legislation and medical professional positions concerning the doctor’s role in assisted dying in western Europe, and to discuss their implications for doctors.		Based on reports from western europe	A society moving towards an open approach to assisted dying should carefully identify tasks to assign exclusively to medical doctors, and distinguish those possibly better performed by other professions.	Role of physicians Multi-disciplinary teams



Author, date, title	Study type	Aim	Study population	Study design	Key findings	Theme
Brassington, I., 2006, <b>Killing people: what Kant could have said about suicide and euthanasia but did not</b> <b>MMAT: n/a</b> Exclude: whether Kant would have approved or not is relevant for this study.	Medical ethics	Setting out to prove that Kant’s arguments about the wrongs of suicide and euthanasia are unconvincing.			The conclusion I am drawn towards is this: the “official”, mainstream interpretation of Kant, according to which he forbids all suicides, all assisted suicide and all euthanasia, is simply not tenable, and in rejecting it, we do not even have to step outside of Kantianism. We can reasonably easily out-Kant Kant.	Excluded
Brock, D W., 1999, <b>A critique of three objections to physician-assisted suicide</b> <b>MMAT: n/a</b>	Medical ethics	Countering objections raised in 1997 supreme cours decision to not legalise PAS			The use of currect objections is not moral and they are easily refuted according to the author.	Autonomy
Brock, D W., 2000, <b>Misconceived sources of opposition to physician-assisted suicide</b> <b>MMAT: n/a</b>	Psychology, public policy, and law	Addressing two prominent sources of opposition to assisted dying: 1) fear of abuse and 2) distinction between assited dying and other forms of End of Life care.		Review of Coombs Lee and Worth’s account of Compas- sion’s first year of experience with Oregon’s act permitting PAS	1) fear of abuse refuted by comparing with “allowing a patient to die”; refusing treatment and or hastening death by more pain relief. 2) distinction between assited dying and other forms of end-of-life care, and the physician’s role. Pointing out that the patient is central and the patient doesn’t value what remains of their life as “life”.	How doctors feel
Buiting, H M., Deeg, D J H., Knol, D L., Ziegelmann, J P., Pasman, H R W., Widdershoven, G A M., Onwuteaka-Philipsen, B D., 2012, <b>Older peoples’ attitudes towards euthanasia and an end-of-life pill in The Netherlands: 2001-2009</b> <b>MMAT: 100%</b>	Medical ethics	This study explored characteristics and time trends of older peoples’ attitudes towards two end-of-life scenarios: euthanasia, which is a legally accepted practice in The Netherlands, and a pill that would enable older people to end their own life when being tired of living in the absence of a severe disease.	N=1284 (2001), N=1303 (2005) and N=1245 (2008)	Three samples aged 64 years or older from the Longitudinal Ageing Study Amsterdam (N=1284 (2001), N=1303 (2005) and N=1245 (2008)) were studied.	An increasing proportion of older people reported that they could imagine desiring euthanasia or an end-of-life pill. This may imply an increased interest in deciding about your own life and stresses the importance to take older peoples’ wishes seriously	Autonomy
Buiting, H M., van der Heide, A., Onwuteaka-Philipsen, B D., Rurup, M L., Rietjens, J A C., Borsboom, G., van der Maas, P J., van Delden, J J M., 2010, <b>Physicians’ labelling of end-of-life practices: a hypothetical case study</b> <b>MMAT: 100%</b>	Medical ethics	To investigate why physicians label end-of- life acts as either ‘euthanasia/ending of life’ or ‘alleviation of symptoms/palliative or terminal sedation,’ and to study the association of such labelling with intended reporting of these acts.	1155 Dutch physicians	Questionnaires	Similar cases are not uniformly labelled. However, a physicians’ label is strongly associated with their willingness to report their acts. Differences in how physicians label similar acts impede complete societal control. Further education and debate could enhance the level of agreement about what is physician-assisted dying, and thus should be reported, and what not.	Decision making Double effect
Buiting, H., van Delden, J., Onwuteaka-Philpsen, B., Rietjens, J., Rurup, M., van Tol, D., Gevers, J., van der Maas, P., van der Heide, A., 2009, <b>Reporting of euthanasia and physician-assisted suicide in the Netherlands: descriptive study</b> <b>MMAT: 100%</b>	Medical ethics	A study of which arguments Dutch physicians use to substantiate their adherence to the criteria and which aspects attract review committees’ attention.	158 files of reported euthanasia cases	158 files examined of reported euthanasia and physician-assisted suicide cases that were approved by the review committees. A study on the physicians’ reports and the verdicts of the review committees by using a checklist.	Dutch physicians substantiate their adherence to the criteria in a variable way with an emphasis on physical symptoms. The information they provide is in most cases sufficient to enable adequate review. Review committees’ control seems to focus on (unbearable) suffering and on procedural issues.	Suffering
Burlá, C., Rego, G., Nunes, R., 2014, <b>Alzheimer, dementia and the living will: A proposal</b> <b>MMAT: n/a</b>	Philosophy	The objective of this paper is to approach advance directives as one of the tools for an adequate advance care planning in Alzheimer’s disease. For an adequate health care planning in Alzheimer disease the living will can be presented to the patient in the early days of their care. The appointment of a health care proxy should be done when the person is still in full cognitive ability, and that the existence and scope of advance directives should be conveyed to any patient in the early stages of the disease.			To preserve patient autonomy it is important that people diagnosed with Alzheimer’s disease make a living will as soon as possible while they are still cognitively sound of mind. If possible, conflicts between the will of carer, physician and patient should be addressed and documented while patient autonomy exists. Respect for the dignity of the human person is the primary concern to encourage patients with Alzheimer to exercise autonomy and to document their wishes in advance directives.	Rationality Autonomy Timing



Author, date, title	Study type	Aim	Study population	Study design	Key findings	Theme
Carlson, W L., Ong, T D., 2014, <b>Suicide in later life</b> <b>MMAT: 100%</b> <a href="#">Print</a>	Geriatrics	To see what can be done about higher rates of suicide amongst older people.			Looks into effects as well as causes of suicide	Planned death or suicide
Chambaere, K., Cohen, J., Robijn, L. Bailey, S.K., Deliens, L., 2015, <b>End-of-life decisions in individuals dying with dementia in Belgium</b> <b>MMAT: 100%</b>	Geriatrics	To describe the prevalence and characteristics of end-of-life decisions in individuals dying with dementia in Belgium.	Physicians certifying a large random sample of deaths (n = 8,627).	Retrospective mail survey.	End-of-life decision-making in individuals dying with dementia differs from that in individuals with cancer, more often involving forgoing of life-prolonging treatment and less often involving intensifying pain and symptom treatment. Considerations typically involve the prospects of the individual with dementia. Optimal processes of advance care planning may address the burdensome decision falling to physicians and family regarding when to allow the individual to die.	Rationality Decision making Carer's influence Slippery slope
Chapple, A., Ziebland, S., McPherson, A., Herxheimer, A., 2006, <b>What people close to death say about euthanasia and assisted suicide: a qualitative study</b> <b>MMAT: 100%</b>	Medical ethics	To explore the experiences of people with a “terminal illness”, focusing on the patients’ perspective of euthanasia and assisted suicide.	18 people	A qualitative study using narrative interviews was conducted throughout the UK. The views of the 18 people who discussed euthanasia and assisted suicide were explored. These were drawn from a maximum variation sample, who said that they had a “terminal” illness, malignant or non-malignant.	Qualitative research conducted on people who know they are nearing death is an important addition to the international debate on euthanasia and assisted suicide. Those who had seen others die were particularly convinced that the law should be changed to allow assisted death.	Autonomy Suffering
Cholbi, Michael, 2015, <b>Kant on euthanasia and the duty to die : clearing the air</b> <b>MMAT: n/a</b>	Medical ethics	Making a case that Cooley’s interpretation on Kant with regards to a “duty to die” is false.		Response to Cooley D. A Kantian moral duty for the soon-to-be demented to commit suicide.	Cooley’s argument for a Kantian duty to die for those who anticipate dementia rests on a category mistake that conflates two distinct aspects of agency or dignity and wrongly assumes that the absence of those features that ground the obligation not to commit suicide entails an obligation to commit suicide. Thus, Cooley’s framework, to which Sharp appeals, is suspect.	Moral dilemmas Ethics
Cicirelli, V G., 1997, <b>Relationship of psychosocial and background variables to older adults’ end-of-life decisions</b> <b>MMAT: 100%</b>	Geriatrics	To determine acceptability of a full range of end-of-life decision options and identify related variables.	388 mixed race healthy adults, aged 60-100.	Semi structured interviews (“what would you do if” questions) based on a questionnaire.	Despite low quality of life, maintaining life (striving to live and seeking treatment) was the most acceptable option, but a significant minority of participants wished to end life (suicide, assisted suicide, or euthanasia) and a moderate number wished to defer the decision to others. In hierarchical regressions, psychosocial variables (religiosity, values, fear of death, etc.) contributed significantly to decisions beyond the effects of demographic and health variables.	Rationality Control
Cicirelli, V G., 1998, <b>Views of Elderly People Concerning End-of-Life Decisions</b> <b>MMAT: 100%</b>	Geriatrics	The aim of this study was to determine elders’ views regarding the acceptability of seven end-of-life decision options;	477 elderly (60-100 yrs) interview-questionnaire MANOVA analyses.	A total of 447 Black and White elders ages 60 to 100 years responded to 17 decision situations depicting conditions with a low quality of life, rating acceptability of each decision option.	Mean percentage of participants finding each decision option acceptable were: striving to live, 52%; refusing or withdrawing treatment, 47%; letting someone close decide, 36%; suicide, 7%; assisted suicide, 12%; voluntary euthanasia, 12%; and allowing the physician to decide to end life, 19%. Views were related to age, ethnicity, education, occupation, and religious affiliation.	Autonomy



Author, date, title	Study type	Aim	Study population	Study design	Key findings	Theme
Cicirelli, V G., MacLean, A., P., 2000, <b>hastening death: a comparison of two end-of-life decisions, Death Studies</b> <b>MMAT: 100%</b>	Medical ethics	This study determined the relationship of psychosocial and background variables to elders’ end-of -life (EOL) decision preferences. Responding to 5 EOL decision scenarios depicting terminally ill elders, 200 elders aged 60–90 indicated preferences regarding extending life (EL), refusing treatment (RT), and assisted suicide (AS). They were also assessed on religiosity, values, fear of death, locus of control , health, socioeconomic status, age.	200 men and women aged 60–90 from a medium-sized Midwestern city (Greater Lafayette, Indiana)	Structured interviews using scenarios and 1-5 scoring	Results of multinomial logistic regression indicated that EOL decisions of three groups (favoring EL, favoring RT, and favoring both AS and RT) were significantly influenced by religiosity, value for preservation of life, value for quality of life, fear of death, and locus of control belief. The importance of safeguarding older adults’ autonomy in EOL decisions was stressed.	Attitudes towards
Cohen-Almagor, R., 2003, <b>Dutch perspectives</b> <b>MMAT: 100%</b>	Ethics	To provide an account of Dutch policy maker’s perceptions on questionable data from Rummelink report in non-voluntary and involuntary euthanasia.		Analysis of dutch euthanasia requests in semi structured interviews	Overall consensus is that policy makers are not worried. The “double effect” usually takes place in cases where patients are so ill and not cognitively sound and dying with terrible suffering. Either way, it is a case by case situation and due care is being taken. The policy makers claim that overall doctors will do what they need to help their patients. Author shows concern, as the rules / guidelines are persistently being broken.	Moral dilemmas Practical dilemmas Timing
Cooley, D R., 2007, <b>A Kantian moral duty for the soon-to-be demented to commit suicide</b> <b>MMAT: n/a</b>	Bioethics	If moral agents have a duty to act as moral agents, then those who will lose their moral identity as moral agents have an obligation to themselves to end their physical lives prior to losing their dignity as persons.			However, there is a plausible interpretation of Kant’s views that states, under certain conditions, not only is the person permitted to kill herself; she is required to do so as a duty to herself qua moral agent. In situations in which the agent cannot keep both her physical and moral lives, killing her body preserves her moral life and dignity as a person.	Rationality
Csikai, E L., 1998, <b>Euthanasia and Assisted Suicide: Issues for Social Work Practice</b> <b>MMAT: n/a</b>	Gerontology	Social workers should prepare to discuss possible requests for information about these practices in the context of patient and family decision making in end-of-life situations.			If euthanasia and assisted suicide are legalized, social workers also need to voice their concerns about potential risks for abuse and contribute to policies in a manner that will protect vulnerable populations. As the debate around end-of-life issues is far from over, social workers have the opportunity to make a significant contribution in the scope and direction of these discussions, especially by knowing where they stand on the issue.	How social workers feel
Daly, P., 2015, <b>Palliative sedation, foregoing life-sustaining treatment, and aid-in-dying: what is the difference?</b> <b>MMAT: n/a</b>	Bioethics	I introduce a novel way to approach this argument based on Bernard Lonergan’s generalized empirical method (GEM). Then I proceed on the basis of GEM to distinguish palliative sedation, palliative sedation to unconsciousness when prognosis is less than two weeks, and foregoing life-sustaining treatment from aid-in-dying.			I conclude (1) that aid-in-dying must be justified on its own merits and not on the basis of these well-established palliative care practices; and (2) that societies must decide, in weighing the merits of aid-in-dying, whether or not to make the judgment that no life is better than life-like-this (however this is specified) part of their operative value structure.	Moral dilemmas
Daskal, F C., Hougham, G W., Sachs, G A., 1999, <b>Physician-Assisted Suicide: Interviews with patients with dementia and their families</b> <b>MMAT: 100%</b> <a href="#">Print</a>	Medical ethics	To determine feasibility of including patients with early-stage dementia in a study of attitudes towards PAS, whether attitudes towards PAS differed between patients and carers and/or the general population	26 patients and 24 pair-matched proxies		Patients and family members were very interested in discussing PAS. The majority were in favor of PAS. It is possible to interview early stage patients. Patients and carer views seem similar as the general public’s.	Carer’s views



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Davis, D S., 2013, <b>Alzheimer disease and pre-emptive suicide</b> MMAT: n/a	Medical ethics	The thesis of this article is that suicide is one reasonable response to impending dementia, whether from AD or some other cause. For people so inclined, however, 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.			Death is irreversible, but so is dementia. People must weigh the risks of shortening their lives unnecessarily against the risks of developing AD and living as long as 20 years with dementia. The risks are, by their very definition, uncertain, but that should not bar people who wish to do so from getting all the information available and acting on their own values. As it becomes easier and better to predict Dementia, this opens up an opportunity to take action; to perform suicide, PAS or euthanasia “before it’s too late”	Timing Personality change
Dees, M K., Vernooij-Dassen, M J., Dekkers, W I., Vissers, K C., van Weel, C., 2011, <b>‘Unbearable suffering’: a qualitative study on the perspectives of patients who request assistance in dying</b> MMAT: 100%	Medical ethics	To explore the constituent elements of suffering of patients who explicitly request euthanasia or physician- assisted suicide (EAS) and to better understand unbearable suffering from the patients’ perspective.	A qualitative study using in-depth face-to-face interviews was conducted with 31 patients who had requested EAS. The grounded theory approach was used to analyse the data.	Qualitative, in-depth, face-to-face interviews. Purposeful sampling was used to ensure diversity in diagnosis.	Medical, psycho-emotional, socio-environmental and existential themes contributed to suffering. Especially fatigue, pain, decline, negative feelings, loss of self, fear of future suffering, dependency, loss of autonomy, being worn out, being a burden, loneliness, loss of all that makes life worth living, hopelessness, pointlessness and being tired of living were constituent elements of unbearable suffering. Only patients with a psychiatric (co) diagnosis suffered unbearably all the time.	Suffering
van Delden, J J M., 2004, <b>The unfeasibility of requests for euthanasia in advance directives</b> MMAT: n/a	Law ethics and medicine	What to do with a competent patient who has written an advance directive requesting euthanasia under certain circumstances. The law stipulates that a physician may act according to that written request, as long as he or she fulfils all other rules of due care. The author defends the view that these requests are neither feasible nor ethically justifiable, and presents both moral and practical arguments, claiming that for consistency reasons one cannot act on the basis of a written statement and fulfil the other rules of due care at the same time.			A regulation for performing euthanasia on an incompetent patient on the grounds of that person’s previously written advance directive is a mistake. It creates inconsistencies both within the law (if present) and with the moral framework that is mostly behind such regulation.	Practical dilemmas Moral dilemmas
van Delden, J J., <b>Slippery slopes in flat countries--a response</b> MMAT: n/a	Ethics	In response to the paper by Keown and Jochemsen in which the latest empirical data concerning euthanasia and other end-of-life decisions in the Netherlands is discussed, this paper discusses three points.			The use of euthanasia in cases in which palliative care was a viable alternative may be taken as proof of a slippery slope. However, it could also be interpreted as an indication of a shift towards more autonomy-based end-of-life decisions. The cases of non-voluntary euthanasia are a serious problem in the Netherlands and they are only rarely justifiable. However,they do not prove the existence of a slippery slope.	Moral dilemmas Slippery slope
Dening, K H., Jones, L., Sampson, E L., 2012, <b>Preferences for end-of-life care: a nominal group study of people with dementia and their family carers</b> MMAT: 100%	Palliative medicine	To explore whether people with dementia and their carers were able to generate and prioritise preferences for end-of-life care. We examined whether carers influenced the choices made by the persons with dementia.	People with dementia (n = 6), carers (n = 5) and dyads of people with dementia and carers (n = 6) attending memory assessment services	Nominal group technique	Quality of care, family contact, dignity, respect, independence and control and carer burden where identified themes. People with dementia had difficulty considering their future selves. Carers wanted much control at the end of life, raising issues of assisted dying and euthanasia. Wishes and preferences of people with dementia and their family carers may differ. To ensure the wishes of people with dementia are respected, their views should be ascertained early in the disease before their ability to consider the future is compromised.	Autonomy Control Rationality



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Deyaert, J., Chambaere, K., Cohen, J., Roelands, M., Deliens, L., 2014, <b>Labelling of end-of-life decisions by physicians</b> MMAT: 100%	Medical ethics	Potentially life-shortening medical end-of-life practices (end-of-life decisions) remain subject to conceptual vagueness. This study evaluates how physicians label these practices by examining which of their own practices (described according to the precise act, the intention, the presence of an explicit patient request and the self-estimated degree of life shortening) they label as euthanasia or sedation.		Large stratified random sample of death certificates from 2007 (N=6927). The physicians named on the death certificate were approached by means of a postal questionnaire asking about ELDs made in each case and asked to choose the most appropriate label to describe the ELD. Response rate was 58.4%.	In the vast majority of practices labelled as euthanasia, the self-reported actions of the physicians corresponded with the definition in the Belgian euthanasia legislation; practices labelled as palliative or terminal sedation lack clear correspondence with definitions of sedation as presented in existing guidelines. In these cases, an explicit life-shortening intention by means of drug administration was present in 21.6%, life shortening was estimated at more than 24 h in 51% and an explicit patient request was absent in 79.7%.	Autonomy
Dieterle, J M., 2007, <b>Physician assisted suicide: A new look at the arguments</b> MMAT: n/a	Bioethics	In this paper, I examine the argumens agains physician assisted suicide (PAS). Many of these arguments are consequentialist. Consequentialist arguments rely on empirical claims about the future and thus their strength depends on how likely it is that the predictions will be realized. Finally, I examine the two most prominent deontological arguments against PAS. Ultimately, I conclude that no anti-PAS argument has merit.			Deontological and Consequential arguments against PAS are investigated and refuted.	Slippery slope
Digby, R., Bloomer, M J., 2014, <b>People with dementia and the hospital environment: The view of patients and family carers</b> MMAT: 50% exluded: about architectural design in care facilities	Geriatrics	The aim was to elicit the perspectives of current inpatients with dementia, and their family carers, about the environment/design features that they believe are necessary for people with dementia, and their family carers.	7 patients (MMSE 15-23) and 4 carers.	In-depth semi-structured interviews	While participants valued care over the physical surroundings, they also offered valuable information about their experience in the ward environment. Despite cognitive difficulties, people with dementia were able to provide useful information about the environment within which they were being cared in.	Excluded
Dixon, N., 1998, <b>On the Difference between Suicide and Active Euthanasia</b> MMAT: n/a	Medical ethics	Those who defend physician-assisted suicide often seek to distinguish it from active euthanasia, but in fact, the two acts face the same objections. Both can lead to abuse, both implicate the physician in the death of a patient, and both violate whatever objections there are to killing. Their moral similarity derives from the similar roles of the physician.			In this paper I examine these and other arguments that active euthanasia is morally more problematic than physician-assisted suicide, and I conclude that none of these arguments is sound.	Slippery slope
Doernberg, S N., Peteet, J R., Kim, S Y H., 2016, <b>Capacity Evaluations of Psychiatric Patients Requesting Assisted Death in the Netherlands</b> MMAT: 100%	Psychological medicine	This study examined a frequently raised concern about the prac- tice: how physicians address the issue of decision-making capacity of persons requesting psychiatric EAS.	66 cases 2011-2014	A review of psychiatric EAS case summaries published by the Dutch Regional Euthanasia Review Committees. Directed content analysis using a capacity-specific 4 abilities model was used to code texts discussing capacity.	Case summaries of psychiatric EAS in the Netherlands do not show that a high threshold of capacity is required for granting EAS. Although this may reflect limitations in documentation, it likely represents a practice that reflects the normative position of the review committees.	Assessing mental capacity



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Domino, G., 2003, <b>Community Attitudes Toward Physician Assisted Suicide</b> MMAT: 50%	Urban Geography	To assess attitudes toward physician-assisted suicide (PAS)	400 adults	Attitudes toward physician-assisted suicide (PAS) were assessed in a sample of 400 community adults, stratified as to gender and socioeconomic class, using a 12-item psychometric scale	There were no gender differences, but significant socioeconomic class differences were obtained with better educated, upper class individuals more favorable in attitude than semi-skilled and unskilled poorly educated lower social class individuals. The majority of respondents support physician assisted suicide, but such support is inversely related to age.	Attitudes towards
Emanuel, E J., 1999, <b>What is the great benefit of legalizing euthanasia or physician-assisted suicide?</b> MMAT: n/a	Ethics	Euthanasia as a means for a quality dying experience. Will legalizing-or permitting – euthanasia and PAS promote – or thwart – a good death for the 2.3 million Americans who die each year in the US? Will people be helped or harmed having PAS available to them?			Benefits: Autonomy, Reducing hopeless suffering and psychological reassurance ( <i>in what way?</i> ). Potential harm: integrity of medical profession, psychological anxiety ( <i>they might kill me?</i> ), coercion of patients to choose PAS against wishes, provision of PAS before appropriate palliative care, euthanasia without full consent (mental incompetence), distress of surviving family members. At date of writing, there is no compelling evidence that PAS will improve care	Quality in dying
Epstein, M., 2007, <b>Legitimizing the shameful: End-of-life ethics and the political economy of death</b> MMAT: n/a	Bioethics	This paper explores one of the most politically sensitive and intellectually neglected issues in bioethics – the interface between the history of contemporary end-of-life ethics and the economics of life and death. It suggests that contrary to general belief, economic impulses have increasingly become part of the conditions in which contemporary end-of-life ethics continues to evolve.			This paper takes its point of departure to be the observation that economic justifications for hastening the death of some people are gradually becoming morally acceptable. It attempts to find out why and how. Specifically, it focuses on the contribution of contemporary end-of-life ethics to this process. In this respect, it has two aims.	Economics
Farrenkopf, T., Bryan, J., 1994, <b>Psychological Consultation Under Oregon’s 1994 Death With Dignity Act: Ethics and Procedures</b> MMAT: n/a	Ethics	Describing protocol to assess end-of-life mental conditions and competence.	APA board	Describing in detail the assessment criteria for mental competence	Assessing mental competence in an assisted dying request is essential. This article describes a protocol on how to carry out this assessment.	Rationality
Fenn, D S., Ganzini, L, 1999, <b>Attitudes of Oregon psychologists toward physician-assisted suicide and the Oregon Death With Dignity Act</b> MMAT: 100%	Psychology	Psychologists survey the practical aspects of assessment on mental competence, depression or psychological disorders.	426 Oregon based psychologists, random sample	Anonymous survey	Mental health issues are essential in the assisted dying debate. More research needs to be done on moral and practical application.	Assessing quality of life and mental competence
Finlay, I G., George, R, 2011, <b>Legal physician-assisted suicide in Oregon and The Netherlands: evidence concerning the impact on patients in vulnerable groups--another perspective on Oregon’s data</b> MMAT: n/a	Medical ethics	Battin et al. examined data on deaths from physician- assisted suicide (PAS) in Oregon and on PAS and voluntary euthanasia (VE) in The Netherlands. This paper reviews the methodology used in their examination and questions the conclusions drawn from it namely, that there is for the most part ‘no evidence of heightened risk’ to vulnerable people from the legalisation of PAS or VE.			The Oregon data demonstrate a greater resort to PAS among better educated and financially affluent persons, particularly those over 65 years of age. This warrants further enquiry to ascertain whether they have vulnerabilities to influence to accessing PAS. We believe Battin et al.’s analysis of the data as regards the PAS scene in Oregon is incomplete.	Slippery slope
Flew, A, 1999, <b>Advance directives are the solution to Dr Campbell’s problem for voluntary euthanasia.</b> MMAT: n/a	Medical ethics	Dr Neil Campbell suggests that when patients suffering extremes of protracted pain ask for help to end their lives, their requests should be discounted as made under compulsion. I contend that the doctors concerned should be referred to and then act upon advance directives made by those patients when of sound and calm mind.			An advance directive should work, and this is how it should look.	Advance Directives



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Frileux, S., Lelièvre, C., Muñoz Sastre, M. T., Mullet, E., Sorum, P. C., 2003, <b>When Is Physician Assisted Suicide or Euthanasia Acceptable?</b> MMAT: 100%	Medical ethics	To discover what factors affect lay people’s judgments of the acceptability of physician assisted suicide and euthanasia and how these factors interact.	Convenience sample of 66 young adults, 62 middle aged adults, and 66 older adults living in western France.	Participants rated the acceptability of either physician assisted suicide or euthanasia for 72 patient vignettes with a five factor design.	Patient requests were the most potent determinant of acceptability. Euthanasia was generally less acceptable than physician assisted suicide, but this difference disappeared when requests were repetitive. As their own age increased, participants placed more weight on patient age as a criterion of acceptability.	Attitudes towards
Galbraith, K M., Dobson, K. S., 2000, <b>The role of the psychologist in determining competence for assisted suicide/euthanasia in the terminally ill</b> MMAT: n/a	Psychology	To establish whether psychological assessment is required in a euthanasia request.		Reviewing legal requirements in Oregon and Canada (where it is not yet legal at this stage).	Psychologists should be included in the assisted suicide/euthanasia process to ensure comprehensive assessments of competency.	Assessing mental competence
Garand, L., Dew, M. A., Lingler, J H., DeKosky, S. T., 2011, <b>Incidence and predictors of advance care planning among persons with cognitive impairment</b> MMAT: 100%	Geriatrics	Persons with mild cognitive impairment (MCI) and Alzheimer disease (AD) are at heightened risk for future decisional incapacity.We sought to characterize advance care planning (ACP) rates over time in individuals who had no advance directives (living will or durable power of attorney) in place when they initially presented for a cognitive evaluation.	Persons (N = 127) with a diagnosis of MCI or early AD (n = 72) or moderate to severe AD (n = 55) and no advance directives upon initial presentation for a cognitive evaluation.	Retrospective analysis of data that had been prospectively collected / Extraction of responses to items pertaining to ACP assessed during annual semistructured interviews.	Younger subjects (younger than 65 years) were significantly more likely to initiate advance directives (43%) than older subjects (37%). This age effect was more pronounced in men than in women as well as in married subjects, those with a family history of dementia, those with no depressive disorder, and subjects with moderate to severe AD (versus those with MCI or early AD) at baseline.	Planning Rationality Autonomy
Gastmans, C., De Lepeleire, J., 2010, <b>Living to the bitter end? A personalist approach to euthanasia in persons with severe dementia</b> MMAT: n/a	Ethical / philosophical debate	In this article, we discuss some practical and ethical dilemmas regarding euthanasia in persons with severe dementia based on an advance euthanasia directive. We are using a personalist approach in dealing with these ethical dilemmas.			The decision on whether to perform euthanasia in persons with severe dementia is linked to how we view people, and to what role autonomy plays in people’s lives. Furthermore, the decision on whether to perform euthanasia also fits in with the global approach of other end-of-life medical decisions. Nevertheless, further ethical analysis is needed, not the least because dementia is becoming more prevalent.	Ethics Autonomy Timing Advance directives Suffering
van der Graaf, R.,van Delden, J J M., 2009, <b>Clarifying appeals to dignity in medical ethics from an historical perspective</b> MMAT: n/a	Bioethics	We think that appeals to dignity in medical ethics can be clarified by considering the concept from an historical perspective.			Dignity refers, in a restricted sense, to the ‘special status of human beings’; it is based on essential human characteristics; the subject of dignity should live up to it; and it is a vulnerable concept, it can be lost or violated. We argue that being explicit about the meaning of dignity will prevent dignity from becoming a conversation- stopper in moral debate. Secondly, an historical perspective on dignity shows that it is not yet time to dispose of dignity in medical ethics.	Moral dilemmas
Georges, J J., The, A M., Onwuteaka-Philipsen, B D., van der Wal, G., 2008, <b>Dealing with requests for euthanasia: a qualitative study investigating the experience of general practitioners</b> MMAT: 100%	Medical ethics	The aim of this study is to describe the experiences of general practitioners (GPs) in The Netherlands in dealing with a request for euthanasia from a terminally ill patient.	31 GPs	The data, collected through in-depth interviews, were analysed according to the constant comparative method.	Dealing with requests for euthanasia is very challenging for GPs, although they feel committed to alleviate a patient’s suffering and to promote a peaceful death.	How doctors feel
Georges, J J., Onwuteaka-Philipsen, B D., Muller, M T., Van Der Wal, G., Van Der Heide, A., Van Der Maas, P J., 2007, <b>Relatives’ perspective on the terminally ill patients who died after euthanasia or physician-assisted suicide: a retrospective cross-sectional interview study in the Netherlands</b> MMAT: 100%	Death studies	This study used retrospective interviews with 87 relatives to describe the experiences of patients who died by euthanasia or physician-assisted suicide (EAS) in the Netherlands. The objectives of the study were to gain insight into the background and history of requests for EAS and into the influence and meaning of EAS on the end of a patient’s life.	87 relatives	Structured interviews	According to the relative, in 92%of patients EAS had contributed favourably to the quality of the end of life. EAS mainly contributes to the quality of the end of the patients’ life because their wishes are respected and further suffering is prevented. It also appeared that knowing how one’s own wishes and requests for euthanasia will be treated generated feelings of trust and control.	How people left behind feel after euthanasia



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Gessert, C E., Forbes, S., Bern-Klug, M W., 2000, <b>Planning End-of-Life Care for Patients With Dementia: Roles of Families and Health Professionals*</b> <b>MMAT: 100%</b>	Geriatrics	We undertook the current study to identify areas where better communication between health professionals and patients/families might be expected to be most beneficial to families facing end-of-life decisions.	28 family members of institutionalised dementia patients in four focus groups	Focus group	We found that participating family members were not well prepared for their decision-making roles. Health professionals should take the lead in ‘normalizing’ the discussion of death. The participants did not have a model for a “good death” in mind; no clear idea of what steps might be taken to increase the chances of a “peaceful” or “good” death. There was limited understanding of where “control” or “agency” resided in end-of-life care.	Carer’s roles
Gildenhuys, P., 2015, <b>The Legitimacy of Prohibiting Euthanasia</b> <b>MMAT: n/a</b>	Medical ethics	John Arras believes that the legalization of highly restricted physician assisted suicide will result in the legalization of active euthanasia without special restrictions, a prediction I grant for the sake of argument. Arras further anticipates that the practices of physician-assisted suicide and euthanasia will be abused, so that many patients who engage in these practices will lose out as a result.			Legalization of physician-assisted suicide or euthanasia brings no social costs. For this reason, and also because a ban on euthanasia is unfair to those who would profit from it, the losses in utility brought about by legalization would have to be very great to justify a ban.	Slippery slope
Gillick, M., Mendes, M L., 1996, Medical care in old age: <b>What do nurses in long-term care consider appropriate?</b> <b>MMAT: 100%</b> <a href="#">print</a>	Geriatrics	To determine whether nurses working in a long-term care institution, who are knowledgable about a full range of conditions common among older people, favor limitations of treatment in old age.	102 nurses	Make and advance directive for themselves, with specific scenarios	Nurses would limit a great deal of care in old age. The greater the degree of physical and cognitive impairment, the more limitations they favor.	How doctors feel
Ginn, S., Price, A., Rayner, L., Owen, G S., Hayes, R D., Hotopf, M., Lee, W., 2011, <b>Senior doctors’ opinions of rational suicide</b> <b>MMAT: 100%</b>	Medical ethics	To assess attitudes towards rational suicide in a representative sample of senior doctors in England and Wales.	363 questionnaires were analysed	Postal survey was conducted of 1000 consultants	Most senior doctors in England and Wales feel that rational suicide is possible. Most doctors who were opposed to physician assisted suicide believed that rational suicide was possible, suggesting that some medical opposition is best explained by other factors such as concerns of assessment and protection of vulnerable patients.	Attitudes towards Rationality
Gjerdingen, D K., Neff, J A., Wang, M., Chaloner, K., 1999, <b>Older persons’ opinions about life-sustaining procedures in the face of dementia</b> <b>MMAT: 100%</b>	Geriatrics	To investigate the attitudes of cognitively sound older adults toward various life-sustaining procedures in the face of dementia.	84 adults, 65+ years old	In-depth interviews	Most surveyed individuals did not desire life-sustaining treatments with any degree of dementia, and the proportion of individuals not desiring such treatments increased with the projected severity of dementia. These findings indicate a need for including dementia in advance directives planning.	Rationality Quality of life
Guedj, M., Gibert, M., Maudet, A., Muñoz Sastre, M T., Mullet, E., Sorum, P C., 2005, <b>The acceptability of ending a patient’s life</b> <b>MMAT: 100%</b> Very specifically France: <b>exclude</b>	Medical ethics	To clarify how lay people and health professionals judge the acceptability of ending the life of a terminally ill patient.	115 lay people and 72 health professionals (22 nurse’s aides, 44 nurses, six physicians) in Toulouse, France.	16 scenarios that combined four factors: the identity of the actor (patient or physician), the patient’s statement of a desire to have his life ended, the nature of the action as active (injecting a toxin) or passive (disconnecting life support), and the type of suffering.	Life ending interventions are more acceptable to lay people than to the health professionals. For both, acceptability is highest for intractable physical suffering; is higher when patients end their own lives than when physicians do so; and, when physicians are the actors, is higher when patients have expressed a desire to die (voluntary euthanasia) than when they have not (involuntary euthanasia).	Excluded
Gunderson, M., 1997, <b>A right to suicide does not entail a right to assisted death</b> <b>MMAT: n/a</b>	Medical ethics	Many people believe that it is permissible for people who are sufferingfrom terminal illnesses to commit suicide or even that such people have a right to commit suicide.			If it is assumed that it is sometimes permissible to kill oneself or to refuse life-saving treatment, it does not follow that assisted death is also permissible. This is also true of the agency principle stated in terms of rights.	Agency principle Autonomy



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Hall, M., Trachtenberg, F, Dugan, E., 2005, <b>The impact on patient trust of legalising physician aid in dying</b> MMAT: 100%	Medical ethics	Little empirical evidence exists to support either side of the ongoing debate over whether legalising physician aid in dying would undermine patient trust.		A random national sample of 1117 US adults were asked about their level of agreement with a statement that they would trust their doctor less if “euthanasia were legal [and] doctors were allowed to help patients die”	Despite the widespread concern that legalising physician aid in dying would seriously threaten or undermine trust in physicians, the weight of the evidence in the USA is to the contrary, although views vary significantly.	Slippery slope
Hains, C A M., Hulbert-Williams, N J., 2013, <b>Attitudes toward euthanasia and physician-assisted suicide: a study of the multivariate effects of healthcare training, patient characteristics, religion and locus of control</b> MMAT: 100% Exclude because research is about situations where euthanasis is a fact	Medical ethics	We aimed to test the comparative importance of a larger range of variables in a sample of nursing trainees and non-nursing controls.	151 undergraduate students (early-stage nursing training, late-stage nursing training and non-nursing controls) UK	Questionnaires	The unexpected direction of association between religiosity and attitudes may reflect a broader cultural shift in attitudes since earlier research in this area. Furthermore, these findings suggest it possible that experience, more than training itself, may be a bigger influence on attitudinal differences in healthcare professionals.	Excluded
Hardwig, J., 1997, <b>Is there a duty to die?</b> Reference chase MMAT: n/a	Ethics	To argue there may well be (soon) a duty to die. As modern medicine continues to save more of us from acute ill- ness, it also delivers more of us over to chronic illnesses, allowing us to survive far longer than we can take care of ourselves. It may be that our technological sophisti- cation coupled with a commitment to our loved ones generates a fairly widespread duty to die.		Normative discussion	But our medicine also delivers most of us over to chronic illnesses and it enables many of us to survive longer than we can take care of ourselves, longer than we know what to do with ourselves, longer than we even are ourselves. A fairly common duty to die might turn out to be only the dark side of our life-prolonging medicine and the uses we choose to make of it.	Being a burden Autonomy
Hendin, H., 2002, <b>The Dutch Experience</b> MMAT: 75%	Ethics	Showing context between hisorical and cultural changing attitudes in the Netherlands linking to permissibility of Euthanasia.	Largely based on statistical set of data from “Euthanasia and other end-of-life decisions in the Netherlands in 1990, 1995, and 2001.”	Critical assessment of “Euthanasia and other end-of-life decisions in the Netherlands in 1990, 1995, and 2001.” Concluding a “slippery slope”.	Dutch Due Care criteria have failed. Interesting case studies to back this up; coercion by family, Chabot case of women suffering from “incurable grief” (her son had died), AIDS case of anxiety about suffering. Author claims that euthanasia request hardly ever get psychiatric consultation, however acording to “Better Off Dead”, episode 7 or 8 I would refute this.	Slippery slope
Hertogh, C M P M., 2009, <b>The role of advance euthanasia directives as an aid to communication and shared decision-making in dementia</b> MMAT: n/a	Medical ethics	This paper focuses on the absence of euthanasia cases concerning patients with dementia and a written advance euthanasia directive, despite the fact that the only real innovation of the Euthanasia Law consisted precisely in allowing physicians to act upon such directives.			AEDs, as a specific type of advance directive, derive their value from the possibility they offer to create and support a shared understanding between doctor and patient before competence is lost. It would therefore be advisable to adjust the Euthanasia Law in this direction in order to avoid misunderstandings and false expectations from people with AEDs.	Advance directives Timing Suffering
Hertogh, C M P M., de Boer, M., Dröes, R M., Eefsting, J A., 2007, <b>Would We Rather Lose Our Life Than Lose Our Self? Lessons From the Dutch Debate on Euthanasia for Patients With Dementia</b> MMAT: n/a	Bioethics	The actual debate concentrates on making euthanasia/assisted suicide possible in the very early stages of dementia. It is concluded that, in addition to a moral discussion on the limits of anticipatory choices, there is an urgent need to develop research into the patient’s perspective with regard to medical treatment and care-giving in dementia, including end-of-life care.			These findings reveal the urgency of a moral question: how far do we allow each other to go in what we ask from our fellow man in view of our right to self-determination or, more specifically, in view of our supposed right to a self- controlled death? Thus we have to conclude that the condition of advanced dementia can never be a reason to perform euthanasia based on an AED.	Advance directives Timing Diagnosis



Author, date, title	Study type	Aim	Study population	Study design	Key findings	Theme
Holm, S., 2015, <b>The debate about physician assistance in dying: 40 years of unrivalled progress in medical ethics?</b> <b>MMAT: n/a</b> Exclude: very specifically about the debate, no practical considerations / implications	Medical ethics	Some issues in medical ethics have been present throughout the history of medicine, and thus provide us with an opportunity to ascertain: (1) whether there is progress in medical ethics; and (2) what it means to do good medical ethics. One such perennial issue is physician assistance in dying (PAD). This paper provides an account of the PAD debate in this journal over the last 40 years.			It concludes that there is some (but limited) progress in the debate.	Excluded
Huddle, T S., 2013, <b>Moral fiction or moral fact? The distinction between doing and allowing in medical ethics</b> <b>MMAT: n/a</b>	Bioethics	The philosophical debate over the doing/allowing distinction remains inconclusive, but physicians and others who rely upon that distinction in thinking about the ethics of end-of-life care need not give up on it in response to these arguments.			That may be due to the distinction’s funda- mental incoherence, as its opponents would likely suggest; or, to the complexity of the ways in which human agency can involve moral responsibility in differing ways – as the distinction’s adherents would maintain.	Ethics Moral dilemmas Practical dilemmas
Huxtable, R., Möller, M., 2007, <b>‘Setting a principled boundary’? Euthanasia as a response to ‘life fatigue’</b> <b>MMAT: n/a</b> Exclude: about a specific “tired of life case”	Bioethics	Autonomy and beneficence: It will be argued that those proponents of voluntary euthanasia who are wary of its use in such circumstances may need to draw upon ‘practical’ objections, in order to erect an otherwise arbitrary perimeter.				Slippery slope Autonomy
Huxtable, R., 2014, <b>Splitting the Difference? Principled Compromise and Assisted Dying</b> <b>MMAT: n/a</b>	Bioethics	Making a case for a middle ground stance on assisted dying.			Making a case for a compromise in difficult moral debates; a neither completely for or against stance. Taking the assisted dying debate as such a moral dilemma.	Moral dilemmas Practical dilemmas
Illingworth, P., Bursztajn, H., 2000, <b>Death with dignity or life with health care rationing</b> <b>MMAT: n/a</b>	Psychology	Identifying three conditions that need to be met in order for true informed decisionmaking to take place and suggest areas that need to be monitored if the choices of the terminally ill are to be truly autonomous.			It is important to establish autonomy in decision making. In this day and age of autonomy, people want to have control over the way they die. To say that this is the dignified way, condemns all other death to be not dignified and that is not right. Importance on assessing cognitive functioning is stressed.	Rationality Control
Jamison, S., 2000, <b>Factors to consider before participating in a hastened death: Issues for medical professionals</b> <b>MMAT: n/a</b>	Psychology, Public Policy, and Law	An emerging problem that health professionals face in working with terminally ill patients is how to respond to the concerns that emerge near the end of life. My aim in this article is to provide tools that may be useful. They also may be of help to clinicians in uncovering the range of motives a patient may have for seeking a hastened death and for assessing the reasonableness of a patient’s request.			The request for a hastened death points to the need for a deeper level of communication between clinicians and patients. Depending on available resources, the physician faced with a patient’s request would do well to turn to psychologists, psychiatrists, social workers, or other practitioners who can perform invaluable services for the patient and also provide important knowledge about the patient to the physician.	Assessing euthanasia requests
Jansen-van der Weide, M C., Onwuteaka-Philipsen, B D., Van Der Heide, A., Van Der Wal, G., 2009, <b>How patients and relatives experience a visit from a consulting physician in the euthanasia procedure: a study among relatives and physicians</b> <b>MMAT: 100%</b>	Death studies	This study investigated the impact of a visit from a consulting physician on the patient and the relatives during the euthanasia procedure in The Netherlands.	86 relatives and 3,614 general practitioners	Written questionnaire	Although almost 1 out of 5 patients has negative experiences, this study indicates that, in general, consultation is not burdensome for patients. Negative experiences with the visit are partly related to the negative advice of the consultant or subsequently to the refusal of the request.	Euthanasia experience How relatives feel
Jochemsen, H., Keown, J., 1999, <b>Voluntary euthanasia under control? Further empirical evidence from The Netherlands</b> <b>MMAT: n/a</b>	Medical ethics	1996 saw the publication of a major Dutch survey into euthanasia in the Netherlands. This paper outlines the main statistical findings of this survey and considers whether it shows that voluntary euthanasia is under effective control in the Netherlands.	Critical assessment of the researchers’ interpretation of the statistics it generated.	Survey	The paper concludes that although there has been some improvement in compliance with procedural requirements, the practice of voluntary euthanasia remains beyond effective control.	Slippery slope



Author, date, title	Study type	Aim	Study population	Study design	Key findings	Theme
Johnson, S M., Cramer, R J Conroy, M A., Gardner, B O., 2014, <b>The role of and challenges for psychologists in physician assisted suicide</b> <b>MMAT: n/a</b>	Death studies	This article reviews legal statutes and analyzes ethical dilemmas psychologists may face if involved. We consider competence both generally and in the context of PAS. Suggestions are made for psychologists completing competence assessments and future directions to improve com- petence assessments for PAS are provided.			In addition, psychologists may want to consult with colleagues following the evaluation. Discussing the data gathered during the assessment with a party who is removed from the immediate process may also help to reduce potential bias.	Assessing mental health Need for psychologists
Johnson, S M., Cramer, R J., Gardner, B O., Nobles, M R., 2015, <b>What Patient and Psychologist Characteristics Are Important in Competency for Physician-Assisted Suicide Evaluations ?</b> <b>MMAT: 100%</b>	Psychology	Identifying characteristics of patients and clinicians, assessing cognitive abilities and effect on reasoning and how the affect a decision for PAS.	216 licensed psychologists	Questionnaires with informed consent, a survey and vignettes case studies.	Link between depression and cognitive reasoning was unclear. Clinicians’ decisions were not based on perceived burdensomeness, but being a burden may be a reason why patient’s would choose assisted dying. The results of this study suggest that personal opinions and experiences of the clinicians have the potential to influence the outcome of the evaluation.	Rationality, choice and control How doctors feel
Jones, D., 2011, <b>Is there a logical slippery slope from voluntary to non voluntary euthanasia?</b> <b>MMAT: n/a</b>	Ethics	John Keown has constructed a logical slippery slope argument from voluntary euthanasia (VAE) to nonvoluntary euthanasia (NVAE). VAE if justified implies that death can be of overall benefit, in which case it should also be facilitated in those who cannot consent (NVAE).		Discussion	Hallvard Lillehammer asserts that Keown’s argument rests on a fallacy. However, pace Lillehammer, it can be restated to escape this fallacy. Its validity is confirmed by applying to VAE some well-established general principles of medical decision making. Thus, either VAE and NVAE must be accepted together or, if NVAE is regarded as unacceptable, VAE should also be rejected.	Slippery slope
Jongsma, K R., Sprangers, M A G., van de Vathorst, S., 2016, <b>The implausibility of response shifts in dementia patients</b> <b>MMAT: n/a</b>	Medical ethics	Dementia patients may express wishes that do not conform to or contradict earlier expressed preferences. Our understanding of the difference between their prior preferences and current wishes has important consequences for the way we deal with advance directives. Some bioethicists and gerontologists have argued that dementia patients change because they undergo a ‘response shift’. In this paper we question this assumption.			We will show that proponents of the response shift use the term imprecisely and that response shift is not the right model to explain what happens to dementia patients. We propose a different explanation for the changed wishes of dementia patients and conclude that advance directives of dementia patients cannot be simply put aside.	Advance directives
Kelleher, M J., 1996, <b>Death on request</b> <b>MMAT: n/a</b>	Ethics	Letter in response to “death on request” film, apparently part of a longer debate.			Comparing film with nazi germany eugenics practises	Moral dilemmas
Kelleher, M J., Chambers, D., Corcoran, P., Keeley, H. S., Williamson, E., 1998, <b>Euthanasia and related practices worldwide</b> <b>MMAT: 100%</b>	Ethics	The present paper examines the occurrence of matters relating to the ending of life.	49 representatives of IASP were sent a twenty-item questionnaire dealing with legal and religious aspects of suicide, attempted suicide, euthanasia, and physician-assisted suicide.	Forced choice Questionnaires with elaboration.	Overall, the results imply a hidden need illegally met in some countries but officially criminal in most. The data, however, do not address or answer the moral question about the relationship between what is and what ought to be.	Attitudes towrads
Kerkhof, A J F M., 2000, <b>How to deal with requests for assisted suicide: some experiences and practical guidelines from the Netherlands</b> <b>MMAT: n/a</b>	Psychology, public policy	The aim of this contribution is to demonstrate that the Dutch law and jurisprudence permit clinicians to deal effectively with requests for assisted suicide			Although there are no empirical data to prove this opinion, it is my belief that the practice of assisted suicide in the Netherlands has had two simultaneous effects: There are more assisted suicides (mainly in terminal illnesses) as well as more effectively prevented suicides (mainly in psychiatric practice). The liberal policy on assisted dying in the Netherlands provides a framework for preventing irrational suicides.	Suffering



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Kleinman, A., 1997, <b>Intimations of solidarity? The popular culture responds to assisted suicide</b> <b>MMAT: n/a</b> Exclude: The PAS debate in cultural societal setting	Medical ethics	What is public opinion on assisted suicide			The signs point toward a time of multiple competing alternatives within the popular culture, and most likely within the professions and the academy as well. Such alternatives may take their origins from assisted suicide, but they appear to be engaging a more basic and broader social agenda that defines the large societal transformation our epoch is ushering in.	Attitudes towards
Kouwenhoven, S C., Raijmakers, N J H., van Delden, J J M., Rietjens, J A C., van Tol, D G., van de Vathorst, S., de Graeff, N., Weyers, H A M., van der Heide, A., van Thiel, G J M W., 2015, <b>Opinions about euthanasia and advanced dementia: a qualitative study among Dutch physicians and members of the general public</b> <b>MMAT: n/a</b>	Medical ethics	We investigated the differing opinions of physicians and members of the general public on the acceptability of euthanasia in patients with advanced dementia.	16 medical specialists, 19 general practitioners, 16 elderly physicians and 16 members of the general public were interviewed	Qualitative study: interviews	Legally, an AED may replace direct communication with patients about their request for euthanasia. In practice, physicians are reluctant to forego adequate verbal communication with the patient because they wish to verify the voluntariness of patients’ request and the unbearableness of suffering. For this reason, the applicability of AEDs in advanced dementia seems limited.	Advance directives
Lee, W., Price, A., Rayner, L., Hotopf, M., 2009, <b>Survey of doctors’ opinions of the legalization of physician assisted suicide</b> <b>MMAT: 100%</b>	Medical ethics	We aimed to measure support for legalising physician assisted dying in a representative sample of senior doctors in England and Wales, and to assess any association between doctors’ characteristics and level of support for a change in the law.	372 questionnaires	postal survey (questionnaire) of 1000 consultants and general practitioners randomly selected from a commercially available database.	More senior doctors in England and Wales oppose any step towards the legalisation of assisted dying than support this. Doctors who care for the dying were more opposed. This has implications for the ease of implementation of recently proposed legislation.	How doctors feel
Leget, C., 2006, <b>Boundaries, borders, and limits. A phenomenological reflection on ethics and euthanasia</b> <b>MMAT: n/a</b>	Medical ethics	This phenomenological analysis does not directly lead to normative conclusions. It helps by both paying attention to, and dealing with, the complexity of the issue with intellectual honesty.			The phenomenological approach to euthanasia as a boundary helps to pave the way toward a wise decision by mapping out the different interests and problems that are connected with each of the perspectives discussed.	Moral dilemmas
Lowe, S L., 1997, <b>The right to refuse treatment is not a right to be killed</b> <b>MMAT: n/a</b>	Medical ethics	A patient’s right to refuse treatment extends to circumstances which may lead to the patient’s death. It is also often assumed, without argument, that this implies a patient’s right to request another agent to intervene so as to bring about his or her death, which would render that agent guilty of murder in the absence of such a request.			Confusion over this issue is brought out by an examination of conflicting opinion concerning the permissible termination of ventilation for mentally competent patients. A wider lesson may be drawn regarding the needfor the ethical assessment of new forms of life-sustaining medical technology.	Moral dilemmas
Manthorpe, J., Samsi, K., Rapaport, J., 2012, <b>‘More of a leg to stand on’: views and usage of the Mental Capacity Act 2005 among staff of local Alzheimer’s Society and carer organisations</b> <b>MMAT: 75%</b> Exclude: Mental Capacity Act not relevant in dutch legal framework	Agining and mental health	Explores the challenges staff in local voluntary organisations focusing on dementia and carers face when they offer information and advice connected to possible loss of decision-making capacity to people with dementia and carers.	17 qualitative interviews	purposively sampled voluntary sector staff in London in 2008–09	Voluntary sector staff generally perceived the act as largely benefiting people with dementia in the exercise of their rights. They also thought that carers would benefit from the act’s provisions, whilst their own involvement in advice, information-giving and referral to other sources of expertise in relation to the MCA differed according to their role and confidence.	Excluded
Martyn, S R., Bourguignon, H J., 2000, <b>Physicians’ decisions about patient capacity: the Trojan horse of physician-assisted suicide</b> <b>MMAT: n/a</b>	Psychology, public policy, and law	Even if all physicians follow elaborate guidelines in determining patient capacity, their judgments will remain subjective and heavily influenced by their own personal values.			Capacity guidelines are the Trojan horse of physician-assisted suicide, because their appealing and reasonable character conceals the real decision-making power placed in the hands of physicians, who in reality evaluate the patient’s quality of life. We should instead concentrate our efforts on a better alternative: quality palliative care for all.	Slippery slope



Author, date, title	Study type	Aim	Study population	Study design	Key findings	Theme
Miller, P., 1997, <b>Struggle</b> <b>MMAT: n/a</b> <a href="#">Print</a>	Medical ethics	To see what qualities are needed to deal with terminality			Although this struggle complicates end-of-life decision making for physicians, it is not the physician alone who battles or denies death. Both the healthcare culture and the broader culture in which we exist must except death as a limit that can not be overcome.	Early diagnosis Death awareness
Millard, P H., 1998, <b>Euthanasia and old age, Letters to the Editor</b> <b>MMAT: n/a</b>	Medical ethics	However, a time series analysis of their data would seem to indicate that an exponential function is operating, as 50% of cases occurred in the last 2 years. This observation would suggest that the number of cases of euthanasia will increase in the next decade because the doctors will have changed their learnt behaviour.		Response to Onwuteaka-Philipsen BD, Muller MT, van der Wai G. Euthanasia in old age. Age Ageing 1997; 26: 487-92.	This observation would suggest that the number of cases of euthanasia will increase in the next decade because the doctors will have changed their learnt behaviour. The study therefore shows that the slippery slope involves people of all ages: no group is immune	Slippery slope
Menzel, P., Steinbock, B., 2013, <b>Advance Directives, Dementia, and Physician-Assisted Death</b> <b>MMAT: n/a</b>	Ethics	A new type of AED for Dementia patients?			A sliding scale AED should work. “Two factors, psychological continuity and narrative identity, fundamentally affect the value of life in dementia.”	Advance directives
Muller, M T., Kimsma, G K., Van Der Wal, G., 1998, <b>Euthanasia and assisted suicide: Facts, figures and fancies with special regard to old age</b> <b>MMAT: n/a</b>	Medical ethics	The objective of this paper is to describe the ethics and incidence of euthanasia and physician-assisted suicide (EAS) with special regard to old age. It is based on an assumption that if and when a practice of euthanasia and EAS is allowed, several vulnerable groups, including the elderly, may become a ‘population at risk’			We conclude that, although euthanasia and assisted suicide are illegal, there is evidence that these practices occur in all countries studied. Most surveys on the incidence of euthanasia show lower figures than those in the Netherlands. Dutch studies do not provide any evidence for the elderly being in danger of becoming ‘victims’ of euthanasia or assisted suicide.	Slippery slope Economy
Nicholson, L., 2013, <b>Risk of suicide in patients with dementia: a case study</b> <b>MMAT: n/a</b> <a href="#">Print</a>	Geriatrics	Looking into ways to improve care for dementia patients to avoid suicide			It analyses recommendations aimed at improving the lived experience of people with dementia and those involved in their care, including providing patients witha formal diagnosis as early as possible.	Case for early diagnosis Specialists, not GPs
Onwuteaka-Philipsen, B D., Muller, M., van der Wal, G., van Eijk, J T M., Ribbe, M W., 1997, <b>Active voluntary euthanasia or physician-assisted suicide?</b> <b>MMAT: 100%</b> <a href="#">print</a>	Medical ethics	To find out why dutch general practioners and nursing home physicians, (NHP_ and patients opt for active voluntary euthanasia rather than PAS, or vice-versa.		2 descriptive, retrospective studies	In many cases active euthanasia was performed because of the condition of the patient. In other cases GPs performed euthanaisa and NHPs assisted in suicide. Active voluntary euthanasia was chosen primarily for medico-technical reasons, where as PAS was primarily chosen for moral reasons.	How doctors feel
Onwuteaka-Phlipsen, B D.,van der Heide, A., Koper, D., Keij-Deerenberg, I., Rietjens, J A C., Rurp, M L.,Vranizan, K., Georges, J J., Muller, M T., Van der Wal, G., van der Maas, P J, 2003, <b>Euthanasia and other end-of-life decisions in the Netherlands in 1990, 1995, and 2001</b> <b>MMAT: 100%</b>	Geriatrics	We replicated interview and death-certificate studies done in 1990 and 1995 to investigate whether end-of-life practices had altered between 1995 and 2001.	Interviews: 1990: 405 physicians 1995: 405 physicians 2001: 410 physicians Death-certificate studies: random samples from the central death registry of Statistics Netherlands	Structured interviews. Death certificate studies investigated casue of death. Cases were an EOL decision was made, the treating physician received an extensive questionnaire to classify death as euthanasia case.	The rate of euthanasia and explicit requests by patients for physicians’ assistance in dying in the Netherlands seems to have stabilised. A slight increase was noted, possibly due to legalisation, and paper trails actually being available.	Slippery slope



Author, date, title	Study type	Aim	Study population	Study design	Key findings	Theme
Onwuteaka-Philipsen, B D., van der Wal, G., 2001, <b>A protocol for consultation of another physician in cases of euthanasia and assisted suicide</b> <b>MMAT: 100%</b>	Medical ethics	Consultation of another physician is an important method of review of the practice of euthanasia.For the project “support and consultation in euthanasia in Amsterdam”which is aimed at professionalising consultation, a protocol for consultation was developed to support the general practitioners who were going to work as consultants and to ensure uniformity.	Ten experts (including general practitioners who were experienced in euthanasia and consultation, a psychiatrist, a social geriatrician, a professor in health law and a public prosecutor) and the general practitioners who were going to use the protocol.	The protocol was developed according to a Delphi method.	The protocol differentiates between steps that are necessary in a consultation and steps that are recommended. Guidelines about four important aspects of consultation were given: independence, expertise, tasks and judgment of the consultant. In 97% of 109 consultations in which the protocol was used the consultant considered the protocol to be useful to a greater or lesser extent. Although this protocol was developed locally, it also employs universal principles. Therefore it can be of use in the development of consultation elsewhere.	Protocol for decision making: Practical tool
Pasman, H R W., Onwuteaka-Philipsen, B D., Ooms, M E., Wigcheren, P T., van der Wal, G., Ribbe, M W., 2004, <b>Forgoing artificial nutrition and hydration in nursing home patients with dementia</b> <b>MMAT: 100%</b> <a href="#">Print</a>	Medical ethics	To investigate the characteristics of patients for whom it is decided to forgo artificial nutrition and hydration (ANH) and the characteristics of the decision making process.	178 nursing home patients with dementia their NHP, nurses and family members.		The primary aim in forgoing ANH was to avoid unnecessary prologation of life; and nurses seemed to have less influence on the decision making progress then Nursing Hom Physicians (NHP) and family members.	Advance directives Moral dilemmas
Paul, P., 2002, <b>Euthanasia and Assisted Suicide</b> <b>MMAT: 50%</b> <b>excluded: low MMAT</b>	Bioethics	Showing US poll results about moral acceptability and legal acceptability of euthanasia.		Gallup poll	Acceptability of euthanasia has been rising since 1970s.	Attitudes towards
Price, A., McCormack, R., Wiseman, T., Hotopf, M., 2014, <b>Concepts of mental capacity for patients requesting assisted suicide: a qualitative analysis of expert evidence presented to the Commission on Assisted Dying</b> <b>MMAT: 100%</b>	Medical ethics	This study aims to explore how the experts presenting evidence to the Commission on Assisted Dying conceptualised mental capacity for patients requesting assisted suicide and examine these concepts particularly in relation to the principles of the Mental Capacity Act 2005.		This study was a secondary qualitative analysis of 36 transcripts of oral evidence and 12 pieces of written evidence submitted by invited experts to the Commission on Assisted Dying using a framework approach.	Assisted suicide should only be open to those with a high degree of mental capacity to make the decision. The ‘boundaries’ around the definition of mental capacity appeared to be on a continuum between a circumscribed legal ‘cognitive’ definition of capacity and a more inclusive definition which would take into account wider concepts such as autonomy, rationality, voluntariness and decision specific factors such as motivation for decision making.	Assessing mental capacity
Rachels, J., 1998, <b>The Principle of Agency</b> <b>MMAT: n/a</b>	Philosophy	if it would be good for a state of affairs to occur ‘naturally’; then it is permissible to take action to bring it about.			Agency: If it would be good for a particular state of affairs to occur ‘naturally’, without being brought about by human action, then it is permissible to act so as to bring it about. If the ‘natural’ occurrence of a astate of affairs would be a good thing, then the fact that performing a certain action would lead to that state of affairs is a morally good reason in favor of doing that action.	Agency Authority
Raus, K., Brown, J., Seale, C., Rietjens, J C., Janssens, R., Bruinsma, S., Mortier, F., Payne, S., Sterckx, S., 2014, <b>Continuous sedation until death: the everyday moral reasoning of physicians, nurses and family caregivers in the UK, The Netherlands and Belgium</b> <b>MMAT: 100%</b>	Medical ethics	Continuous sedation is increasingly used as a way to relieve symptoms at the end of life. Current research indicates that some physicians, nurses, and relatives involved in this practice experience emotional and/or moral distress. This study aims to provide insight into what may influence how professional and/or family carers cope with such distress	82 interviews with physicians, 78 interviews with nurses and 32 interviews with relatives	international qualitative interview study involving interviews with physicians, nurses, and relatives of deceased patients in the UK, The Netherlands and Belgium	Findings from this study demonstrate that various factors are reported to influence the degree of closeness (four types of ‘closeness’, namely emotional, physical, decisional, and causal) to continuous sedation (and thus the extent to which carers feel morally responsible), and that some of these factors help care providers and relatives to distinguish continuous sedation from euthanasia	How doctors feel



Author, date, title	Study type	Aim	Study population	Study design	Key findings	Theme
Raus, K., Sterckx, S., Mortier, F., 2011, <b>Is continuous sedation at the end of life an ethically preferable alternative to physician-assisted suicide?</b> MMAT: n/a	Bioethics	A U.S. Supreme Court ruling noted that the availability of CS made legalization of physician-assisted suicide (PAS) unnecessary, as CS could alleviate even the most severe suffering. This view has been widely adopted. Our goal is to determine the extent to which CS can be considered to be an alternative to PAS and to identify the grounds, if any, on which CS may be ethically preferable to PAS.		Literature review: an in-depth analysis of four versions of this “argument of preferable alternative.”	Our main conclusion therefore is that CS should not be seen as an ethically preferable alternative to PAS or as the preferred end-of-life practice tout court, but as a practice that may be ethically acceptable in some cases, just as other options such as, for example, nontreatment decisions and physician-assisted suicide may be acceptable in other cases.	Moral dilemmas Double effect
Raus, K., Sterckx, S., Mortier, F., 2012, <b>Continuous deep sedation at the end of life and the ‘natural death’ hypothesis</b> MMAT: n/a	Bioethics	We argue that the labeling of death following CDS as ‘natural’ death is related to a complex set of mechanisms which facilitate the use of this practice. However, our criticism does not preclude the view that CDS may be clinically and ethically justified in many cases.		Literature review	We attempt to show that the label ‘natural’ cannot be unproblematically applied to the nature of this end-of-life practice. We argue that the labeling of death following CDS as ‘natural’ death is related to a complex set of mechanisms which facilitate the use of this practice. However, our criticism does not preclude the view that CDS may be clinically and ethically justified in many cases	Moral dilemmas Natural death Decision making
Ravenscroft, A J., Bell, M D., 2000, <b>‘End-of-life’ decision making within intensive care--objective, consistent, defensible?</b> MMAT: 100%	Medical ethics	To determine the objectivity, consistency and professional unanimity in the initiation, continuation and withdrawal of life-prolonging procedures in intensive care—to determine methods, time-scale for withdrawal and communication with both staff and relatives—to explore any professional unease about legality, morality or professional defensibility.	13 Intensive Care Units in west yorkshire	A structured questionnaire directed at clinical nurse managers for intensive care.	The survey reported a lack of consistency and objectivity in decision making in this area, with accompanying unease amongst staff	How doctors feel
Raymond, M., Warner, A., Davies, N., Iliffe, S., 2014, <b>Palliative care services for people with dementia: A synthesis of the literature reporting the views and experiences of professionals and family carers</b> MMAT: 100%	Dementia	This is a synthesis of the concerns and challenges for carers at the end of life. These accounts are often insightful and provide several views of carers’ and professionals’ experience. Having a close relationship as a carer gives a unique and poignant view. What emerges from this review is a range of perspectives that provide contrasting views of the heterogeneity of carers and professionals.	12 carer accounts	Systematic literature review and insights from professionals and carers	What emerges from this review is a range of perspectives that provides contrasting views of the heterogeneity of carers and professionals. This may be helpful for professionals and policy makers to consider when planning end-of-life care strategies for people with dementia. The insights drawn from hearing directly from carers may be powerful learning tools.	Carers experiences
Rietjens, J A C., van Tol, D G., Schermer, M., van der Heide, A., 2009, <b>Judgement of suffering in the case of a euthanasia request in The Netherlands</b> MMAT: 100%	Medical ethics	In the Netherlands, physicians have to be convinced that the patient suffers unbearably and hopelessly before granting a request for euthanasia. The extent to which general practitioners (GPs), consulted physicians and members of the euthanasia review committees judge this criterion similarly was evaluated.	300 GPs, 150 consultants and 27 members of review committees were sent a questionnaire with patient descriptions.	Questionnaire	There is variance between GPs, consultants and members of the euthanasia committees in their judgement of the patient’s suffering. Possible explanations could be differences in their roles in the decision-making process, differences in experience, or differences in views regarding the permissibility of euthanasia.	Suffering
Rietjens, J A C., van der Maas, Paul J., Onwuteaka-Philipsen, B D., van Delden, J J M., van der Heide, A., 2009, <b>Two decades of research on euthanasia from the Netherlands. What have we learnt and what questions remain?</b> MMAT: 100%	Bioethics	Systematic periodic research is crucial for enhancing our understanding of end-of-life care in modern medicine, in which the pursuit of a good quality of dying is nowadays widely recognized as an important goal, in addition to the traditional goals such as curing diseases and prolonging life.		20 year overview of research on euthanasia. Review of various studies.	Medical end-of-life decision-making is a crucial part of end-of-life care. It should therefore be given continuous attention in health care policy and medical training. Systematic periodic research is crucial for enhancing our understanding of end-of-life care in modern medicine, in which the pursuit of a good quality of dying is nowadays widely recognized as an important goal, in addition to the traditional goals such as curing diseases and prolonging life.	Slippery slope Good death



Author, date, title	Study type	Aim	Study population	Study design	Key findings	Theme
Rosenfeld, B., 2000, <b>Methodological issues in assisted suicide and euthanasia research</b> MMAT: n/a	Psychology and law	This review describes the primary methodological issues and difficulties found in the existing assisted suicide and euthanasia literature.		Review	The methodological issues discussed fall into several broad categories, including difficulties in operationalizing and measuring dependent variables, sampling constraints and biases, confounding influences on independent variables, and statistical considerations. These issues are discussed along with implications for the interpretation of the results reported. Where possible, potential solutions are offered, along with recommendations for future research.	Attitudes towards
Rosenfeld, Barry, 2000, <b>Assisted suicide, depression, and the right to die</b> MMAT: n/a	Psychology, Public Policy, and Law	This review summarizes the literature on assisted suicide and euthanasia to clarify both the strengths and limitations of existing research and to outline an agenda for future research.	Based on reviewed articles, a large population overall.	Selective review on study design, reviewed separately for each response group in order to maintain objectivity.	Overall attitudes are positive towards assisted dying, however gaps were identified: factors that would influence these attitudes, understanding why the attitudes are as they are, what influence anxiety has on euthanasia decisions. Legalization of assisted suicide may also have a therapeutic benefit for terminally ill patients, who often report feeling less distressed merely by knowing that they have the option to end their lives when they feel the time has come.	Control
Rurup, M L., Muller, M T., Onwuteaka-Philipsen, B D., van der Heide, A., van der Wal, G., van der Maas, P J., 2005, <b>Requests for euthanasia or physician-assisted suicide from older persons who do not have a severe disease: an interview study</b> MMAT: 100%	Psychological medicine	To determine how often requests are made for euthanasia and physician-assisted suicide (EAS) in the absence of severe disease and how such requests are dealt with in medical practice in The Netherlands.	Participants: 125 general practitioners (GPs), 77 nursing home physicians (NHPs), and 208 clinical specialists.	Retrospective interview study.	Most physicians in The Netherlands refuse requests for EAS in the absence of severe disease. Most patients persist in their request. In an ageing population more research is needed to provide physicians with practical interventions to prevent suicide and to make life bearable and satisfactory for elderly people who wish to die.	Tired of life
Rurup, M L., Onwuteaka-Philipsen, B D., Jansen-Van Der Weide, M C., Van Der Wal, G., 2005, <b>When being ‘tired of living’ plays an important role in a request for euthanasia or physician-assisted suicide: Patient characteristics and the physician’s decision</b> MMAT: 100%	Health policy	Mental health status may be closely related to an instability of intentions toward a premature death, but little is known about such instability following an explicit request for euthanasia or physician-assisted suicide (EAS) and patient characteristics associated with a change of mind.	1681 GPs provided descriptions of the most recent explicit request for EAS they had received in the preceding 18 months.	A questionnaire was sent to 6596 general practitioners in The Netherlands (response rate 60%).	These findings suggest that mental health status must be carefully assessed, and possible instability of desire must be taken into account in the course of a request for EAS. These results require replication, and future studies should adopt a prospective method.	Assessing mental health
Rurup, M L. Onwuteaka-Philipsen, B D. Van Der Heide, A., Van Der Wal, G., Van Der Maas, P J., 2005, <b>Physicians’ experiences with demented patients with advance euthanasia directives in the Netherlands</b> MMAT: 100%	Geriatrics	To estimate the incidence of (compliance with) advance euthanasia directives of patients suffering from dementia in the Netherlands and to gain knowledge about the experiences of physicians.	410 physicians in the Netherlands	Retrospective interview study.	Most nursing home physicians think that the suffering of patients with dementia can be unbearable and hopeless as a consequence of dementia, but most physicians do not consider dementia to be grounds for euthanasia, unless perhaps the patient has an additional illness.	Advance directives Suffering
Rurup, M L. Onwuteaka-Philipsen, B D. van der Wal, G., van der Heide, A., van der Maas, P J., 2005, <b>A “Suicide Pill” For Older People: Attitudes of Physicians, the General Population, and Relatives of Patients who died After Euthanasia or Physician-Assisted Suicide in The Netherlands</b> MMAT: 100%	Death studies	In the Netherlands there has been ongoing debate in the past 10 years about the availability of a hypothetical ‘suicide pill’, with which older people could end their life in a dignified way if they so wished.	Data on attitudes to the suicide pill were collected in the Netherlands from 410 physicians, 1,379 members of the general population, and 87 relatives of patients who died after euthanasia or physician-assisted suicide.	Interviews, questionnaires	The general population and relatives were more in favor than physicians. Fifteen percent of the general population and 36% of the relatives thought a suicide pill should be made available.	Attitude towards



Author, date, title	Study type	Aim	Study population	Study design	Key findings	Theme
Sayers, G M., Perera, S., 2002, <b>Withholding life prolonging treatment, and self deception</b> <b>MMAT: n/a</b> <a href="#">Exclude: Detailed discussion about terminology to reduce anxiety</a>	Medical ethics	To compare non-treatment decision making by general practitioners and geriatricians in response to vignettes. To see whether the doctors’ decisions were informed by ethical or legal reasoning.	17 GPs and 18 geriatricians	Qualitative study. The doctors were asked whether patients described in five vignettes should be admitted to hospital for further care, and to give supporting reasons.	Little attempt was made to link decision making with ethical or legal concepts and there may have been non-recognition, or denial, of the ethical consequences of failure to admit. The process of decision making may involve deception. This may be conscious, or unconscious.	Moral dilemmas Attitudes towards Multi-disciplinary team
Schoonman, M. K., van Thiel, G. J. M. W., van Delden, J. J. M., 2014, <b>Non-physician-assisted suicide in The Netherlands: a cross-sectional survey among the general public</b> <b>MMAT: 100%</b>	Medical ethics	The aim of the current study was to investigate the opinion of the Dutch general public on non-physician- assisted suicide.	1113 respondents	A cross-sectional survey among the Dutch general public	The Dutch public prefer involvement of a physician in assisted suicide (69%). The Dutch general public consider non- physician-assisted suicide in some specific cases a tolerable alternative for patients with a rejected request for physician-assisted dying if the assistance is limited to the provision of information. However, the majority do not support the legalisation of non-physician-assisted suicide.	Non-physician assisted suicide Multi-disciplinary team
Schroepfer, T A., Noh, H., Kavanaugh, M., 2009, <b>The myriad strategies for seeking control in the dying process</b> <b>MMAT: 100%</b>	Gerontology	This study explored the role control plays in the dying process of terminally ill elders by investigating the aspects of the dying process over which they seek to exercise control, the strategies they use, and whether they desire to exercise more control.	84 terminally ill elders receiving hospice care	In-depth face- to-face interviews	The results revealed that all 84 elders were using at least 1 primary control strategy in their dying process, 83 of whom did so in combination with another primary or compensatory secondary control strategy. Decision making, independence, mental attitude, instrumental activities of daily living, activities of daily living, and relationships were aspects of the dying process over which the respondents sought to exercise control. Over half of the respondents wanted more control; however, they felt their illness prevented it.	Control
Seidel, G., 1995, <b>Suicide in the elderly in antiquity</b> <b>MMAT: n/a</b> <a href="#">print</a>	Ethics	A look at greco-roman antiquity to look at cases of suicide in the elderly		A look at greco-roman antiquity	Acceptibility of suicide varied. The author identified 6 reasons for suicide with varyng levels of acceptability: 1. Pain, sickness, old age, 2. Military. 3. Political. 4. Mental. 5. Grief, depression. 6. No reason. 1, 2, 4 seem most acceptable.	Reasons and acceptability in antiquity of euthanasia and suicide
Sercu, M., Pype, P., Christiaens, T., Grypdonck, M., Derese, A., Deveugele, M., 2012, <b>Are general practitioners prepared to end life on request in a country where euthanasia is legalised?</b> <b>MMAT: n/a</b>	Medical ethics	To explore how general practitioners in Flanders (Belgium) deal with euthanasia.	52 general practitioners (GPs).	Qualitative analysis of semistructured interviews	Four attitudes can be identified: (1) willing to perform euthanasia; (2) only willing to perform as a last resort; (3) feeling incapable of performing; (4) refusing on principle. The situation where GPs have to consider the request and if they grant it to perform the act may result in arbitrary access to euthanasia for the patient.	How doctors feel Case for multi-disciplinary team
Shaw, A B., 2002, <b>Two challenges to the double effect doctrine: euthanasia and abortion</b> <b>MMAT: n/a</b>	Medical ethics	The validity of the double effect doctrine is examined in euthanasia and abortion. In these two situations killing is a method of treatment. It is argued that the doctrine cannot apply to the care of the dying. Firstly, doctors are obliged to harm patients in order to do good to them. Secondly, patients should make their own value judgments about being mutilated or killed. Thirdly, there is little intuitive moral difference between direct and indirect killing.			Drawing a moral distinction between the direct and the indirect killing gives counterintuitive results. It is suggested that pragmatic rules, not ethics, govern practices around euthanasia and cause it to be more restricted than abortion.	Moral dilemmas Double effect
Short, B W., 2003, <b>History “lite” in modern American bioethics</b> <b>MMAT: n/a</b>	Bioethics	To prove that moral and ethical discussions are based on false historical philosophical ideas.		Critical assessment of main philosophers.	In pursuit of historical truth, one must get the arguments of historical giants such as Kant and Locke right in order to be able to refute them. A big debate about assisted dying would require us to be correctly informed in history.	Moral dilemmas Practical dilemmas



Author, date, title	Study type	Aim	Study population	Study design	Key findings	Theme
Singer, P., 2003, <b>Voluntary euthanasia: a utilitarian perspective</b> MMAT: n/a	Bioethics	This essay reviews ethical arguments regarding voluntary euthanasia and physician-assisted suicide from a utilitarian perspective. I shall begin by asking why it is normally wrong to kill an innocent person, and whether these reasons apply to aiding a person who, when rational and competent, asks to be killed or given the means to commit suicide. Then I shall consider more specific utilitarian arguments for and against permitting voluntary euthanasia.		Essay	The utilitarian case for allowing patients to choose euthanasia, under specified conditions and safeguards, is strong. The slippery slope argument attempts to combat this case on utilitarian grounds. The outcomes of the open practice of voluntary euthanasia in the Netherlands, and of physician-assisted suicide in Oregon, do not, however, support the idea that allowing patients to choose euthanasia or physician-assisted suicide leads to a slippery slope.	Moral dilemmas
Stauch, M., 2000, <b>Causal authorship and the equality principle: a defence of the acts/omissions distinction in euthanasia</b> MMAT: n/a	Medical ethics	This paper defends the acts/omissions distinction which underpins the present law on euthanasia, from various criticisms (including from within the judiciary itself), and aims to show that it is supported by fundamental principles.			Assuming all other factors are equal, the infringement of this principle provides an additional reason against actively killing a patient, which is not present in cases of passively letting die.	Moral dilemmas How doctors feel
Steel, E., Kulbe, J., 2003, <b>Care of patients near death: another view</b> MMAT: n/a	Geriatrics	The choice is hard, between certain death, even if it is promised to be comfortable and dignified, and hope, even if it is a burdensome treatment that offers small chance of limited benefit. Dying patients are often expected to make such painful choices. Perhaps what is most painful is to be dying. A person whose near future necessarily contains all this will often need a trusted, unhurried companion, acting with gentle advocacy and humility.			We argue here that the legalistic (obtain advance directives), technical (implant a morphine pump), and so-often violent (consider euthanasia) solutions favored by our society in other contexts may be of only secondary importance in the care of those near death. Rather, a deeper sympathy with the person facing death is at the core of good care for the dying.	Good death
van der Steen, J T., Hertogh, C M P M., de Graas, T., Nakanishi, M., Toscani, F, Arcand, M., 2013, <b>Translation and cross-cultural adaptation of a family booklet on comfort care in dementia: sensitive topics revised before implementation</b> MMAT: n/a	Medical ethics	Families of patients with dementia may need support in difficult end-of-life decision making. Such guidance may be culturally sensitive.		qualitative content analyses for cultural adaptation	Providing artificial feeding and fluids and discussing euthanasia may be particularly sensitive topics, and guidance on these subjects needs careful consideration of ethical aspects and possible adaptations to local standards and practice. The findings may promote cross-national debate on sensitive, core issues regarding end-of-life care in dementia.	Moral dilemmas
Steinbock, B., 2005, <b>The case for physician assisted suicide: not (yet) proven</b> MMAT: n/a	Medical ethics	Any change in law and social policy should not be based solely on individual cases, heart wrenching though these may be. Instead, we need to assess the need for PAS, and weigh this against the risks of mistake and abuse.			My point is rather that before the rest of us climb on the PAS bandwagon, there are many crucial issues to be hammered out. The discussion should continue. At present, the case for legalising PAS seems to me to be still—in the words of the Scottish verdict—not proven.	Slippery slope
Stevens, K. R., 2006, <b>Emotional and psychological effects of physician-assisted suicide and euthanasia on participating physicians</b> MMAT: 75%	Law and Medicine	Assessing the reported emotional and psychological effects of participation in physician-assisted suicide (PAS) and euthanasia on the involved physicians.	Good selection of reviewed material; big study population.	Articles in medical journals, legislative investigations and the public press were obtained and reviewed to determine what has been reported regarding the effects on physicians who have been personally involved in PAS and euthanasia.	Many doctors who have participated in euthanasia and/or PAS are adversely affected emotionally and psychologically by their experiences.	How doctors feel <i>Article feels biased – no counter examples are being presented.</i>



Author, date, title	Study type	Aim	Study population	Study design	Key findings	Theme
Stoyles, B J., Costreie, S., 2013, <b>Rethinking voluntary euthanasia</b> MMAT: n/a	Philosophy	Our goal in this article is to explicate the way, and the extent to which, euthanasia can be voluntary from both the perspective of the patient and the perspective of the health care providers involved in the patient’s care.			Where there is no patient perspective, there can be nothing that is morally important from this perspective—the very notion is incoherent. We might suggest that the interests of the other people involved—the proxy decision makers, family, and the providers whose moral integrity is on the line—should be given priority over the patient’s interests.	Slippery slope
Sullivan, M., 1999, <b>Ethics of assisted suicide and euthanasia</b> MMAT: n/a	Ethics	Making a point that euthanasia isn’t a medical decision, but a moral one.			Nurses must remain informed about the debate and have knowledge on both sides of the debate.	Moral dilemmas Practical dilemmas
Sullivan, M D., 2003, <b>Hope and hopelessness at the end of life</b> MMAT: n/a	Geriatric Psychiatry	Modern dying is more prolonged and more shaped byhuman choice than ever before. Therefore, hope and hopelessness play a more active role in the dying process. Hopelessness is not a simple product of prognosis, but is shaped by state and trait psychological factors. Hope at the end of life can come in various forms: for cure, for survival, for comfort, for dignity, for intimacy, or for salvation.			Hopelessness at the end of life is therefore not simply the absence of hope, but attachment to a form of hope that is lost. The concept of anticipatory grief may help us interpret hope and hopelessness at the end of life. Improving end-of-life care will require looking beyond prognosis and preferences to understand the dynamics of hope and hopelessness.	Grief
Sulmasy, D P., Travaline, J M., Mitchell, L A., Ely, E W., 2016, <b>Non-faith-based arguments against physician- assisted suicide and euthanasia</b> MMAT: n/a	Philosophy	Presented here are four non-religious, reasonable arguments against physician-assisted suicide and euthanasia:			(1) <i>“it offends me,”</i> suicide devalues human life; (2) slippery slope, the limits on euthanasia gradually erode; (3) <i>“pain can be alleviated,”</i> palliative care and modern therapeutics more and more adequately manage pain; (4) physician integrity and patient trust, participating in suicide violates the integrity of the physician and undermines the trust patients place in physicians to heal and not to harm.	Slippery slope
The, Anne-Mei., Pasman, R., Onwuteaka-Philipsen, B., Ribbe, M., van der Wal, G., 2002, <b>Withholding the artificial administration of fluids and food from elderly patients with dementia: ethnographic study</b> MMAT: 100%	Geriatrics	To clarify the practice of withholding the artificial administration of fluids and food from elderly patients with dementia in nursing homes.	35 patients with dementia, eight doctors, 43 nurses, and 32 families	Qualitative, ethnographic study in two phases.	Doctors’ decisions about withholding the artificial administration of fluids and food from elderly patients with dementia are influenced more by the clinical course of the illness, the presumed quality of life of the patient, and the patient’s medical condition than they are by advanced planning of care. In an attempt to understand the wishes of the patient doctors try to create the broadest possible basis for the decision making process and its outcome, mainly by involving the family.	Carer’s roles Quality of life
Thomson, J J., 1999, <b>Physician-assisted suicide: two moral arguments</b> MMAT: n/a	Ethics	Explaining why the two moral arguments are bad arguments			Theoretical moral dilemmas versus real life action.	Moral dilemmas
Tomasini, F., Stoic <b>Defence of Physician-Assisted Suicide</b> MMAT: n/a Exclude: specifically about stoicism	Bioethics	To begin, the plausibility of rational suicide is explored. Following on, the classical stoic idea of rational ends of suicide is then reframed for a more contemporary audience in the socially relevant context of physician-assisted suicide.			As such, the implications for future research are more practical than philosophical: one might, for example, study how to secure rationally physician-assisted suicide in a robust institutional setting or, one could look into devising a robust legal framework.	Excluded
Vink, T., 2016, <b>Self-euthanasia, the Dutch experience: In search for the meaning of a good death or eu thanatos</b> MMAT: n/a	Bioethics	My main purpose in this article is to establish the meaning of a ‘good death’ when death is self-chosen. I will take as my point of departure the new notion of ‘self-euthanasia’ and the corresponding practice that has evolved in the Netherlands in recent years. Both physician-euthanasia and self-euthanasia refer to an ideal process of a good death.			if we also accept the existence of a fundamental moral difference between ending another person’s life and ending your own life, and if we accept this moral difference to be also relevant to the normatively laden good death, then this difference represents a strong reason for preferring self- euthanasia to physician-euthanasia.	Good death



Author, date, title	Study type	Aim	Study population	Study design	Key findings	Theme
Voorhees, J R., Rietjens, J A C., Van Der Heide, A., Drickamer, M A., 2014, <b>Discussing physician-assisted dying: Physicians the United States and the Netherlands</b> <b>MMAT: 100%</b>	Gerontology	This study aims to further our understanding of the experiences of physicians when discussing physician-assisted dying (PAD) within the context of doctor–patient relationships in various sociolegal settings. Although patients bring up PAD in diverse settings, little is known about how physicians experience these discussions, and such experiences have not been directly compared across countries.	36 physicians	A total of 36 physicians in the Netherlands and the United States (including Oregon) were interviewed using individual semistructured interview guides.	Physicians found discussions to be emotionally intense, but often rewarding. Where PAD was legal, physicians utilized existing criteria to guide communication, and discussions were open and honest with patients and colleagues. Where PAD was illegal, conversations were less explicit, and physicians dealt with requests in relative isolation. In addition, physicians’ views of their professional role, patients’ rights, and religion influenced both their willingness to have PAD discussions.	How doctors feel
Wasserman, J., Michael Clair, J., Ritchey, J., Ritchey, F J., 2005, <b>a Scale To Assess Attitudes Toward Euthanasia Introduction and Literature Review</b> <b>MMAT: n/a</b> Exclude: Not relevant to dutch legal framework		After analyzing shortcomings of previous work, we offer a systematically designed scale to measure attitudes toward euthanasia.		Literature review + assessment scale.	The results of our pretest show that our attitude towards euthanasia (ATE) scale is both reliable and valid. We delineate active and passive euthanasia, no chance for recovery and severe pain, and patient’s autonomy and doctor’s authority. We argue that isolating these factors provides a more robust scale capable of better analyzing sample variance.	Excluded
Watts, D., T., Howell, T., Priefer, B., A., 1992, <b>Geriatricians’ attitudes toward assisting suicide of dementia patients</b> <b>MMAT: 100%</b> print	Geriatrics	To identify Geriatricians’ attitudes toward assisting suicide of dementia patients.	727 US geriatricians.	Mailed questionnaire survey.	Most responding geriatricians would not consider assisting suicide of dementia patients, and most appose easing restrictions on PAS. Many, however, could accept (unassisted) suicide of a competent dementia patients, and many would consider suicide themselves stricken with dementia.	How doctors feel
Werth, J L., 1999, <b>When is a mental health professional competent to assess a person’s decision to hasten death?</b> <b>MMAT: n/a</b>	Ethics & Behavior	Guidelines for a mental helath professional to assess if a consultant of professional has the right training to be competent in end-of-life decision making.			People need special skills to aid ‘clients’ in requesting a hastened death. How do you deal with these requests?	How doctors feel
Werth, J L., 2000, <b>The Appropriateness of Organizational Positions on Assisted Suicide</b> <b>MMAT: n/a</b>	Ethics & Behavior	This article argues that providing suggestions about how a professional can assist a person considering hastening death—is appropriate for an organization whose members are clinical practitioners rather than theorists.			The only tenable position, from a client service perspective, is to neither oppose nor support assisted suicide but instead to provide guidance for professionals who will be working with people wanting to address such issues.	How doctors feel Attitudes towards Case by case assessment
Westerhof, G J., Barrett, A E., 2005, <b>Age identity and subjective well-being: A ‘comparison of the United States and Germany</b> <b>MMAT: 100%</b> Exclude: not about dementia or euthanasia	Gerontology	This article investigates the theoretical and empirical relationship between age identity and subjective well-being (SWB) in a cross-national context. Feeling younger than one’s actual age is considered a self-enhancing illusion that contributes to SWB even beyond factors predicting age identities and SWB, such as health and socioeconomic status.	5336 adults	Data are from respondents between 40 and 74 years of age who participated in the National Survey of Midlife Development in the United States (N¼ 2,006) or the German Aging Survey (N¼ 3,331).	Feeling younger than one’s actual age is related to higher levels of life satisfaction and positive affect and to lower levels of negative affect, even when controlling for sociodemographic variables.	Excluded
Wheithman, P J., 1999, <b>Of assisted suicide and “the philosophers’ brief”</b> <b>MMAT: n/a</b>	Ethics	The brief states that every person has the right to make momentous personal decisions which invoke religious or philosophical convictions about life’s value for himself.			Author urges the medical profession to address quality in dying	Moral dilemmas

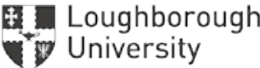


Author, date, title	Study type	Aim	Study population	Study design	Key findings	Theme
Van Wijmen, M P S., Rurup, M L., Pasman, H R W., Kaspers, P J., Onwuteaka-Philipsen, B D., 2010, <b>Advance directives in the netherlands: An empirical contribution to the exploration of a cross-cultural perspective on advance directives</b> <b>MMAT: 100%</b>	Bioethics	This study focuses on ADs in the Netherlands and introduces a cross-cultural perspective by comparing it with other countries.	1621 people	A questionnaire was sent to a panel comprising 1621 people representative of the Dutch population. The response was 86%.	Many people do not have ADs. Low education and the presence of a religious conviction increase the chance of not wanting to draw up an AD. Also not having experienced a request for euthanasia from someone else, and the inconceivability of asking for euthanasia yourself, increase the chance of not wanting to draw up an AD.	Advance directives
Wijsbek, H., 2012, <b>‘To thine own self be true’: On the loss of integrity as a kind of suffering</b> <b>MMAT: n/a</b>	Bioethics	Making a case for unbearable suffering – even if it’s not physical.			Loss of integrity as unbearable suffering; using the Boomsma / Chabot case as an example.	Suffering
Williams, N., Dunford, C., Knowles, A., Warner, J., 2007, <b>Public attitudes to life-sustaining treatments and euthanasia in dementia</b> <b>MMAT: 100%</b>	Geriatrics	Issues surrounding end of life care, such as how aggressively to treat life threatening medical conditions in patients with dementia and when, if ever, to withhold or withdraw treatment require further scrutiny and debate.	725 members of the general public, London, UK	cross-sectional survey	Our survey suggests that a large proportion of the UK general public do not wish for life-sustaining treatments if they were to become demented and the majority agreed with various forms of euthanasia.	Attitudes towards
Wolf, S M., 2004, <b>Physician-Assisted suicide</b> <b>MMAT: n/a</b> <a href="#">Print</a>	Medical ethics	This article articulates the major arguments for and against permitting PAS. It then offers concrete recommendations for addressing concerns about end-of-life care that have surfaced in the assisted suicide debate.			The debate is complex and multi-disciplinary, requiring attention to ethical, legal, clinical and empirical arguments. Improvement may require improving end-of-life care and a case by case analysis. What is the limit of patient autonomy?	Autonomy
Wong, W., Eiser, A R., Mrtek, R G., Heckerling, P S., 2004, <b>By-person factor analysis in clinical ethical decision making: Q methodology in end-of-life care decisions</b> <b>MMAT: 100%</b>	Bioethics	To determine the usefulness of Q methodology to locate and describe shared subjective influences on clinical decision making among participant physicians using hypothetical cases containing common ethical issues.	Convenience sample of internal medicine attending physicians and house staff (n = 35) at one midwestern academic health sciences center.	Qualitative study using by-person factor analysis of subjective Q sort data matrix.	Q sorting and by-person factor analysis are useful qualitative methodological tools to study the complex structure of subjective attitudes that influence physicians in making medical decisions.	How doctors feel/decide



Appendix B

Informed consent forms



1

**Interview Consent Form**

A dignified death for Dementia patients  
Marije de Haas

The interview will take about 1 hour. We don’t anticipate that there are any risks associated with your participation, but we will be discussing sensitive situations. You have the right to stop the interview or withdraw from the research at any time. Thank you for agreeing to be interviewed as part of the above research project.

Ethical procedures for academic research undertaken from UK institutions require that interviewees explicitly agree to being interviewed and how the information contained in their interview will be used. This consent form is necessary for us to ensure that you understand the purpose of your involvement and that you agree to the conditions of your participation.

Would you therefore read the accompanying information sheet and then sign this form to certify that you approve the following:

- the interview will be recorded and a transcript will be produced
- the transcript will be translated to english by Marije de Haas
- you will be sent the english transcript and given the opportunity to correct any factual errors
- the transcript of the interview will be analysed by Marije de Haas as research investigator
- access to the interview transcript will be limited to Marije and her supervisors
- any summary interview content, or direct quotations from the interview, that are made available through academic publication or other academic outlets will be anonymized so that you cannot be identified, and care will be taken to ensure that other information in the interview that could identify yourself is not revealed
- the actual recording will be kept for the duration of the PhD and thereafter destroyed
- any variation of the conditions above will only occur with your further explicit approval

**Quotation Agreement**  
I understand that my words may be quoted directly (translated to english). With regards to being quoted, please tick any of the statements that you agree with:

☐

I wish to review the notes, transcripts, or other data collected during the research pertaining to my participation.

☐


I agree to be quoted directly.

☐

I agree to be quoted directly if my name is not published and a made-up name (pseudonym) is used.

☐

I agree that the researchers may publish documents that contain quotations by me.



2

All or part of the content of your interview may be used;

☐

In academic papers, policy papers or news articles

☐

On our website and in other media that we may produce such as spoken presentations

☐

On other feedback events

☐

In an archive of the project as noted above

By signing this form I agree that;

- I am voluntarily taking part in this project. I understand that I don’t have to take part, and I can stop the interview at any time;
- The transcribed interview or extracts from it may be used as described above;
- I have read the Information sheet;
- I don’t expect to receive any benefit or payment for my participation;
- I can request a copy of the transcript of my interview and may make edits I feel necessary to ensure the effectiveness of any agreement made about confidentiality;
- I have been able to ask any questions I might have, and I understand that I am free to contact the researcher with any questions I may have in the future.

Date

Printed Name

Participants Signature

Researchers Signature

Date

This research has been reviewed and approved by Loughborough University. If you have any further questions or concerns about this study, please contact: Marije de Haas, m.de-haas@lboro.ac.uk.



# Appendix C

## Glossary

**Advance Euthanasia Directive:** This is a document where a patient can state their health care provisions. It is not a statutory requirement for euthanasia. It is not a legally binding document, but may provide clarity when a patient is unable to express their wishes .

**Carer (also used care-giver):** A full-time non-professional care-giver.

**Death:** Death is the cessation of all vital functions and results in the end of life.

**Dementia:** A collection of many illnesses, including Parkinson’s disease, vascular dementia and Alzheimer’s disease. All chronic diseases with similar symptoms in which there is deterioration in memory, thinking and behaviour. It is a terminal disease.

**Diegetic prototypes:** Prototypes that are real only within the proposed narrative.

**Dilemma:** A situation in which a difficult choice has to be made between two or more alternatives, especially ones that are equally undesirable (Google dictionary).

**Do Not Resuscitate Agreement (DNR):** A DNR agreement indicates that the person does not want to be resuscitated in a medical emergency.

**Due care criteria:** By law, physicians who perform euthanasia or assist in suicide are committing a criminal offence. However, they are not criminally liable if they comply with the statutory due care criteria and notify the municipal pathologist of their actions. The statutory due care criteria say that the physician must:

- be satisfied that the patient’s request is voluntary and well-considered;
- be satisfied that the patient’s suffering is unbearable, with no prospect of improvement;
- have informed the patient about their situation and prognosis;
- have come to the conclusion, together with the patient, that there is no reasonable alternative in the patient’s situation;
- have consulted at least one other, independent physician, who must see the patient and give a written opinion on whether the due care criteria set out above have been fulfilled;
- have exercised due medical care and attention in terminating the patient’s life or assisting in the patient’s suicide. (RTE, n.d.)

**Euthanasia:** In this thesis euthanasia is used as *“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”*. Many other forms of assisted dying do exist and there are various ways to help a person to die. For Dutch requirements on asking assistance in dying refer to: <https://www.government.nl/topics/euthanasia/euthanasia-assisted-suicide-and-non-resuscitation-on-request>.

**Physician:** The patient’s general practitioner, or qualified physician for making decisions about end-of-life.

**Professional care-giver:** The qualified carers, physicians, nurses, palliative carers and nursing home staff.

**SCEN:** Euthanasia in the Netherlands Support and Assessment





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