AUTONOMOUS UNTIL THE END

An Ethnographic Study of Needing to Control Death and Dying in the Netherlands.

Cecilie Knagenhjelm Hertzberg.

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Department of Sosial Anthropology
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ABSTRACT

Based on an ethnographic fieldwork done at the Dutch “right to die” organisation in the Netherlands, I explore and discuss the Western perception on autonomy, identity, and independency in relation to old age.

After about thirty years of debate, the Netherlands legalised assisted dying in 2002. The law was first and foremost for those who were terminally ill or had a chronic illness. The Dutch “right to die” organisation, NVVE, had an essential role in the legalisation of assisted dying in the Netherlands. With influence within politics and frequently having a place in the Medias spotlight, NVVE has grown to be an organisation that expands all over Netherland. are an essential part of this thesis. To be able to receive assisted dying, one needs to fulfil the due care criteria. Several groups within the Dutch society feels discriminated because of the criterions. By making the law available for those who experience unbearable suffering, the people diagnosed with dementia, individuals with a mental illness or those who are tired of life, are not able to request and receive assisted dying.

The baby boom generation will be and are responsible for the biggest group of elders in our time. Their ideals concerning independency, identity, and autonomy tends to influence the way we think about our health and becoming old. What happens when these factors are threatened by old age? The fear of dying without autonomy, control, and identity has led to a new conception death. The fact that many Dutch citizens cannot reives assisted dying has led the NVVE to invent a new legitimised concept - the autonomous route. This method is especially relevant for elders in the fourth age. Consequently, the society could lose some of its diversity were the elders or people diagnosed with dementia will be ones who suffer. To be in control and keep autonomy are important factors when dying a good and dignified death. However, the need to state what is considered a “good” or a “bad” death has led the organisation to push boundaries.

Keywords: death, autonomy, dignity, control, assisted dying, euthanasia, old age, baby boom generation, independence, identity, the Netherlands.
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A big thank you to all my friends & family. You have all supported me in different ways.

In addition, a special thanks to the department of Social Anthropology who has helped funding this project.
It was a warm summer afternoon and the residents at Oslo nursing home had just finished dinner. Some wished to sit on the balcony to enjoy a fresh glass of juice, while others wanted to watch something on the telly. Rolf, an elderly man, chained to his wheelchair, preferred to be rolled back to his room. Being an outsider, he only sat with the other residents during meals. Rolf liked his space and wanted to be alone. In Rolf’s room, I asked if he needed anything. He gazed at me with a familiar sad look and said “I can’t stand this anymore, why do I have to go on? All I want is to let go. I don’t understand why I can’t just die.” I recall how hard it was to find the right words. The only answer I had was that I understood. But did I? After all, I was just a young student who could bike home as my shift ended.

***

My colleagues and I were enjoying our dinner while the residents watched television. We talked about what it must be feels to live in a nursing home. Kari said while chewing her food, “I would rather die than be in a nursing home.” I shared her opinion. Neither one of us wanted to find ourselves in Rolf’s situation. A brief pause, silence, ensued and we sat there waiting for nothing. Later we agreed that assisted dying should be legal in Norway.

***

These two episodes aroused my curiosity. As an anthropology student, I saw an opportunity to investigate assisted dying. Should a law permit doctors to take lives? In order to investigate and find an answer to this question, I had to travel to the Netherlands, the first country to legalise assisted dying.
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INTRODUCTION

A middle-aged woman came over to me during a conference and introduced herself as Hanna. I could sense she was eager to talk to me, as I was a new face within the NVVE environment. I introduced my project and myself and expressed I was interested in the volunteer’s role. She lowered her voice and told me she wanted to share how her aunt died. Her aunt was a very old woman with a strong death wish and therefore contacted with NVVE. After all, she was a member and needed help to die. A volunteer was sent to her house, but he could not help her completing her wishes, since volunteers cannot actively help the members in the process towards death. Hanna told me she was there the next time the volunteer came over for a visit. Her aunt was in such a rush to die, so she wondered what she could do to assist her. While Hanna listened, the volunteer guided the elderly woman in how to order lethal pills from the internet. Later, Hanna ordered the pills and they came in the mail about one week later. Now, everything was in place for her aunt to die. When the volunteer returned, they discovered that Hanna had forgot to order anti-vomiting tablets, and without those, the elderly woman would not be able die, since she would vomit the essential pills. The volunteer happened to have anti-vomiting tables at home, so he biked back to get them. After a while, he returned and gave the pills to the elderly woman. Hanna described her aunt passed away peacefully in her own bed.

This illustration represents several aspects of my fieldwork. I will refer back to this case during this thesis, as it is relevant for all my chapters.

AIM OF THE THESIS:

I based this thesis on a fieldwork done at the Dutch “right to die” organisation “Nederlandse Vereniging voor een Vrijwillig Levenseinde” or “The Dutch organization for volunteer euthanasia” also called NVVE. NVVE is part of “The World Federation of Right to Die Societies” (WFRtDS), which is a federation that connects the “rights to die” organisations from around the world.
NVVE takes part in a world movement, a movement that has an agenda of advocating assisted dying and help those who wish to die. This thesis will therefore not focus especially on Dutch identity and culture, but rather, on the time we live in. Many Dutch citizens are not able to receive assisted dying because they do not fulfil the *due care criteria*\(^1\). I will discuss the problems with these criterions. During the fieldwork, I was told many times that the debate started, not ended, when assisted dying was legalised in the Netherlands. NVVE is currently pushing new boundaries and causing new debates. I will explore some of the ideas associated with becoming old in the Western societies. As we will see throughout this thesis, old age is associated with for example dependency, lonesomeness, loss of the self, and a feeling of not belonging. Inspired by the values of the baby boom generation, I will discuss why individuals in the Western societies tends to have a fear of becoming old and how this anxiety leads many in the *fourth age*\(^2\) to have a wish to die. I will examine NVVE´s role in a society that associate old age with negative factors. I will show the emergence of new concepts and how these redefine the perception of old age and human worth. Additionally, I will discuss what it means to die a *good death* for NVVE.

**INTRODUCTION OF CONCEPTS:**

**Assisted dying:**

As I mentioned above, NVVE is a “right to die” organisation, which mean they are pro-assisted dying and therefore advocates among others assisted suicide and euthanasia. Assisted dying is a common term used on both assisted suicide and euthanasia and involves that a person gets help to die with the help of a doctor. The term euthanasia is used when a doctor injects a lethal fluid directly into the patient vein. When a patient gets assisted suicide, he is the one to take the lethal drug. This involve that the patient either takes pills given by the doctor or has an intravenous line with an opening that the patient administers. Then, when the patient opens the line, lethal liquid will stream into the vein. The doctor is present when a patient dies by assisted suicide, but is not the one to perform the final act, which is the main difference between these two methods. Assisted suicide is almost never used in the Netherlands, which means that euthanasia in the most common used when receiving assisted dying. Throughout the thesis I will mainly use the terms assisted dying and euthanasia.

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1. I will explain this in chapter one.
2. I will explain this term below.
Autonomy:
The concept of autonomy will be used throughout this thesis. I will show some of the theories concerning this matter in chapter two and will therefore not elaborate this further. Nevertheless, I find it necessary demonstrate the definition that illustrate how my informants perceive autonomy, “the ideals implicit in this concept of autonomy includes independence and self-determination, the ability to make rational and free decisions, and an ability to accurately assess what constitutes the individual’s own best interest” (Agich, 2003, p. 1).

Western world:
Throughout the thesis, I will switch between using the concepts of Western world and Western societies. These two concepts are used in the literature and theories I have read and therefore adapted.

The rest of the concepts I use, will be explained when I use them the first time.

BABY BOOM GENERATION:
The forerunners of the baby boomers influenced this generation’s perception of health and body. During the 19th century, there was an individualisation of the living body within clinical medicine. This individualisation led people to obtain a biological citizens, where the universal human right was to protects the body’s life and dignity (Rose, 2001, p. 21). As we will see below, individualisation of the body has been adapted by the baby boom generation. The baby boom generation are acknowledged as the greatest generation of all time. Born between 1946 and 1964, they will and are responsible for the biggest group of elderly in human history (Lyon, 2010). The baby boom generation is originally a US phenomenon. However, the term has been used in Europe as well.

The Western world went through a numerous changes after Second World War. The baby boomers were part of a youthful population that helped reshape and change the values (Lyon, 2010). Gilleard and Higgs (2007) argue that this generation were responsible to have created an important cultural wave, were the need to fulfil one’s own interest was the most significant one. The wish to be liberated, have a choice, autonomy and self-expressions are characteristics for this generation (pp. 16, 21). Some of the most defining moments in the 20th century took place in the 1960s. Martin Luther King Jr., Malcom X, the Beatles, the Rolling Stones were significant value changers who put a mark on the society (Lyon, 2010). This was also the time were generational differences became clear, this meaning a dislike for the previous generation who had maintained and manged the existing society. The aversion was
mainly not to become similar the previous generation (Gilleard & Higgs, 2007, pp. 16-17). Gilleard and Higgs (2007) claim that the youthful rebellion had become institutionalised as an eternal process of individualisation and personal differentiation (p. 18). Defining their social status and personal value according to their professional achievement is characteristic for the baby boom generation. According to Lyon (2010), they have a you can do it spirit that helped them not only shape their personal independence but also their work ethics.

The baby boomers are usually describes as hardworking, dedicated, and having an evident focus on career. They are motivated by position, benefits, and prestige in addition to being confident, independent, and self-reliant. This generation grew up in an era filled with changes and a conviction that is possible to change the world. As a result, they do not hesitate to challenge already established practises. Since work is an important arena for the baby boomers, they tend to define themselves and self-worth on their professional achievement (Gordon, 2016; Kane, 2017).

The baby boomers was a new social movement that established a politic around youth, freedom and identity (Gilleard & Higgs, 2007, p. 23). Self-actualisation, self-expression, self-reliance, self-independence, self-sustainability and selfness itself are a philosophy the baby boomers have introduced (Allison, 2016, p. 669; Kane, 2017). This generation has contributed to the social, political and economic systems we know today and are often described as having strong generational identity and sense of independence (Aging, 2017; Lyon, 2010). In the next section, I will argue this has had an influence on how we perceive aging, death and dying.

**BEING OLD IN THE WESTERN WORLD:**

Rose claims that medical thoughts have been involved with questions on how we should live. What kind of creatures we are; what kind of obligations we have to ourselves and to others; what kind of technics we can and use to improve ourselves and what kind of person we should strive to be (Rose, 2001, p. 20). We live in a time where people get older and older. Life expectancy has increased in industrialised countries and 50% of the population in Western countries will turn eighty years old (Kinsella, 1996). In addition “health has become a fundamental and required goal of the individual” (Higgs, Leontowitsch, Stevenson, & Jones, 2009, p. 689). The medicalisation of the human body has made it possible to live a long life. What are the consequences of such a development? Being old is associated with dependency, and different losses such as autonomy, control, the self (Agich, 2003; Das, 1990;
Laird, 1979; Seale, 1998). There is a contradiction between the wish of becoming old after a long lived life and not wanting live in old age or be categorised as old. In this part, I will show the different perceptions on old age in the Western societies. We will see that the Western view on old age is similar in most literature I present: being old has a low status in the Western societies (Kaufman, Shim, & Russ, 2004; Slevin, 2010, p. 1003).

The baby boom generation are and will be responsible for the biggest group of elders of all time. They bring their long-lived ideals and values into old age and this affect the way old age is perceived and experienced. As we know, they tend to attach their identity and self-worth to their professional life. This can have an effect on how they experience retirement age and old age. Scholars have divided old age into two groups (Higgs et al., 2009; Laslett, 1996): the third and fourth age. The third age is described as a period in life where both self-realisation and activities are seen as possible. In addition, health is central to this age group as it is a way to prevent physical and mental decline. The fourth age one the other hand is associated with dependency, disability, weakness and ultimately death (Higgs et al., 2009, pp. 688-689). All together, these factors can threaten a person’s identity. According to Higgs et al. (2009), the elders health determine their social status, either as active third agers or dependent fourth agers (p. 690). The baby boomers demonstrated against the previous generation’s morals and values. This is still relevant and can help to explain why so many are afraid of becoming old.

It is not just the fear of losing health it is also a fear of becoming what they once demonstrated against “a typical old person” (Roth et al., 2012). The fear of becoming “a typical old person” has made a new term ageism emerge. George J. Agich (Agich, 2003) argues that old age is often seen as a period in life, which is dominantly characterised by the loss of capacity. The loss of autonomy of elders takes many forms. However, the course of devaluation does not just happen within the person. It is also a product of assumption on how it is to be old in Western societies (Agich, 2003, p. 52). Ageism is a word used on these stereotypes concerning on old age. Agich define ageism the following way “A process involving the systematic stereotyping of and discrimination against people just because they are old” (Agich, 2003, p. 52). Furthermore, Agich claims the “elders are often defined as senile, rigid in thought and manner and old fashion in morality and skills” (Agich, 2003, p. 52). According to Veena Das (1990), the Western societies look at old age and aging in a new way. Because of the development of geriatrics, we see aging and old age as a disease. Das claims the geriatrics appeared because of three different factors. The first one is the deterioration of the body while aging. As a result, the body becomes a home to numerous
pathologies. The second reason is that the immune system of the elders is weakened and therefore it is argued that “the clinical pharmacological management need specialised training” (p. 33). The last and third reason for the appearance of geriatrics is the symptoms of disease in old age are different from the classical symptoms. Because of these three reasons, it was argued that we needed specialised skills to treat the elders in our society. Das claims that geriatrics makes it difficult to understand what is normal and what is pathological when it comes to the aging body. Because of this the specialists in geriatrics has replaced the terms normal and pathological with function and dysfunction (Das, 1990, p. 33). Furthermore, Das argues that the societies that shows a lot of concern with the welfare of the elderly are the societies that most definitely objectifies old age as a carrier of disorders (p. 33). Kathleen Slevin argues that the elders experience their bodies in an environment of “profound cultural silence” (Slevin, 2010). Additionally, Slevin claims growing old is seen as a disease, but it can be straightened out if one is committed to “aging successfully.” This means that the term to accept old age with grace is no longer practised (Slevin, 2010, p. 1004). Agich (2003) claims that some people feel the need to resemble a middle-aged person in order to age successfully. The anti-aging industry is a consequence of the negative feeling toward elders. This does not just mark biomedicalisation of old age but also the low status to being old (Kaufman et al., 2004; Slevin, 2010, p. 1003). The growth of the anti-aging industry has made a distinction between natural and normal ageing. According to Higgs et al. (2009) natural aging is coming to terms with physical decline (pp. 687, 691). Normal aging on the other hand is related to the limits to both the durability and healthy old age, it is about taking care of oneself and delay the aging process (pp. 687, 691). Furthermore, Higgs et al. argue that natural aging is a constant reminder to the individual of the failing body. The older the individual gets and the more the body fails, the more the individual will feel the need to accept the boundaries that follows (p. 697).

The body has become important to our sense of identity in modern societies. Our bodies are not only evaluated, they are also judged in ways that defines our self-worth. In addition our self-identity is connected to how our bodies appear and perform (Slevin, 2010, p. 1003). To resist old age is a way to fight invisibility and exclusion (Slevin, 2010, p. 1017). Clive Seal (1998) argues aging and dying involve the experience of loss, the most important one is the loss of the self (p. 150). Furthermore, Seal claims social bonds are broken when the body fails, when it is becomes difficult to maintain self-identity and when the normal expectation of relationship between people cannot be fulfilled. This is especially relevant when being
disabled since the person will feel shame because the barriers of privacy can be broken. By needing help with the most basic human needs, can feel as an invasion and loss of the self (Seale, 1998, p. 149). Seal argue that aging is also the experience of dying because of the different losses. Slevin claims that “Aging is paradoxically ‘both within our control and beyond our control’” (Slevin, 2010, p. 1005).

Das (1990) assert that the welfare state intervenes with the life cycle. The elders are being controlled instead of having control. When admitted to a nursing home every daily activity is measured and documented (p. 34). My informant Daan³ had some strong opinions on this matter “The people do not want to go to nursing homes anymore. They want to be helped at home until they cannot do it anymore, then they want to end their life”. The elders are expected to go to nursing homes and be better. By letting the elders live at home, they keep their autonomy, which, I have shown above, is important to the baby boomers. It is important to be in control not only over one’s own body, but also over the daily life. By being measured, the elders are constantly reminded that they are old and that their body is failing. Carobeth Laird did fieldwork in an American nursing home at the end of the seventies. She was then 79 years old and admitted herself to the home. What she discovered is as relevant for today’s nursing homes. Laird felt a profound loss of control over daily life and an overwhelming sense of isolation. She also lost her own perception of reality and sense of time in addition to the feeling of losing her self-identity (Laird, 1979). According to Agich (2003), nursing homes and other types of institution meant for the elders, segregate the old population from the society (p. 52). Many people sees old age as joyless and terrible and nursing homes only make matters worse (p. 56).

During my fieldwork, a new Dutch phenomenon was brought to my attention. The concept of being tired of life or feeling that one’s life is completed. Throughout this thesis, I will only use the term being tired of life. The Dutch public seems to become more open toward the possibility of self-directed death. There is a lot of debating on whether a person over 70 who feel tired of life should be able to receive assisted dying (Wijngaarden, Leget, & Goossensen, 2015, p. 1). Van Wijngaarden et al. (2015) base their discussion on interviews done with twenty-five people over 70 years of age. The research reveals that the elders do not wish to experience the process of getting worse and being dependent on others. The wish to die when being tired of life is to preserve self-determination, autonomy, and reasonability. Furthermore,

³ I will introduce Daan later in the thesis.
elders have a wish to be visible, recognised, wanted, needed, valued, depended upon, and attended to by others. To feel important and responsible toward people is fundamental for the quality of life and self-esteem for the elders (Wijngaarden et al., 2015, p. 7). When these feelings are not met, a person will feel tired of life and therefore have a wish to die (Wijngaarden et al., 2015, p. 4). Based on this, the definition of being tired of life is “a daily experience seems incompatible with people’s expectations of life and their idea of whom they are. While feeling more and more disconnected to life, a yearning desire to end life is strengthened” (Wijngaarden et al., 2015, p. 1). The feeling of loneliness, the pain of not mattering, not being able to express oneself, multidimensional tiredness and scared of being dependent are components that make a person feel tired of life (p. 1).

EUTHANASIA IN THE NETHERLANDS FROM 1960 UNTIL 2001

Youngner and Kimsma (2012) explain that during the 1960s, there was a cultural change in the Dutch society. As many other countries in Europe, Netherland was ready to reshape the old patterns, especially the tabooed subjects sex and death. The Netherlands used to be one of the most religious and traditional countries in the Western Europe, however this changed radically during the 1960s. There were several reasons for this: An internationalisation of Dutch politics, the economic boom, and the making of a post-war welfare. The traditional ways of thinking were attacked at every angle. The people questioned why dated ideas concerning life and death should stay in this “new” modern world. The Dutch citizens argued that they should move away from moral limitation and abandon the outdated past. This resulted in a collective feeling where all moral attitudes and taboos were gone. These attitudes and were remade and provided a new insight in a contemporary era (Youngner & Kimsma, 2012).

Furthermore, Youngner and Kimsma (2012) point out that the Dutch doctors assisted in people’s death in the years before 1960, but there was no public debate concerning this topic. During the early days of the euthanasia debate (the end of 1960s-middle of 1970s) there were some sign that euthanasia could be of social value. The Netherlands is a small but densely populated country with a lot of water. This was problematic for the Dutch population and played a role in not only the abortion debate but also the euthanasia debate. Through the 1960s, the number of elders rose and it became difficult to assist them all. This became a social problem. The Dutch healthcare cost rose 450% from 1963 until 1972. As a result, the Dutch were forced to ask themselves if they could afford to keep everyone alive. However, this side of the debate ended when Andries and Truus Postma-Van Boven argued that
economic motives should never be used as a motive to let people die. At the end of the decade, this became the standard answer to this problem. Not to forget, several leaders from the euthanasia movement argued that euthanasia was an individual choice. Another important factor in the Dutch euthanasia debate is the comparison of the Nazis euthanizing during the Second World War. The proponents argued “their” type of euthanasia were different from the Nazis. Not surprisingly, the elders of the Dutch community had a bad relationship with the word “euthanasia.” The opponent wished to use the “Nazi example” to prove the danger of euthanasia. On the other hand, the proponent felt this comparison to be unfair. Nevertheless, the Nazi example was always in the background of the debate. Consequently, the proponents always stressed the importance of euthanasia as a voluntary request. At the end of the day, the Nazi example did not get a lot of attention. Both the population and the Dutch medical practise thought of the Nazi example as incomparable to their own views on a euthanasia law. By the 1970s and 1980s, both the liberal protestant and the Dutch humanists were encouraging euthanasia. An important part of the discussion was right to die as a volunteer act. This became a focus throughout the seventies and eighties. The argument was that mentally stable people should be able to choose when to die. In addition, the debate concentrated on the people who were capable of making an individual decision. One of the main arguments was that euthanasia should be an individual choice, which in theory does not have anything to do with the larger society. The Dutch claims their euthanasia policy has made death and issues at the end of life as less taboo and more “bespreekbaar” or “discussable” (Youngner & Kimsma, 2012, pp. 3-17).

It can be difficult to understand how the doctors could perform euthanasia before its legalization without being prosecuted. Over the decades ahead of the legalization, the Dutch court ruled the euthanasia cases as force majeure. This means that euthanasia was permitted when a doctor faced an unresolvable conflict with the law. Although euthanasia was designated as illegal, a doctor who needed to help his suffering patient made euthanasia an unavoidable act. Before euthanasia was legal, the Dutch courts and the Royal Dutch Medical Association (KNMG) felt the need to make guideline for the doctors. These guidelines were to help doctors in choosing patients who could receive euthanasia or assisted suicide (Hendin, 1997, p. 48). The guideline made by the Dutch court and KNMG were as follow:

1. Voluntariness-The patient’s request must be freely made, well considered, and persistent.
2. Unbearable suffering- The patient’s suffering cannot be relieved by other means (i.e., other alternatives must have been considered).

3. Consultation- The attending physician should consult with a colleague.

(Hendin, 1997, pp. 48-49)

In the next part of this chapter, we will see that these guidelines will be used as an inspiration for the criteria in the euthanasia law. If the guidelines are followed and the doctor report his patient death as an “unnatural death” he will not be prosecuted.

An important milestone in the Dutch euthanasia history is the case of Dr. Boudewijn Chabot. Chabot, a Dutch psychotherapist, helped a woman of fifty-five to die. This woman, who goes by the pseudonym “Netty Boomsma”, was a physically healthy woman. According to Chabot, Netty did not endure from clinical depression or had a psychiatric illness. However, she was suffering and wished to die. After about three months of therapy, Chabot offered Netty lethal drugs. She died in her dead son’s bed on September 27 1991. This case created a new legal ground for assisted suicide and euthanasia for patients who did not suffer physically but psychologically. After several rounds in court, which ended in the Dutch Supreme Court, it was decided that mental illness could be a reason to give assisted suicide. Chabot was only found guilty in not having another psychiatric consultant to contemplate Netty’s case. The Netty case is seen as a pioneering, since it legally established mental suffering as a basis for euthanasia (Hendin, 1997, pp. 60-69).

During the decades before euthanasia was legalised, it was all about pushing boundaries. The Dutch citizens, the doctors got used to bringing up questions concerning end of life practise. By doing so, taboos concerning death and dying were slowly fading away. During my fieldwork, several of my informant explained the importance of pushing boundaries. When boundaries are overstepped little by little, a new norm takes form

**LITTERATURE ON ASSISTED DYING:**

In this section, I will briefly introduce some of the literature on assisted dying. Two monographies stick out within the anthropology of assisted dying. Frances Norwood- *The maintenance of life* (2009) an American anthropologist who did her fieldwork in the Netherlands in the beginning of 21st century, focused on the communicative and social aspects of euthanasia. She discovered the importance of communicating during the process of requesting and receiving assisted dying. Robert Pool- *Negotiating a good death* (2000) gives the reader a description of the euthanasia practise in the Netherlands. He shows why patients
request euthanasia, the social factors that influence doctor’s decision and how doctors and patients talk about a peaceful death. The psychiatrist and suicide expert Herbert Hedin- *Seduced by death* (Hendin, 1997) conduct research on assisted dying in the Netherlands during the nineties. Assisted suicide was still not legal at this point, but practised. Hedin investigates the implication of this practice. Many articles could be included in this section. Dutch articles on assisted dying are widespread as the topic is well researched in the Netherlands. In this thesis, I mainly use Wijngaarden et al. (2015) and Schuklenk and Vathorst (2015). I will not elaborate the content of these articles since they are referred to and explained in the thesis.

**METHOD:**

This has not been a fieldwork in the classical sense. Conducing anthropological fieldwork in a big metropolitan city can be difficult. In addition, death and dying are private matters. I was therefore aware that I might not get full access to the field. I started my fieldwork at NVVE. Nadya, my contact person was responsible to send out a monthly newsletter on email to all the volunteers. In the February Issue of the newsletter, she posted an advertisement on who I was and what I researched. She included my email address, so those interested to talk could contact me. Consequently, nine volunteers responded.

**Moving around:**

Instead of living with my informants, I moved in and out of the field. I used the most common Dutch transportation, the bike, to move around Amsterdam. While biking through the city, I did not just get to know the city. I also felt a part of the Dutch community. I took the train when meeting informants outside of Amsterdam. I saw the typical Dutch countryside, with old clay houses, farm animals and the characteristic water canals. With these means of transport, I immersed into the Dutch culture.

**Gaining access:**

While planning the fieldwork autumn 2015, I was aware that it could be difficult to get access to the field. I was preoccupied with questions of who to contact first and how to get in contact with the field. To get a foot in, I contacted Robert Pool, head of medical anthropology department at the University of Amsterdam. We email back and forth about my project and he put me in contact with one of his PhD students, Natashe. Natashe offered to help me with practicalities and be my “unofficial” supervisor. With the help of Natashe, I got in contact with NVVE. My contact person at NVVE, Nadya helped me get in contact with the
volunteers and get access to all the conferences. I shared an office with the coordinators and Nadya when being at the NVVE office.

**Structure of the fieldwork:**
NVVE is an organisation that extends all over the Netherlands. As we will see in chapter one, the volunteers play an important role in the organisation. Therefore I chose to live in Amsterdam, where the NVVE office is situated. The Netherlands is not a big country in area, I could therefore travel around with the excellent Dutch railway system. I was at the NVVE office Mondays and Fridays, I talked to the people working there and wrote my fieldnotes. The rest of the week, I travelled around to meet the volunteers. The volunteers are the people I talked to most during the fieldwork; they are an essential part of this thesis. The people working at the NVVE office are also important part of this thesis.

**Conferences:**
As mentioned I attended many conferences and meetings organised by NVVE. The organisation put a lot of effort into these happening. The attendants could any time help themselves to different types of beverages and snacks. In addition, lunch was included if the conferences lasted the whole day. At the end some conferences, the people working for NVVE had a borrel. A borrel is a typical Dutch phenomenon, were people socialise in an informal setting to have drinks and some food.

I attended five conferences and meetings organised by NVVE. The first one was a week after I arrived Amsterdam and was therefore my first real meeting with the field. It was a conference especially for the younger members of NVVE, the people under forty. Some days later, I attended a conference for all members. This conference was a turning point during the fieldwork. I will get back to this in chapter two. In March, I participated at a workshop for NVVE’s members. This day, I heard about the autonomous route for the first time. I will explain this concept in chapter two. In April, I took part of a schooling day for the volunteers in NVVE. During this day, there were different lectures and workshops for the volunteers. The last, but greatest conference I attended was Euthanasia 2016. This conference was a part of the World Federation of Right to Die Society (WFRtDS) and is organised in a different country every two year and hosted by an organisation belonging to WFRtDS. It was organised by NVVE in Amsterdam while I conducted my fieldwork. NVVE worked towards the conference my entire fieldwork. Scholars, scientists, and organisations from all over the world attended the conference. It was four days with a tight program. The lectures and workshops were divided into four disciplines: Science, medical, legal, and campaigning.
Except for *euthanasia 2016*, the conferences took place outside of Amsterdam. I attended most of them with an informant who could translate. All the gatherings were in Dutch, except for *euthanasia 2016*.

**Conversing with people:**
I conducted 15 informal interviews/conversations during my fieldwork. There are several reasons to why I chose this method. To talk about death and dying can be a private matter. By making the mood informal and rather have a conversation than a typical interview, I got closer to my informants. To converse require that both share personal information about themselves and this was something I lived by to make the informant feel comfortable. By doing so, they opened up and told me more about their opinions and meanings. The majority of the people I conversed with were volunteers. When talking to people working in the NVVE office, I choose a more formal and structured interview style. Since we were in the office, I did not want to put them at ease in their workplace. My original plan was to record all of my conversations with my informants. However, I quickly changed my mind. To talk about private matters can be difficult and I sensed that a recorder would hinder my informants to opening up. As we will see throughout the thesis, some had strong opinions (and radical) on sensitive objects. I took notes while talking to them and quoted them directly in my notebook. Before meeting an informant, I prepared different topics for us to talk about. The topics changed according to whom I met and how my fieldwork was progressing. When interviewing volunteers we met either at their house or in a café. Even though the participants were flexible on were to meet, my policy was traveling to all my informants. This was a good way to see the country and a nice gesture toward the informants. In addition, I met several of my informants at conferences and meetings. This was also a place to talk with them in an informal setting.

**Observing people:**
I was unsure about how I could observe people while conducting my fieldwork. However, this solved itself the first official day in the field. As I mentioned above, I attended a conference for the young members of NVVE just a week after I arrived. I remember how nervous I felt and how lost I was upon arrival. I did not know who to speak to and all of a sudden, I felt timid and shy. Luckily, I had met some of the people in the NVVE office just a few days earlier. Herman, a coordinator, took care of me and translated the most important part of the lectures. To my surprise, I wrote plenty of fieldnotes during this conference. Everything from atmosphere, what kind of people attended, and general observation in the room. This tactic
was something I used at all the conferences I attended. I took fieldnotes from what I saw, heard, and sensed. It was fruitful to be able to observe people without understanding what was being said. I could then concentrate on all the things happening around me.

**Ik spreek geen Nederlands- I don´t speak Dutch:**
To conduct a fieldwork and not being able to speak a single word of the natives language can be a hindrance for an anthropologist. I will not pretend that it did not harm my fieldwork, because it did. This was my biggest obstacle. Not to understand a word during conferences can be exhausting, I listened to Dutch for many hours. Yes, I had someone sitting by my side translating the most essential. However, sometimes the feeling of being in the way was strong, which I understand since everything had to be translated. It was also uncomfortable that people always had to speak English when I was in the room. This was especially during the Friday borrel at the NVVE office. When being tired, most people want to speak their own language. This was something I respected and understood. The most negative factor about not speaking Dutch was that I missed information. Not just at conferences, but the mundane conversations in the office. I simply missed out on a lot and could not be a part of the conversation unless it was in English. Despite all this, I managed to conduct a good fieldwork. The Dutch speak English very well and for that, I am grateful.

I gained sensitive information from many of the volunteers. Therefore I have anonymised all volunteers and all people working at NVVE. I have changed their names and not mentioned their profession or where they live. I obtained an oral consent and the project is approved by NSD.

**Positioning:**
To conduct anthropological research differs from other disciplines. A reason for this is that the anthropological fieldworker bring herself into the field, the anthropologist personality, ethnicity, sex, age and so one can define what kind of access one get.

I travelled to the Netherlands with my little family, which includes my partner Jørgen and my son Luke. Being a mother in the field can be a way to get access to information. When introducing myself to my informants, they naturally asked where I lived in Amsterdam. When telling them that I lived with my partner and son, I could see that they thought of me differently. If I was talking to a female informant, I was *one of them*, not only a student but also a mother. In addition, I believe it is necessary to include some rather personal information about my family. My son was born in week 31 and has trisomy 21. By sharing
something so private about myself with my informants, I felt they opened up to me. They told me about their personal life and difficulties they had met. Additionally I sensed that my informants respected me, I had been through something difficult. To share personal information about oneself was a way for me to not just get access to the field but also a way to start a conversation. I believe that in order for people to share, one have to share as well. This is especially relevant when it comes to sensitive topics as for example death and dying.

Another way I gained access to the field was to help NVVE promote *Euthanasia 2016*. The work consisted of sending out invitations to universities and organisations in Scandinavia that might be interested in the topic. By helping out with this, the people in the NVVE office looked at me in another way. I was now one of them and we worked toward a common goal: to get as many people as possible to attend the conference. This also resulted that I got free entrance. In addition, I helped with practicalities during the conference.

I have worked in a nursing home for three years. Therefore, I did not think that this fieldwork would be difficult for me personally. I am used to talking about death, seeing people in pain and comforting them. Because of this, old people are close to my heart. I have learned a lot from the elders and people with dementia. Being patient, caring, understanding in addition to seeing old age as a natural process that will happen to all of us. During this fieldwork, I was not aware of the opinions I would meet on aging and dementia. This was something that influenced my fieldwork a lot. It was difficult not to show my true emotions. At one point, I was so exhausted to pretend I was someone else, that I had to take a week off.

**STRUCTURE OF THE THESIS:**

In the first chapter of this thesis, I will give an outline on the Dutch law on assisted dying. I will discuss some of what I believe are the main problems with it. I will then give a description of NVVE and the people working for the organisation. In chapter two, I will shortly present some thoughts on autonomy. Then I will present the different autonomous routes. Next, I will explain why my informants make a distinction between suicide and the autonomous route. Thereafter I will discuss the autonomous route and Durkheim’s three types of suicide. In the last part, I will discuss if the autonomous route really is autonomous. In chapter three, I will first analyse with the help of Van Gennep if the autonomous route can be seen as a ritual and therefore is ultimately a form of sacrifice. I will then discuss whether feeling like a burden can lead some to choose the autonomous route. In the last section of this chapter, I will discuss whether assisted dying and the autonomous route can lead to a *sorting*
society. In the last chapter, I will discuss some of the perceptions of what constitute a good or bad death. Then I will discuss what constitutes a good death and a bad death for NVVE. The last section will be devoted to a conclusion.
CHAPTER 1. ASSISTED DYING IN THE NETHERLANDS.

“Everybody loves life until something happens” Eric, April 2016.

The World Health Organisation (WHO) defines health as a state of physical, social and mental wellbeing (Das, 1990, p. 27). Veena Das criticise this definition, she argues we need to look at the experience of wellbeing and by doing so we can understand that health is a subjective matter (Das, 1990, p. 27). As we will see in this chapter, the Dutch law on assisted dying is defined through the state of health rather that the experience of health. Consequently, the citizens in the Dutch community interpret the law in different ways and this leads to debates on who should and should not be able to receive assisted dying. I will start this chapter by demonstrating the criterions that needs to be fulfilled in order to receive assisted dying in the Netherlands. Then I will discuss some of the problems concerning these criterions. In the next part of the chapter, I will focus on the organisation NVVE. I will briefly describe how NVVE was established and who they are today. Then I will explain the volunteers and the complexity of their role toward the members. In the last section of this chapter, I will describe what NVVE proved their members.

THE DUTCH LAW ON ASSISTED DYING:

In order to understand NVVE and their work, it is necessary to discuss some of the problems concerning the Dutch law on assisted dying. As we will see in in this chapter, many people are not able to receive assisted dying because they do not meet the criterions sited below. This results that NVVE finds new ways of helping their members to die.

The due care criteria:

After about thirty years of national debate, the Dutch Termination of Life on Request and Assisted Suicide Act was a fact on April 10, 2001 (Norwood, 2009, p. 23). It is still illegal to kill someone on request. However, if the due care criteria are fulfilled, the law makes it possible for a doctor to help a patient to die by assisted suicide.

- The patient has made a well-informed request voluntary;
- There is unbearable suffering with no prospect of improvement;
The patient has been properly informed about his/her medical situation and prospects;
The doctor and the patient have concluded mutually that there is no other reasonable solution for the patient’s situation;
An independent doctor has been consulted, for example an SCEN doctor, who has seen the patient and offered his opinion in writing about the required due care;
Euthanasia is conducted in great care.

(NVVE, 2016c)

The problems with the due care criteria:
As I will discuss further down there are several problems with the criterions sited above. The due care criteria are interpreted in various ways by the Dutch citizens, this causes debate on who should and should not receive assisted dying.

The first criteria, “The patient has been properly informed about his/her medical situation and prospects” can be difficult to fulfil if the patient is not able to function socially. For example, people with dementia can have problems understanding their medical situation and prospect. As a result, the Dutch Ministries of Public Health and Security and Justice updated the assisted dying guidelines concerning dementia in January 2016. The new criterions state if a person has a written euthanasia request before getting too ill, the doctor can help the patient to die when being under the impression that the patient is suffering unbearable. Communication between doctor and patient is an important factor when giving and requesting assisted dying. Dementia is an illness that gradually takes away the mental capability of a person and therefore the communicative aspects around assisted dying disappear. By changing the due care criteria so the people with dementia will be able to receive assisted dying, new problems will rise. I will get back to this topic in chapter three.

Another criterion causing debate is “the patient has to experience unbearable suffering with no prospect of improvement.” What is unbearable suffering? Is it only physical pain or is it also psychological pain? It is difficult to define unbearable suffering because suffering is a personal matter. People suffer in various ways and have different perception on suffering. For example, “Netty Boomsma” suffered unbearably because of the death her son and therefore wished to die. Her suffering was not physical, be she still felt unbearable pain. However, she could not request assisted dying because according to the due care criteria her suffering was
denoted as unbearable. In the Netherlands, patients with a terminal disease and people suffering from a chronic illness can request euthanasia. This group of people is according to the Dutch law, experiencing unbearable pain. Thus, the doctor fulfils most of these euthanasia requests. However, what about the ones who suffer psychologically? Or people who are diagnosed with dementia? A person can seem to be in a physical, social, and mental state of wellbeing, but the experience of one’s own health can be different. According to Schuklenk and Van De Vathorst (2015) psychiatric patient are discriminated by the Dutch physicians. They argue that pain and suffering for a patient with psychiatric illness is not visible on/in the body the same way that it is in a terminal or chronic ill patient. The patients suffering is concealed and hidden within the mind. Because of the difficulty to see the illness, it is more challenging to diagnose and therefore to cure it. Arthur Kleinman argues that there is a difference between the patient’s experience of illness and the doctors attention the disease (Kleinman, 1988, p. pxii). When a person have a euthanasia request, the doctor follow a procedure according to what kind of disease the patient has. The patient on the other hand, might feel that his illness is not being taken seriously. Byron J. Good argues that both the doctor and the patient see the disease differently:

Disease is located in the body as a physical object or physiological state, and whatever the subjective state of individual minds of physicians and patients, medical knowledge consists of an objective representation of the diseased body. (…) For the person who is sick, as for the clinician, the disease is experienced as present in the body. But for the sufferer, the body is not simply a physical object or physiological state but an essential part of the self. (Good, 1994, p. 116)

Good explains how disease and suffering is a subjective experience. The doctor and the patient both know the illness is present in the body. However, when a person suffers, the body is not only a body but also an essential part of how the patient perceives himself. This is an important matter because as Good argues, disease is a subjective experience. The sickness and the suffering become not only a part of the body itself, but also a part of the person who suffer. Therefore, when one of the criteria to receive euthanasia is to experience unbearable suffering, it is important to remember that suffering is a subjective matter. It is difficult to place suffering in only one box, where the sufferer is terminal ill or have a chronic illness.

Furthermore, this leads to another criteria that can be difficult to achieve, assisted dying can only occur when there is no prospect of improvement. Even though a psychiatric patient have
tried every medication and method there is, there will always be a possibility that a new treatment or medication will be made. There are some cases where the euthanasia request of psychiatric patients has been approved, but the patient reconsider and ends up not going through with it. An explanation can be that the patient feels in control over the situation and therefore wants to wait. When a euthanasia wish has been granted the patient can wait until ready before proceeding with the request. My informant Nina, a retired nurse living in small town outside of Amsterdam with her husband, works as a volunteer for the NVVE. Nina tells me about a member who had her euthanasia request fulfilled but then reconsidered:

There was a psychiatric ill woman. She had tried every treatment and medication. The woman wished to die a euthanasia death. It took a while before the euthanasia was granted. However, when she finally got the green light, the woman changed her mind. She did not want to die anymore. (Fieldnotes, March 2016)

This woman had lost hope because none of the treatment or medication worked. However, by getting her euthanasia wish granted, she knew that when ready, she would receive euthanasia. Nina thought this woman changed her mind because the woman was in control of her destiny. She could get euthanasia when she was ready. I heard several similar story’s while conducting my fieldwork. The case shown by Nina can lead us to think that a granted euthanasia request can affect the way psychiatric patients perceive their life and that the sense of control leads them to live happier life. Psychiatric illness includes many different forms of mental state and therefore we cannot assume that every psychiatric patient is suicidal. Sometimes there is just a strong wish for the suffering to go away. When a person know he is in control and can end the suffering whenever, can be a reason to why some psychiatric patient stops feel the need to die. To be able to receive euthanasia is more a reassurance; the possibility is there when the time is right.

The fact that a patient has to make a “well-informed request voluntary” is another ambiguous criterion for both the doctor and the patient wishing euthanasia. For example if the patient is not able to speak. An essential factor to receive euthanasia is to be able to ask for it oneself. Thus, it can be challenging to request assisted dying for patients who are unable to speak. In these cases, it is important to have talked to the doctor in advance and expressed a future euthanasia wish. The doctor always ask the patient right before giving the lethal injection if she still wish euthanasia. This is the last chance for the patient to confirm and a way to for the doctor to feel secure about his action. If a patient is not able to express himself, the doctor can
for example ask him to squeeze his hand as a yes. Another problematic factor with the “well informed request voluntary” criteria is if the patient has dementia. The patient might have wished euthanasia before the illness was too progressive. However, doctors are hesitant to give assisted dying when the dementia is too far along. As I mentioned above, the Dutch Ministries of public health and Security and justice has changed the guidelines on this matter but doctors are still reluctant to give euthanasia to people with dementia. During the fieldwork, my informant stressed the importance of receiving euthanasia at the right time when been diagnosed with dementia. The person cannot be too healthy or too sick, but in between.

The due care criteria function as a guideline for the doctor when a patient request assisted suicide. However, the criterions can be interpreted differently and have a tendency to not consider the patients suffering. Human health is a complex matter, were both physical and psychological suffering is a subjective experience. This subjectivity has led some people to believe that euthanasia has become a right rather than an option for the terminally ill. As we will see throughout this thesis, some wish to widen the guidelines, hence more people will be able to receive assisted dying. In addition, NVVE is guiding their members who cannot get help die from a doctor. Will this lead to a society who sort out the vulnerable? I will discuss this question in chapter three.

THE NVVE- “THE DUTCH ORGANIZATION FOR VOLUNTEER EUTHANASIA.”

“Working for the NVVE is a precious peace of work” Eric, April 2016.

“When you this kind of work you have to love people” Tim, April 2016.

The birth of NVVE and the NVVE today:
In 1972, a 78-year-old widow lived in a nursing home. She had suffered from cerebral haemorrhage and was therefore partly paralysed. She had several conversions with both the staff of the nursing home and her daughter about her wish to die. The woman repeatedly asked her daughter, who was a doctor, for help to die. The daughter, Ms. Postma, gave in and administered a lethal injection of morphine. When this came to the attention of the director of the nursing home, he called the medical inspectorate, which alerted the prosecutorial authorities. In 1973, Ms. Postma stood on trial in Leeuwarden for “killing on request” and received a conditional jail sentence of one week with one-year probation. The advocates for
Ms. Postma organized themselves, and became the NVVE. Their main goal was a social and public acceptance for euthanasia (Griffiths, Bood, & Weyers, 1998, pp. 51-53).

Today, the NVVE has about 164 000 member spread all over the Netherlands (NVVE, 2016a). The NVVE office is situated in the central area, overlooking the beautiful canals and bridges of Amsterdam. The office space is light and airy with several departments. The atmosphere is always busy, phones are constantly ringing and people are always working. There is about thirty people working in the different departments of the office: the media/promotion department, the policy department, the coordinators and administrative department. The media/promotion department’s job is to promote the NVVE and give the organization good media coverage. The NVVE uses several important media apparatuses such as Twitter, Facebook and an active website. By sharing pictures, ideas and opinions from conferences and in addition publishing news on twitter and Facebook, the NVVE reaches out to not only their members but also the rest of the Dutch population. In addition to being on social media, the NVVE administer the website “thisistheend.nl”. Here anyone can watch documentaries free of charge about euthanasia and other topics on dying. Additionally, NVVE reaches out to an international audience by subtitling many of the documentaries. One of my informants explained that the media loves the NVVE because they cause debate and “drama” in the Netherlands. Another informant told me: The media loves the debate, *euthanasia gets a lot of publicity*. The NVVE is always at the centre of the debates concerning assisted dying, as advocates for not just euthanasia but also for new methods of dying. I will get back to this later on in the thesis. The people in the policy department work towards NVVE’s future goals. I will explain these in chapter three. The coordinators are the ones who put the members and the volunteers in contact with each other. They are set up in relation to which region they live in and to what kind of help the volunteers need. Members also call the coordinators if they have questions about euthanasia and the law. The coordinator’s job is important because they talk directly to the members. They are the “eyes and the ears” of the organisation as one of them told me.

**The volunteers:**

NVVE has about 150 volunteers working all over the country. Their tasks consist of organizing and holding conferences, giving help at the office in Amsterdam and function as consultants for the members. Most of my informants were volunteers working as home consultants, thus I describe this group of volunteers. This group of volunteers are mostly retired highly educated Dutch citizens in the third age. The member has to call a coordinator
in the Amsterdam office to be able to receive consultation. Next, the coordinator calls the volunteer who is best suited to help the member and who live in same region. The volunteer then calls the member and they arrange a meeting at the member’s house. The home consultant’s task is to advise and guide the member when it comes to assisted dying. The member might have questions about the advanced directives (I will get back to this below) or how to proceed with a euthanasia request after being diagnosed with dementia. The volunteer can also accompany the member to the doctor if needing help to talk about an eventual euthanasia request. If a member wishes to die but does not fulfil the due care criteria, the volunteers can provide guidance on how the member the member can his life. I will get back to this topic in the next chapter. A volunteer can also function as a power of attorney (proxy) for members who do not have any family or friends. In addition paying a visit to the member once a year, the volunteer can discuss the member with the doctor without his consent. Additionally, the member can contact the volunteer when having questions. There is not supposed to be a personal relationship between a volunteer and a member but a home consultant becomes a proxy the relationship has a tendency to become closer. The member can only contact the volunteer through email, as this is a way to protect the home consultant. Nevertheless, many give out their phone number, this occurs especially when a volunteer function as a proxy. Further, down in this chapter we will see difficulties that can occur if the relationship between a volunteer and member moves towards a friendship.

**Relationship between volunteer and member:**

The coordinators and the volunteers have different opinions on how to “treat” the members. The coordinators wish the relationship between a home consultant and his client to be as sober as possible. On the other hand, the volunteers feel it is impossible not to get too personally involved with a member. My informant Lisa was the first volunteer to contact me. We met in the beginning of March and she expressed an eager to share her thought. Lisa is a retired woman living with her husband. She function both as a home consultant and helps members with the advanced directives (I will get back to this further down). Lisa told me she works as a volunteer because of how she was raised and how she is as a person. She has always thought of euthanasia as something that should be legal and has never been afraid of talking about death. Lisa explains: “Amsterdam does good stuff, but they don’t know what’s happening in the field. It is easy for them to tell ‘do this and do that’, but I have made it clear to them that I will decide how I wish to do my things”. Lisa shows here that the coordinators

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4 Many of my informants call the NVVE office in Amsterdam for Amsterdam.
do not wish the volunteer to get to close to the member, as it can be difficult for the member to understand the role of the volunteer. After all, the volunteer is not supposed to be a friend, but rather a helper. Lisa described a problematic situation she got in to because she functioned as a proxy to a member:

Jan was an eighty-year-old man with both psychological and physical issues. He suffered from post-traumatic stress after being in different wars. Jan lived in the Netherlands because people wanted him dead. He lived in a safe house. Because of Jan’s psychological illness, he didn´t get along with many people. However, since Lisa comes from a military family she could relate to him and he to her. Jan warmed up to her. He wished to die, but his doctor did not want to fulfil the euthanasia request. Lisa wanted to help Jan because she thought he was sick enough to get it. He was very lonely and had a hard time expressing himself. Lisa contacted the clinic in Den Haag5. They sent a psychiatric to evaluate Jan. The psychiatrist approved the request for euthanasia. Lisa helped him find a doctor who was willing to perform euthanasia. On the request of the doctor and the man, she was with Jan when he died. After his death, the doctor and Lisa waited for the medical staff to come and confirm the death. After a few hours, they arrive. They told Lisa that she is responsible for Jan. He has written that she will be responsible for everything after his death. This is something Lisa had never agreed upon or heard of. The medical staff told her to call the carrier to pick up the body. Lisa agreed, but after that, she did not want any responsibility. When the carrier arrives, Lisa had to pay him! She didn’t want to do this, so they agreed to call the lawyer and that he would take care of further arrangements6. (Fieldnotes, March 2016)

This case illustrates how complicated the relationship between a volunteer and a member can become. Jan thought of Lisa as his closest friend. On the other hand, Lisa did not feel the same way. When she spoke of this case, she was proud of how she had handled it then she said, “There is something more to a person than euthanasia”.

Lisa introduced me to Jos and Frank for whom she functioned as a proxy. Jos is an elderly retired man living alone. He has children, but does not have any contact with them. Jos

5 The Clinic in Den Haag is a clinic established by NVVE. This is where all the declined euthanasia cases are sent to.
6 This is a story Lisa told me, I noticed after ending my fieldwork and going through my notes that this might be a bit over the top. However, even though some of the details might be hard to trust, I believe that this relationship between Lisa and the elderly man was real.
became a member of NVVE because he was growing old and did not want to go into a “mental nursing home.” Since he does not have any family or friends to rely on, Lisa is his proxy. According to Jos, life would be difficult if the NVVE did not exist. Jos explains his relationship with Lisa is not formal, but not extremely friendly either. He likes when Lisa comes over and he can phone whenever he wishes to. Frank, the other member Lisa introduced med to, is also an elderly man living alone. Unlike Jos, Frank has no children, but a sister living in France. Frank became a member of the NVVE after his wife died of a massive stroke while on vacation. He thought NVVE could take care of him if anything happens. Frank explained he does not see Lisa as a friend, but rather as someone, he can talk to whenever he needs. He feels reassured that she knows how to take care of him. Frank believes that the NVVE can take care of him medically. What he means is that if something happens, the NVVE will help him with the medical situation. Frank explains that his life would be difficult of NVVE did not exist. The cases of these men explain some of the complexity within the relationship between a volunteer and a member. They are not friends, because there is no reciprocity between them and the volunteer does not expect anything in return from the member. However, the members expect a lot from the volunteers since they think of the volunteers as someone who can rescue them. In case from the introduction, the elderly woman got angry when the volunteer could not help him die. As a member of NVVE, she expected to get help to die when she needed. Although Lisa can only provide guidance and not help them directly, both Frank and Jos insinuate that she will help them when they are ready. Being old in the Western societies is associated with loneliness and being an outsider. The elders who do not have loved ones, are easily isolated from not just people, but from society itself.

When elders no longer feel part of the community and do not have loved ones surrounding them, it can lead to a rupture in their social fabric. Social fabric is a concept used to describe the multidimensional nature of health. The human body consist of certain basic needs such as water, having roof over the head, being surrounded by loved ones and being a part of a community. Additionally humans rely on a safety nett that will catch them if falling. This can for example be access to medical help or a health institutions (Janzen, 2002, p. 2). The combination of having a safety nett and the basic needs being covered is according to Janzen (2002) the social fabric of health. Lisa’s story about Jan and my conversations with Jos and Frank are descriptions of a life where the social fabric has been destroyed. By not having loved ones and being left out the community, they miss some of the basic needs in a human
life. In addition, the Dutch government is closing nursing homes (DutchNews.nl, 2013), so they do not have an institution that will be able to take care of them. The social changes in the Dutch society have led them to become a member of NVVE. This point to a direction where NVVE can both function as a safety nett and help with the basic needs for their members. NVVE will then help their lonely members to rebuild some of the social fabric that has been destroyed. If taking into consideration that many elders feel segregated from the society and experience loneliness, NVVE emerge as an organisation that recognise the ones who are not seen by the rest of the population. Hence, NVVE function as an anchor to the world outside for their lonely members.

My last day in the NVVE office I told Floor, a coordinator, whom I always thought of as a bit strict, that some of the members I talked to needed the NVVE to exist because without them life would be hard. I could see that she first looked a bit surprised, but then her eyes became tearful. It was clear that she did not understand how much NVVE meant to some members. During my time at NVVE, there were rumours in the office concerning the “proxy service.” Some wished to remove this service because the relationships between the volunteer and the member were becoming too complicated. The majority of volunteers and members hoped to continue with this arrangement. If NVVE make the lonesome member´s feel seen and cared for and restore their social fabric, it must be worth risking having a few “complicated relationships.”

**The members:**

It was difficult to gain access to the members of NVVE during my fieldwork, as I only met them during conferences. A volunteer often accompanied me and functioned as my informant and translator. Jos and Frank are the only members I got the chance to talk to, thus the descriptions below are based on my observations during conferences.

The NVVE has about 165,000 members spread all over Netherland (NVVE, 2016a). The members are an important part of the organization, not only because they pay an annual fee (17; 50 euro), but also because they push and require a lot from NVVE which make the organisation evolve. The members I observed during conferences and meetings were active and outspoken. When watching them I could clearly sense they were resourceful strong-minded people. The members were not afraid to ask critical questions or share their opinion during Q&A. I noticed that the majority of people attending the conferences and meetings were in their early retirement age, thus belonging to the baby boom generation and the third
age. In addition, there seem to be an equal amount of women and men. During conferences, the atmosphere was light and humorous, people seemed happy to be there. However, the members also seemed impatient towards NVVE. They wanted things to happen, they seemed almost angry when asking questions. According to my informants, many people become a member of the NVVE when they experience that someone close has died a bad death. Another reason to become a member is the need to secure their future experience of dying, as for example with Jos, Frank, and Jan. The NVVE recently created a new offer for their younger members: NVVE joungeren or NVVE young. This is an offer for the members under forty years. The NVVE started this initiative because the younger members were concerned with other issues than the elderly members. They wished especially to discuss psychiatric illness and euthanasia, a topic that is quite relevant for young people. NVVE young organize conference and meetings especially for their young members. They also meet up in groups around the country to discuss with each other.

The non-resurrection medallion and the advanced directives documents:
When becoming a member of NVVE, the person receives an envelope containing different documents and a non-resurrection medallion. The non-resurrection medallion is a neckless with a plate containing the person’s picture, name, birthdate, and signature. Once having this around the neck, health personnel are not allowed to resuscitate the person. The medallion causes some difficulties. For example, when a surgeon has to operate on a NVVE member bearing the medallion, but cannot resuscitate if something goes wrong, or when the ambulance personnel purposely do not save a person wearing the medallion and therefor has to handle an angry crowd watching. Despite this, many people outside of the NVVE want this medallion, but do not wish to become a member of the organization. Hence, the government is working towards making this medallion available for everyone.

The documents in the envelope are the advanced directives documents. The advanced directives are documents made for the members of NVVE, by having these documents they can write their wishes for the final stage of life. Advanced directives are also referred to as a living will or just the will. There are five different advanced directive documents. The first one is a document for euthanasia request. The second document is an addition to the first: a request for euthanasia concerning dementia. The third document is for treatment prohibition and the forth document is an addition to the third: treatment prohibition for a completed life. The fifth and last document is a power of attorney concerning decision-making. This means that the person being power of attorney has the right to gain knowledge about medical
information and speak on behalf of the concerned. Usually a family member acts as power of attorney. However, as I have explained above, an NVVE consultant can also become power of attorney for a member. Instead of calling themselves power of attorney, the informants used words such as medical guardian or proxy. “Sana” a woman with an academic background and an expert at the euthanasia law meant the advanced directives were unnecessary “The will is overrated, it doesn’t give any rights. The one thing you need to do when you wish for euthanasia is managing to express it yourself; the will is just some kind of security that sometimes helps the doctor to understand your wishes.” As I have mentioned above, the number one criteria for receiving euthanasia is to be able to ask for it oneself. Except in the case of dementia, where a person can receive euthanasia based on the documents. Several of my informants stressed the fact the one must talk to and show the advanced directive documents to the doctor. The documents can help the doctor if for example the patient is not able to speak. According to several of the volunteers, many members are stressed before filling out the document but when everything is in order, the person is able to relax. Nina explained to me the importance of telling about the living will:

I have my own will and my husband knows about it. It is very important to talk about your wishes on how to die. It is not enough to fill out a will. You also have to talk about it. In that way, your family knows what to do if there is an emergency or you get ill. (Fieldnotes, March 2016)

Sana is an expert on the surrounding of assisted dying and Nina work as volunteers for NVVE. Hence, they know exactly how to fill in the documents and the importance of talking to the doctor and loved ones about one’s own wishes. Jos, on the other hand did not understand the value of talking about the directives to the doctor “Lisa know where my documents are, they are in the safe. She keeps advising me to remind the doctor of my euthanasia wish and ask in what kind of situation the doctor would help. I have my documents in order, so everything will be ok.” After meeting with Jos I talked to Lisa, she explained that many of the members tuck away their advanced directives because they assume that as long as the papers are in order they will receive assisted dying when ready for it. It can seem that many of the Dutch citizens do not know how the law on assisted dying functions. They are convinced that they will receive assisted dying just because it is legal. However, as I have explained, in order to receive assisted dying the due care criteria need to be fulfilled. Maybe the thought of being able to get euthanasia is a reassurance in itself, but when understanding that they cannot get help to die, the seed has already been planted. They will still want some
kind of assisted dying, even though the Government and doctors are unwilling or unable to provide them with such a service. The effect may then be alternative ways of opting for assisted suicide outside of the legal realm. Hence, some will find new ways to die. I will discuss this matter further down in the thesis.

“Levenseindekliniek” - End of life clinic:
The “Levenseindekliniek” or *The End of Life Clinic* is a mobile clinic for people who have had their euthanasia request declined by the general practitioner. The Clinic was established by NVVE in 2012 by their former director Petra de Jong. Since the clinic is mobile, it does not function as a hospice or hospital. Instead, the doctors travel to their patients. Nonetheless, the Clinic has an office in Den Hague were all the cases are reviewed and handled. Every Dutch citizen can ask for help from the clinic but declined euthanasia cases are prioritized: Psychiatric illness, dementia, and patient with non-fatal diseases. The staff in Den Hague is the first to evaluate the cases. They research if the case meets all the criteria according to the euthanasia law. The entire medical background of the patient is checked and all previous doctors are consulted. The doctor from the team conduct several conversation with the patient and investigate if the *due care criteria* are met. Then, if everything is in order and the patient fulfil the criterions, he is able to die at home surrounded by family and friends (Levenseindekliniek, 2016). The first year, the clinic had about thirty cases and there were only a few teams. Now, five years later, the clinic has grown to become an organization. They have about 50 teams and treated 400 cases in 2016 (Levenseindekliniek, 2016).

NVVE´s three routes:
The NVVE make a clear distinction between three ways or *routes* of dying, where the “medical route” is the one we are familiar with and using in general in the Western societies. The medical route is where the doctor decides what is best for the patient. The doctor determines how and when the patient should die. The most common way of doing this is through palliative care for a patient with a terminal illness. Palliative care is primarily pain relief, but often lets patient slip into a sort of coma because of the high dose of sedates (morphine). The NVVE does support this method, as my informants felt the doctor had too much control over the patient’s destiny.

The “helper’s route” is another way of meeting death. The helper’s route is a combination of a doctor’s involvement and a third party. This route is not legal in the Netherlands, but something NVVE work to be legalise. Since the helper’s route is a combination of getting
help from a doctor and receiving assistance from a third party, the doctor only prescribe a lethal drug. Then, the third party, who can be a family member, a friend, or a NVVE volunteer, gives the drug to the patient. In this way, the doctor does not preform the euthanasia, but a “helper” does. This method can remind of assisted suicide, where the person takes the lethal drug given by the doctor. Even though this method is illegal in the Netherlands, there are several cases were someone has helped a friend or a family member die. One of the most famous example of the helper’s route is the Albert Heringa case. Albert Heringa helped his mother die with the help of lethal drugs on her explicit request. Heringa’s mother, Moek, was not ill, but she was old and tired of life. After 99 years on this planet, she was ready to die. Heringa filmed the entire process in order to prove that Moek took the pills herself, but also to cast light on these cases where a person is tired of life and no longer wish to go on (Rosens, 2010). The volunteers I talked to where positive to the Albert Heringa case because he pushed boundaries and that is how assisted dying was legalised. The helper’s route is one of NVVE’s goals, as the patient is more on control over his situation. There was not a lot of focus on this route during my fieldwork, since it was not legal, but only something that my informants hoped to happen in the future.

The “autonomous route” is the third route NVVE is advocating. This route consists of dying completely without the interference of a doctor. In this way, the person is in complete control of his/hers destiny. Since the autonomous route had a central role during my fieldwork, I will devote the next chapter to this.

In this chapter, I have argued that several problems surface because of the Dutch assisted dying law is too vague. The due care criteria are made from a physician’s point of view, where health is considered as an objective matter. However, pain and suffering are subjective feelings, thus both people suffering from physical and psychological pain can experience unbearable pain. The objectification of suffering has led some people in the Dutch community to feel discriminated, as their suffering is not taken seriously. Additionally, it can seem that many of the Dutch citizens are not aware of the due care criteria and therefore believe they are entitled assisted dying. When the disappointment of not being able to receive assisted dying is a fact, some will turn to NVVE. I have also shown the some of the complexity within the relationship between a member and a volunteer functioning as a proxy. The Dutch government is closing nursing homes, so the ones who do not have loved ones to take care of them who fall through. As a result, some members become dependent on their home
consultant. We can see that NVVE have a tendency to function as a safety net for these members and helps restore some of their *social fabric*.
CHAPTER 2: NEW WAYS OF DYING

“We should be able to finish our life when we want” Daan, 2016.

“Death is your decision, your life” Frank, 2016.

NVVE claims the debate started, not ended, when euthanasia was legalised in 2002. In addition, as I have explained in chapter one, many Dutch citizens are not able to receive assisted dying. This has pushed NVVE to act on behalf of their members. Meaning they have invented the concept “autonomous route,” in order to help their members who wishes to end their life but do not fulfil the due care criteria. Only a few Dutch citizens knows about the autonomous route, just a small percentage of the NVVE members are aware of it, as they are inaugurated when a volunteer believes it is the right time. In this chapter, I will first show some of the perspectives concerning autonomy; I will especially focus on the loss of autonomy in old age. I will then explain the five different autonomous routes NVVE promotes. In the next part, I will describe how my informants relate to the autonomous route. In the other half of this chapter I will discuss, with the help of my informants, the similarities and differences between the autonomous and suicide. Inspired by Durkheim’s three suicide types, I will analyse how the autonomous route can be seen as a type of suicide. In the last section of this chapter, I will discuss the ambivalence concerning the autonomous route as autonomous.

SOME PERSPECTIVES ON AUTONOMY:

Autonomy in the Kantian tradition is associated with the concept of free will, meaning that the person is no longer a subject to externally created laws (Lock, 1996, p. 208). Autonomy in bioethics underlines the ideals of independence, self- determination, rational free choice and the individual’s own best interest (Agich, 2003, p. 1). The view on autonomy is usually a composition of deep and varied liberal tradition of thought and cultural concepts who shapes the self or the way people think about the self (Agich, 2003, p. 1; Traphagan, 2013, p. 27). Furthermore, Traphagan (2013) point out there are two common factors concerning theories on autonomy in the West. The first is liberty, which involve freedom from controlling power or influence. The second common factor is agency, this makes people able to act upon and make their own choices, with little involvement from the controlling authorities (Traphagan, 2013, p. 33). In the Western tradition autonomy is associated with freedom, being able to
make own choices and having desires and wishes in life. This means that people act autonomously when they are able to be in control of their life and decisions (Rendtorff, 2008, p. 78). The new technologies in the medical world, take away the patients autonomy. The discussion concerning biomedical technology usually circles around the question of individual rights, autonomy and justice (Lock, 1996, p. 210). According to Margaret Lock, the biomedical technologies do not make a patient autonomous. She claims that the need to reduce suffering has led its focus to control and repair individual bodies (Lock, 1996, p. 209).

Veena Das argues that Western societies perceive old age as an illness. A consequence to this perception, it is difficult to understand what is considered as normal behaviour within the body of the elders and what can be defined as an actual disease (Das, 1990). Autonomy in a modern liberal society is to be able to choose for oneself. This type of autonomy is considered to be the greatest form of value (Rendtorff, 2008, p. 78). This makes it understandable that for example many of the elders in Western societies do not want to be admitted into a nursing home. As I have mentioned in the introduction, elders lose their autonomy in many ways (Agich, 2003). According to Das, the nursing homes are controlling the elders and underestimates and undermine their autonomy (Das, 1990). When going from being an independent citizen to be a dependent patient/resident in a nursing home, some elders can feel that they lose their autonomy. By not being able to decide when to get up in the morning; what and when to eat; actives during the day; and when to go to bed, can reinforce the feeling of losing autonomy. James S. Taylor (2013) argues it is important to relate self-deception to autonomy. This is especially relevant for the elders in the Western societies, were people deceive themselves when facing death or having a serious illness. Taylor claim this group will experience less autonomy in the decision making (p. 137). Agich express that people who needs long-term care have serious illness, which hinders them to function independently or being able to choose rationally.

THE AUTONOMOUS ROUTE:

“The autonomous route is killing yourself softly” Tim, April 2016.

Before conducting my fieldwork at NVVE, I was unaware of the concept “autonomous route.” The autonomous route is explained by the NVVE as a way of dying without a doctor’s interference. This means that the physician does not have a role in his patient’s death. My informants at the NVVE office, the volunteers, and the members argue that the doctor should not have the power to decide when and how a person should die. Furthermore, they explain
that a person should be in complete control over his own death. The autonomous route can also be referred to as auto-euthanasia, which is description of an act of some who intentionally and independently chose to end his life. In addition the death is a well thought and is based on a persistent wish. Usually loved ones knows what is about to happen and a physician is not involved (Wijngaarden et al., 2015, p. 2). It is important to point out that NVVE only represent a small part of the Dutch population, thus the autonomous route is not a common concept or practice in The Netherlands.

The autonomous route targets especially the elders who do not fulfil the due care criteria. This is especially relevant concerning the new group of people emerging in Netherland, which claim to be “tired of life.” These individuals are usually elderly citizens who are concerned with the different losses followed by old age (Wijngaarden et al., 2015). The combination of a failing body and losing the lust for life makes this group of elderly not wanting to live anymore. In addition, the wish to be more in control over own destiny. Hence, the autonomous route can seem as a valid option. The data present below will be from encounters I had with the volunteers who advised the members in NVVE about the autonomous route. Being able to guide a member through the autonomous route is essential when being a home consultant from NVVE.

NVVE’s webpage:
NVVE has a webpage only accessible for their members. This webpage contains information on how to kill one self. The “Peaceful Pill Handbook” is a part of this information. Written by the Australian physician Philip Nitschke, the book informs the reader on different ways of killing oneself (Nitschke & Stewart, 2011). Another type of information the member get on the webpage are different lethal combinations of pills. For personal reasons I did not become a member of NVVE and therefor did not obtain a lot of information concerning this webpage. The people working at NVVE office were reluctant to give me information because it had been misused before. I was told that a woman, who worked as a volunteer in the office, asked a lot about the webpage. She disguised her curiosity with an excuse that her German friends needed the information. One day she did not show up for work and did not take the phone for several weeks. After a while, NVVE learned that the woman had killed herself.

Stop eating and drinking:
To stop eating and drinking is the second autonomous route. According to my informants, this method requires a certain type of health. The person needs to be fragile and preferably old to
succeed in this manner of dying. My informants articulated that there are special hospices in
the Netherlands that can help and guide a person through this process, were the doctor and
nurses are schooled and follow specific guidelines for these cases. The Netherlands is not the
only country to guide elders in stop eating and drinking. This method is also used in India.
T.N. Mandan (1992) describe a Jain practice of “self-initiated ritual death”. In this ritual, a
period of fasting leads to death, were the purpose is that the “outer body” becomes the enemy
“starvation practise” among Banares, where elders travel to and spend their last days at a
house designed for this purpose. Only elders who have decided that it is time to die are
welcomed into these type of houses. Hence, if a person has an infection, disease, or cancer, he
will not be able to enter. Seale explains that the Jain and the Banares demonstrate an
acceptance towards death (Seale, 1998, pp. 165-166). NVVE’s idea to control death by stop
eating and drinking can remind of to these two examples illustrated by Seal. By taking control
over their own body until it fails, the elderly people of the Dutch society and especially the
NVVE members, feel their death is autonomous and their own decision.

Ordering pills from China or Mexico:
The third autonomous route NVVE teach their member is how to order lethal pills from China
or Mexico. This is the most common used route among NVVE’s member and volunteers.
There are different types of pills one can order. Either the member orders a number of pills
that together constitute a lethal dose. Alternatively, they order Pentobarbital, which is used in
assisted suicide as well. As we can see in the first case from the introduction, it is necessary to
order anti-vomiting pills when ordering lethal pills, if not doing so this method might not
succeed. This process of ordering pills is called “collecting.” It takes time to order all the
pills, especially if there are a lot of them. Many of my informants stored the pills at home. By
having them in the house, my they felt some kind of security and control. The fact that they
could them when ready was reassuring. This method does not just attract the elders, but also
the younger members of NVVE. I heard of one case where a woman in her twenties planned
to die by this method. She had been abused as child and consequently was suffering
psychologically. My informant, Paul, advised and helped her through this process. Even
though ordering pills can seem as an easy task, there are several problems linked to this
method. The most common one is that the buyer never receives the ordered pills because they
have been confiscated by the Dutch custody or the web page where the pills were orders is a
fraud. Additionally, one can receive fake pills. When attending euthanasia 2016 the “right to
“die” organisation led by Dr Philip Nitschke, *Exit international*, sold special kits that had all the equipment necessary to test lethal pills ordered online. Daan an elderly retired man who works as a volunteer described to me the difficulties of ordering lethal pills from China or Mexico:

People who order pills from China or Mexico can be tricked. The pills are expensive and you don’t know the quality. Daan has ordered pills three times and have never received them. (Fieldnotes, May 2016)

Another difficulty with this method is that not everyone is able to use the internet. Especially the older generation can have problems, as this group is usually not used to the internet. Mia, who we now from the previous chapter explained:

Many of the members are old and not able to use the internet. This is a problem. However, the only thing that needs to be done is pressing the button where it says “order.” Someone else can do the rest. There is no way to control this, but there have to be guidelines. (Fieldnotes, April 2016)

Mia explains how a person, who is unable to use the internet, can still obtain the pills. Still, a family member or a volunteer ordering pills for another person, is considered to be in a legally grey area. One of the biggest concerns the volunteers expressed during their schooling day consisted of how “far they could go” when it comes to ordering pills for a member:

There are a lot of question on how much a consultant can do to help a member without getting into trouble. Floor says that one can help a lot. The most important factor is that it is legal. For example, that it is the member that presses the button. (Fieldnotes, April 2016)

Both Floor and Mia confirms that as long as the member is the one who press the ordering button, the volunteer has not done anything illegal. Mia mentions above that there has to be guidelines when helping members with this task. During the fieldwork, I never heard of any guidelines concerning this. The last problematic aspect of ordering pills from the internet is that it is an expensive project. Not everyone is able to afford the pills and especially not if it is necessary to order them several times.

**The plastic bag method:**

The *plastic bag method* can seem as the most drastic autonomous route. Growing up as small kids, we all learn that it is dangerous to put a plastic bag over the head. However, this method
is according to NVVE a good way to die autonomously, besides my informants claims the corps looks beautiful when dying by this method. Tim is an elderly retired man with a kind face and a soothing voice. He is the plastic bag method expert in NVVE. This means that he arranges courses for the other volunteers on how to perform this method. The volunteers can then teach it to the members who wishes to die by this route. Tim and I met at the NVVE office where he gave me a demonstration of the plastic bag method.

The most important factor in this method is to have strong and fast sleeping pills. You can find a list of good sleeping pills on NVVE’s webpage for members. Once you have the sleeping pills, you take them. Then you put on a cap and a facemask. The cap is to prevent the plastic bag to go into your face and the facemask is to prevent the plastic to go into your mouth. Then you put a plastic bag over your head. It is important to have a rubber band to put around the neck; it has to be tight, but not so tight that you cannot speak. Before you fall asleep, you hold the rubber band a little bit outside of your neck. When you fall asleep, your hand will lose the rubber band and it will seal the plastic bag. You will faint and then die after about ten minutes. (Fieldnotes, April 2016)

Tim stresses the importance of practicing this method. First and foremost, the member has to get used to wear the face mask, this can for example be done while watching TV. The member also needs to obtain the right kind of sleeping pills. This can be difficult because the doctor might be reluctant to prescribe fast and strong sleeping pills. Especially if the patient never had problems sleeping. Then, the member has to find others ways to obtain the pills. When everything is in order and the member has practiced the method several times, Tim holds a final exam. This is a way for Tim to know if the member is ready and everything will go smoothly during the act. Tim actually held this type of exam for a member at the NVVE office just before I met him.

Many of the volunteers are a bit reluctant to this method because they assume it to as drowning, but Tim underlines that it quite different. The member is able to breath and then falls asleep while the air is changing in the plastic bag. As mentioned above, one looks beautiful when dying this way. This is why, according to him, most women dies by this method. A person does not have to die alone when dying from the plastic bag method, but it is crucial for the member to write an explanatory letter, in this way the loved ones will not get in trouble. If dying alone, the person needs to arrange for someone to find the body, through for
example talking to the neighbours and agreeing on a sign. Tim has guided eight persons to die by the plastic bag method. He always sees the member before performing the method and Tim describe the atmosphere as calm and happy.

The pill of Drion:

*The Pill* or the pill of Drion as it also called is the first type of autonomous route I was introduced to. The first time I heard about it was at a conference organized for the members of NVVE in February 2016. At the end of the conference, the floor was open for questions; an elderly woman raised her hand:

She sounds angry when she speaks. Kaia whisper to me that the woman is asking for when NVVE is getting the Pill legalized. More people agree with her, they start to talk. The people seems impatient, they need the Pill. I can feel the desperation in their voice. (Fieldnotes, February 2016)

The pill of Drion was originally an idea by the Supreme Court judge and professor of civil law, Huib Drion. He wished there existed a suicide pill for people who are *tired of life* or feel that their life is completed. Inspired by Huib Drion, NVVE wishes to legalise a lethal pill for this group of people. The main idea with this pill is that one can take it without involving the doctor. Even though it is not legal yet, NVVE considers it as an autonomous route. “The pill exist, we just need it to be legal” was something I heard several times during the fieldwork.

NVVE distributes small boxes at every conferences. The box is white with NVVE´s logo and *Laastewil pil?* (Last will pill?) written on its lid. The box is filled with small mint pastilles that represent the pill.

Since *the Pill* is not legal in the Netherlands, NVVE´s former director Petra de Jong founded the corporation *laastste will* (last will) in 2013. The purpose of this corporation is to find a way to make, distribute, and legalise the pill. NVVE is a renowned organization in the Netherlands. Hence, they do not want to upset either their member or the rest of the Dutch community by making a controversial pill. I had the chance to meet the director of the corporation, Jos van Wijk:

Jos tells me about the pilot for the Pill. They do have a company who wants to make it and a pharmacist who wants to deliver it. They also have a safety box where the Pill will be stored. It will only be for the members in the beginning. He hopes to start the experiment within the year. Jos says that *the Pill WILL* happen. (Fieldnotes, May 2016)
While the corporation works with a pilot for the pill, the policy workers in NVVE have done the same. This pilot was presented to the volunteers during their schooling day in April:

Helena gives a lecture on the pilot for the Pill. They want a doctor involved in the process because this will make it easier to get it passed in the parliament. After the presentation, there are many questions. This is an engaging topic for the volunteers. They get hopes! (Fieldnotes, April 2016)

My informants did not like this pilot because is NVVE wants to include a doctor. If a doctor is involved, the pill will not be a part of the autonomous route. Another reason to why my informants did not like the pilot is that is only for people over 75 of age. My informant meant that there is no age limits to “feel tired of life” or the feel that one´s “life is completed.”

The idea of the pill is not the only a wish to be completely autonomous, but also a way to abandon the need to order lethal pills from the internet. As I have shown above, ordering pills online can cause several problems for the byer, where in the end, death might not be certain. People can be deceived, lose their money and receive fake pills, thus the pill is perceived as a safe option that will secure the user´s death. The pill awakened feelings of anger and engagement in NVVE’s members and it caused debates during conferences and meetings, people shouted at the director and at each other. The questions were consistent: When is the pill going to legal? Where is the pill? Why is it not legal yet? The pill is the ultimate autonomous route for NVVE. It is a dream of being able to control death without being dependent on loved ones or the doctor. My informants believes it as a person choice and right when and how to die. The pill can also be part of the social fabric for NVVE’s members, a necessary medical substance that will secure them a good health and a joyful old age.

The baby boom generation bring their values of self-determination, autonomy, and individualism into old age. As a result, the debate on how to determine when and how has emerged within the Western societies, these factors are associated with a good death (Wijngaarden et al., 2015). The autonomous route symbolizes some of these values, as self-determination and autonomy are the main objectives of this method. The quotes from Daan and Frank at the beginning of this chapter illustrate the necessity to be in control and be able to decide the manner and time of death.
THE AUTONOMOUS ROUTE AND THE VOLUNTEERS.

“My generation is coming now” Sophie, April 2016.

So far, I have demonstrated the different autonomous routes, in this section I will describe how the volunteers relate to this method. Not every volunteer is comfortable guiding people in the autonomous route. I spent time with volunteers who are active to promote the autonomous route, such as Tim and Paul and home consultants who were more reluctant to give advices on this route and therefore only referred the member to NVVE’s webpage or did not give advice at all.

The volunteers I talked to belongs to the baby boom generation and as I have mentioned in the introduction this generation stands for values such as individuality, identity and basing their social identity on professional achievement (Agich, 2003; Lyon, 2010). Frank and Daan claims that they should be able to end their life when they want. Eric says, “Life is an individual thing,” Paul state, “The people can take care of their own destiny (...) the aim of the ground law is freedom. I do not believe the government has the right to decide when and how we should die, this takes away the freedom.” Tim believes “the autonomous route is about taking my own decision. Do it myself and go through the doctor.” We can see here that the values of the baby boom generation influence the volunteers and this might affect their perception of death. Since they are the ones who meet and talk directly with the members, we have to ask whether the volunteers can influence the members somehow. Paul described what happened when he advised an elderly woman to choose the autonomous route:

Paul tells me another story of an old woman who wished to die. She was tired of life but did not want to include her three daughters in what she was thinking. She was afraid they would prevent her, as they were very smart and successful. A nephew ordered the poison from China. Everything went according to the plan and the woman died. Afterwards, the daughters were very angry with Paul, for not being included in the plan. (Fieldnotes, March 2016)

Paul guided this woman and her nephew through the autonomous route. His knowledge might have influenced her in choosing this death. This case also illustrates some of the issues I discussed in chapter one, where I showed the complex relationship between a home consultant and a member. Considering being old in Western societies is not highly estimated, the autonomous route can have a tendency to target the elders of the Dutch populations. As I specified in the introduction, old age is associated with several losses, such as the losses of the
self, loss of control and loss of autonomy and for many the loss of self-worth and identity. Hence, the volunteers facilitate and teach the autonomous route to the elders who might already be fragile and easy influenced, thus the home consultant can have an important role in the death of a member. The case I illustrated in the introduction shows this, since the volunteer gave the elderly woman anti-vomiting, which resulted in her death. Most of my informant agreed that they influenced the member’s perception of death, but most of them did not take responsibility for the member’s death method. The volunteer justify their action by saying they hinder suicide. In the next segment, we will see that my informants make a clear distinction between suicide and the autonomous route.

SUICIDE AND THE AUTONOMOUS ROUTE:

Emil Durkheim defines suicide as, “suicide is applied to all cases of death resulting directly or indirectly from a positive or negative act of the victim himself, which he knows will produce this result” (Durkheim & Simpson, 1952, p. 44). If using this definition, the autonomous route can be seen as suicide. However, my informants separate the act of suicide from dying by the autonomous route. The clearest example of this was when Paul said, “I work as a volunteer to prevent suicide.” Several of my informants got offended when I asked whether the autonomous route and suicide was the same act. Eva, a volunteer with a strict and confident appearance, was the first one introducing me to the concept of the autonomous route. We met for lunch in Eva´s hometown about one hour by train from Amsterdam.

Eva starts talking about the autonomous route, this is the first time I have heard of this concept. The autonomous route is basically to die without a doctor. Eva explains that the NVVE can help with this. They can teach people how to die with medication and how to take this medication or with a plastic bag. When I ask her if this classifies as suicide she gets strict with me. She explains that clearly suicide is done in a “flash” as for the autonomous way is a well thought action. (Fieldnotes, March 2016)

Mia, who I introduced in chapter one, explained the difference between suicide and the autonomous:

Mia explains that suicide is an impulsive act. It is also a way of killing oneself that is more aggressive for oneself and the people around you. The autonomous route is not an impulsive act; it is planned and well thought. (Fieldnotes, April 2016)
Both Mia and Eva describe suicide as an impulsive act where the person does not think about the loved ones left behind. The autonomous route on the other hand is a well thought and planned action. Ordering pills from China or Mexico and waiting for them, practicing the plastic bag method or waiting to starve to death are all methods that takes time and planning, thus the autonomous route can be a process leading to death. My informants on the other hand describe suicide as an abrupt act. Still, the wish to not live anymore and act on this wish can require planning and thinking. For example, people who commit suicide tend to leave a letter or a note to the loved ones. Or, the person needs to get the equipment necessary to commit suicide. If taken this into consideration, suicide can also be a process. So, why are my informants reluctant to see the similarities between suicide and the autonomous route? One way of understanding this is to investigate some of the history behind the word suicide. For many, suicide is a taboo, as it is associated with feeling of shame and exclusion, which can be rooted in religion. The Netherlands is a country billed on Christian values where all life is sacred. Even though my informants are not religious, the Christian view on suicide can unconsciously be a part of their moral. It is necessary to look back in history, to be able to understand why suicide still is taboo. Van Gennep (Gennep, 1960) presents four categories of believes occurring when a person commits suicide. Here, I will focus on the categories three and four, as they are the most relevant. Van Gennep claims “the person who has committed suicide cannot be incorporated with the other dead and must wander between the two worlds of the dead and that of the living (...)suicide is punished in the next world ” (Gennep, 1960, p. 161). This means that the person who commits suicide will not be buried with the other dead, thus in the Christian sense, outside of the cemetery. The dead does not lay in consecrated earth, which means he will not be “saved” and sent to paradise. Additionally, suicide was perceived as a crime, which casted shame on the remaining family. Even though these believes can be considered to be outdated, the old ideas on suicide has left traces in peoples mind. This can be an explanation to why my informants are reluctant to see the similarities between suicide and the autonomous route.

Further, it is fruitful to explore at the meaning behind the word suicide to understand my informant’s point of view considering suicide and the autonomous route. The Dutch word for suicide is zelfmoord, which means to murder oneself. Murder is associated with criminality and is seen as a horrible act. Ludek Broz believes when thinking of suicide as murder, the victim, and the murder becomes the same person. Furthermore, Broz argues that by linking

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7 (Boissevain & Verrips, 1989)
murder to suicide, the person who commits suicide will be blamed at the same level as a murderer who takes a life (Broz, 2015, p. 97). NVVE does not want to be associated as an organization who helps people to commit suicide, thus to be able to help their member they have invented a new concept, the autonomous route. The word *suicide* has a different meaning and identity than the term *autonomy*, as the latter is associated with freedom, independency, and control, which tends to be valuable for the baby boom generation. When inventing a new concept associated with highly estimated values, NVVE legitimise both their role and the members act and by doing so, NVVE reshape the meaning of killing oneself.

So far, I have discussed why my informants make a distinction between suicide and the autonomous route. Nevertheless, other factors distinguish suicide from the autonomous route. Albeit, the autonomous route is to kill oneself, but according to my informants it is done differently than with suicide. My informants often characterize suicide as jumping off or in front of, for example a building or a train. I attended a conference organised for the younger members of NVVE, in addition to being open for people who felt curious about the organisation. Here I met a young man who opened up to me:

> I stared conversing with a young man, he was not a member of NVVE, but was curious. His girlfriend had just committed suicide a few months earlier by jumping in front of a train. She had been mentally ill for a long time and had several suicide attempts behind her. The young man wished she had died from euthanasia, so she could have said goodbye to her family and friends. He emphasised several times that he wished she did not have to die alone. (Fieldnotes, February 2016)

This young man’s story can make us understand the value of the autonomous route. If his girlfriend had chosen to die by this method, she would most likely not died alone, meaning she could have been able to say goodbye to her loved ones. The young man would probably not be as traumatised by her death, which can lead to a burdensome grieving process. The autonomous route is then a way to die that tends to be easier for both the person who commits suicide, but also for the people left behind. Finding the corps of someone who has committed suicide can also be birdsome. During *euthanasia 2016*, NVVE screened the documentary “Mothers don’t jump from buildings” (Lindemans, 2013). The film focus is the debate on whether people suffering from a psychiatric illness should be able to receive assisted dying, but it is as relevant for this discussion as well. Elena Lindemans, whose mother suffered from psychiatric illness, make the documentary. Hers mother euthanasia request was declined in
2002 and as a result, she committed suicide by jumping from a tall apartment building. In the documentary, Lindemans goes back to the apartment and talk to the people who saw her mother jump into death. The documentary shows that the death affected many people, from those who saw her jump, to the individuals who looked out the window, to the persons who were in the backyard and to the genitor who had to wash away the blood. If a suicide is done publically, it can affect the people who see the act. The autonomous route on the other hand, is not done in public, as it tends to happen behind closed doors. When seeing the suicide from the perspective of the ones left behind, it can seem that the autonomous route can be a better solution. The loved once have a chance to say goodbye, the person who commits suicide do not have to die alone and the death might not influence arbitrary bystanders. The autonomous route can then be seen as a considerate death. Previously in this chapter I discussed that suicide is associated with shame and taboo, and this might be a factor to why my informants distinguish between the autonomous route and suicide. The girlfriend and the mother from the two cases above might have felt shame and despair when committing suicide. When dying by the autonomous route, the member might not feel this way because a volunteer, NVVE and loved ones legitimises the death. A member who chose to die by the autonomous route, experience a death that is “up in the open” and talked about, thus the opposite of taboo, mentionable.

The autonomous route can classify as suicide if using Durkheim´s definition. Nevertheless, as we have seen, suicide is associated with several negative factors, so in order for everyone who wish to die a dignified \(^8\) death, NVVE has invented the autonomous route, which is not just a considerate death towards loved ones, but also towards oneself.

**DURKHEIM´S THREE FORMS OF SUICIDE:**

I have shown that my informants make a clear distinction between suicide and the autonomous route. In this part, I will discuss the similarities between the autonomous route and Durkheim´s three types of suicide.

The first type of suicide is *egoistic suicide*. This type of suicide is committed when person does not feel integrated in the society (Durkheim, 1951[1897]; Norwood, 2009, p. 75). People who choose the autonomous are often elders who feel *tired of life*. These people tends to feel lonely and distant from not only other people, but also the community (Wijngaarden et al., 2015, pp. 1,4). In addition, elders can experience the feeling of being segregated from the

\(^8\) I will discuss dignity in chapter four.
society, either by living in a nursing home or living at home but not being part of the community (Agich, 2003; Allison, 2016; Seale, 1998). As I have discussed in the introduction, the baby boom generation are the ones who advocated the social, political and economic systems we know today (Aging, 2017; Lyon, 2010), so by not being able to contribute when approaching the forth age, they might be left with a feeling of not having a place in the society. Eva consulted an old man who chooses to die by the autonomous route:

I counselled a 90-year old homosexual man. He was depressed and tired of life. He did not have any family. I advised him to order medication from China. A friend helped him and he got the medication in the mail. He had in the house for a couple of weeks until he was ready to take it. (Fieldnotes, March 2016)

This man felt lonely and depressed, in addition to being tired of life. Because of these feelings, he wished to end his life. As a member of NVVE, he was provided with guidance in the autonomous route. This case can be seen as the same thing as egoistic suicide because the elderly man did not feel integrated into the society. However, NVVE would not classify this as suicide because it was a well-planned and well-thought act. In addition, my informants would claim that it differs from suicide because the act was done openly. If taking into consideration that it is the thought behind the act that defines if it was suicide or not, this would classify as a suicide. The man wished to die because he did not feel part of the society, thus swallowed the pills on purpose, and died consequently. As such, this fits well with what Durkheim conceived as an egoistic suicide.

The second suicide type is altruistic suicide. This type of suicide happens when a person is over-integrated in the society (Durkheim, 1951[1897]; Norwood, 2009, p. 75). This means that the person cares about the society’s norms and goals so much that he completely neglect his own needs and goals, thus he takes his life for a cause. The baby boomers way of thinking on independence, control, and autonomy has helped to shape the contemporary Western societies. When becoming old some of these characteristics might disappear and might affect how they perceive themselves, which can be difficult to handle for this generation. Not just because those are highly valuated values, but also because one might feel like a burden to the society and loved ones. These factors might lead some to choose the autonomous route and then a way for the elders in the fourth age to die before becoming dependent and feeling like a burden. Hence, we can recognise the similarities between autonomous route and altruistic
suicide, since both of the deaths happens when the person think of the society’s needs and goals

The third type of suicide is anomic suicide. A person commits this type of suicide when social regulation are not functioning properly (Durkheim, 1951[1897]; Norwood, 2009, p. 75). This type of suicide happens when the society is under a lot of change or stress. A person committing anomic suicide will do it because of a crisis. The suicide will then be an abrupt act that not well thought about. The autonomous is the opposite of this, as it is a well-thought and well-planned act. Hence, the autonomous route cannot be classified anomic suicide.

IS THE AUTONOMOUS ROUTE AUTONOMOUS?

My informants argue that individuals control their own life and therefore should be able to control their own death. Hence, the doctor should not have an influence on when a person can die or not. However, how autonomous is the autonomous route? The members who chose to die by the autonomous route are autonomous in the Kantian tradition because they are not under the governments or the doctor’s control. However, the volunteer must guide the member in order for him to die by this method. If seeing it from this perspective, the member is then dependent on the volunteer. In addition, the member relies on help if not being able to manage the internet. In the case from the introduction, we can assume that the elderly woman would not have died if it had not been for the anti-vomiting the volunteer gave her. Hence, the volunteer can influence the member, but dying is still experienced as the member’s choice.

Räikkä and Varelius (2013) believe it is necessary to look at the reasons behind a person’s choice. Can a choice be completely autonomous if someone or something has affected it? Räikkä and Varelius argue that a choice is not autonomous when it is affected by additional circumstances. They refer to this concept as “adaptive preferences” (Räikkä & Varelius, 2013). Elders in the Western societies can have a feeling of not mattering, dependency and experiencing ageism; additionally, old age is viewed as a disease (Das, 1990). If choosing the autonomous route because of prejudice against old age, the choice can be defined as adaptive preference. James Taylor (2013) believes we have to link self-deception to autonomy. When becoming old and feel that the body fails, one is likely to have a feeling of self-deception. If a person is diagnosed with dementia, the person might be afraid of not only losing the self, but also be bereaved of the control and the autonomy. This feeling of self-deception can lead to choosing the autonomous route.
The autonomous route can both be seen as autonomous and not. A member dies a autonomous death when choosing the autonomous route because she chooses the time and place of the death, the feeling of being in control and not under the doctors influence straightens the feeling of autonomy. On the other hand, the member is not just dependent on the volunteer to be able to die be the autonomous route, but also on loved ones if not able to use the internet, thus the autonomous route seems to be more as the helper’s route. In addition, we have to consider the reason behind the choice. If a person wish to die because of old age and the disabilities connected to it. It will not be a free choice, but a choice based on the circumstances. Considering this, the member is not autonomous.

In this chapter, I have demonstrated how my informants differentiate the autonomous route from suicide. Suicide is seen as an abrupt act where the person does not think of the ones left behind. The autonomous route on the other hand, is a well-planned and well-thought act, to which the relatives are prepared for. I have argued that people choosing the autonomous route do not only do it for themselves, but also for the people left behind. In this sense, the autonomous route can be seen as a considerate death. I have also argued elders might chose to die by the autonomous route because they do not feel part of the society and feel like a burden to loved ones and because of this, the autonomous route can be seen as an egoistic suicide and an altruistic suicide. Additionally, I have discussed whether the autonomous route is autonomous. The members can be influences by the volunteers, their own self-perception, and external circumstances, which can lead them to choose autonomous route. On the other hand, the member chooses the time and manner of death. If using Agich (2003) definition of autonomy, the autonomous route will be autonomous because the member feel independence, self-determination and is able to make a rational and free decision. NVVE has made an option for a dignified death for those who cannot receive assisted dying, a death that is chosen, but which is more considerate to those left behind. The member might be autonomous from the government and the doctor, but not from NVVE.

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9 From the introduction
10 I will discuss this in chapter four.
CHAPTER 3: A NEW SOCIETY EMERGING

In this chapter, I will first discuss, with the help of Arnold van Gennep, if the autonomous route can function as a new form of death ritual. Further, I ask whether the autonomous route may be perceived as a sacrifice, where the people who are tired of life and feel like a burden sacrifice themselves (to death) for the family and society. Then, I will discuss the concept of feeling like a burden in old age and if the autonomous route and assisted suicide can reinforce this feeling. In the last section of this chapter, I explore if assisted dying and the autonomous route can lead to a sorting society, where the goal is to sort out the ones who do not “fit in”.

THE AUTONOMOUS ROUTE AS A RITUAL:

Emil Durkheim (1912) and Radcliff- Brown (1933) argues that ritual reinforce the collective feeling and social integration. Keesing and Strathern (1998) argues that a ritual is, “individual concerns are systematically related to public concerns; collectively enacted dramas have private and unconscious meanings” (p. 319). This means that rituals can be a way to transform what is understood to be a social necessity into something personal desirable. A ritual can also be a manner for people to communicate with each other “in different aspects of their social structure” (Leach, 1954; Parkin, 2015, p. 717). It might be fruitful to discuss whether the autonomous route can be perceived as new a form of death ritual, as this can help to understand some of the social changes, which is happening within the Western societies.

The autonomous route as a rite of passage:

Arnold van Gennep claims that rites of passage symbolise a change of status in the human life cycle. This can for example be birth, puberty, marriage, or death (Gennep, 1960, p. 718; Parkin, 2015). Further, he state there are three phases of a rite where the first one is separation, the person has to separate herself from the community that she is a member of. The second phase is liminality, when being in the liminal phase, the person who performs the rite is not regarded as a member of the community and as a result, she is perceived as an outsider. The transition from one status to another takes place during this phase. The third and last phase is incorporation. This is where the participant is reincorporated into the society (Gennep, 1960, p. 718; Parkin, 2015).

Is it possible that old age can be the first stage of a rite of passage, where the elder’s feels separated from the Dutch community? As I have mentioned several times before, many elders...
in the *fourth age* tend to feel lonely, like a burden, and insignificant which can segregated them from the rest of the society. A member of NVVE who have these feelings might contact the organisation, which leads to the second phase of the ritual, *liminality*. Elders in the *fourth age* tends to wait for death, this waiting can be seen as a liminal phase. A member who gets information and guidance in the autonomous route can feel that the liminal phase is intensified. The *plastic bag method* needs to be learned and practised; lethal pills from China or Mexico needs to be ordered and expected; stop eating and drinking leads to a stage of feeling feeble. All these stages, where the member is waiting for a death and knows it will occur, can intensify the liminal phase. When death is evident, the member can move to the last phase of the rites, *incorporation*. An old person in the *fourth age* can be reincorporated to the society by dying a death that is socially accepted. A member choosing the autonomous route, prove her independence, autonomy and the ability to be in control, which is an essential to the Western societies. Through the autonomous route, the member takes back these essentialities, thus when dead is reincorporated into society.

The autonomous route can be perceived as a social necessity, where the member chooses to die before becoming a burden. On the other hand, it can also transform into a personal desire, where the members need to control death is a way to preserve personal dignity. Hence, the need to die before reaching the *fourth age* has contributed to the emergence of a new death ritual in the Netherlands. A ritual that communicates the person autonomy, independence, and control over own body and life.

**The autonomous route as a sacrifice:**

*Voluntary death* is a Siberian practise, where the relatives grant the wish of an elderly ill family member who express a wish to die (Willerslev, 2009, p. 693). Rane Willerslev argues that *voluntary death* can be a form of sacrifice. Furthermore, he explains there is a distinction between suicide and *voluntary death* among indigenous groups. A suicide is an individual performed event with no definite rules, thus it is not ritualised. But when dying a *voluntary death* there are a number of ritual arrangements. Willerslev describes that suicide among the indigenous groups is as a sign of character weakness. *Voluntary death* on the other hand is a highly praiseworthy death (Willerslev, 2009, pp. 693-698).

There are similarities between the autonomous route and the practise of *voluntary death* in Siberia. Being in the *fourth age* can leads some members of NVVE to die by the autonomous
route, and just as voluntary death, the NVVE members will experience this death as a respected form of dying.

Voluntary death is a ritual blood sacrifice (...): it is a means of exchanging soul-stuff with deceased ancestors in accordance with how such exchange ought to be done, which stands in conscious contrast to how it is usually done: Through the killing of a domestic animal or other surrogate for the “real thing”. As such, voluntary death represent I argue, nothing less than the optimal and therefore rarely realized sacrifice. (Willerslev, 2009, p. 694)

Willerslev argues that the optimal sacrifice toward the deceased ancestors is a person committing a voluntary death. While, people choosing the autonomous route sacrifice themselves to the society and the loved ones. By doing so, the person will die a dignified death according to the society and therefor accomplish a socially accepted death. In the previous chapter, I argued that there are similarities between altruistic suicide and the autonomous route, where the fear of being a burden is stronger than the will to live. There is a resemblance between altruistic suicide and sacrifice, as both happens when a citizens dies in order to not become a hindrance to relatives or the society. Furthermore, Willerslev (2009) argues that it is substitution that defines what an act can be considered to be a sacrifices, “[sacrifice is] essentially a game of displacement and replacement, in that the sacrifice of a thing is a surrogate act for the ultimate paradigm underlying all sacrifices, the sacrifice of oneself” (Willerslev, 2009, p. 700). According to Willerslev, sacrifice is an act of replacement, where it is a way to replace a thing with something else, a sort of exchange. The people choosing to die by the autonomous route will substitute their “undignified life” with a good and dignified death. The prosperity of living a life with no independence, control, autonomy in addition to feeling like a burden and losing oneself can make some members of NVVE choose death, thus sacrifice themselves.

FEELING LIKE A BURDEN IN OLD AGE:

“It’s nice to want to be old, not be old” Daan, May 2016.

In the previous section I argued that the autonomous route can be a new form of ritual that originate from the way the Western societies perceive old age and dying. In addition, I have discussed whether the autonomous route is a form of sacrifice, where the intention is to die in order not to become a burden. In this part, I will discuss whether the autonomous route and assisted dying can lead some elders to feel like a burden.
New technologies and medicalisation of the body has contributed to an increasing aging population. According to Sharon Kaufman, we have not thought about the consequences of having a population that will live longer (Kaufman, 2006). By making people older, the Western societies have created a group of leftovers she calls social waste, she describe these people as the ones who no longer fit into the society (Allison, 2016, p. 665). The Dutch healthcare system has gone through some changes over the last six years. It has been argued that the elders suffered when the left-wing was replaced by the right-wing. The consequences of these changes that made an impact on the collectively funded long-term care and nursing homes, as the institutions are being closed to save money (Anthea Tinker, 2013, p. i). Many elders are being forced to move out of the nursing homes because of cut in governmental funding’s (DutchNews.nl, 2013). This has made elders more dependent on loved ones and their neighbours. Many elders in Western countries live their final stage of life in a nursing home, or are being taken care of by their family, thus it seems to be a general feeling that people who need care feel like a burden (C. McPherson, K. Wilson, & M. Murray, 2007, p. 115).

Agich argues that societies who values productivity and material wealth over other values focus in general more on the youthful population. A consequence of this is the elders might see themselves as old-fashioned and unnecessary (Agich, 2003, p. 56). Elders who live alone are or will become dependent and this might impair the persons membership to the community (Seale, 1998, p. 152). The participants in van Wijngaarden et al. (2015) study, saw themselves as disposable, unnecessary and unimportant to loved ones and the society, this made them feel useless and marginalised (p. 5). Elders tends to be excluded from essential cultural and social events, this can make this group have trouble to be a part of normal social participation (Agich, 2003, p. 54; Seale, 1998, pp. 150-151). The elderly citizens can feel isolated from the rest of the society when living in a nursing home (Agich, 2003, p. 52). Hence, by not being a part of the social participation as well as feeling segregated from the society, elders can have a feeling of not belonging. As I have shown throughout this thesis, the baby boom generation is responsible for the new population of elders. Self- reliance, self-independence, self-sustainability and selfness itself are values this generation have shaped (Allison, 2016, p. 669). Most of the baby boomers have lived their entire life as full and active members of the society. They tend to base identity on their social and economic contribution. Hence, by not being able to contribute socially and economically
and feel as *social waste* (Allison, 2016), this generation might feel they have lost grip on the world and have therefore feel as an outsiders (Wijngaarden et al., 2015, p. 5).

To feel needed and valuable are important factors to a person, especially in old age (Agich, 2003, p. 53; Allison, 2016, p. 665). Many find it necessary to find something meaningful to do with their spare time when reaching retirement age. A way to feel useful when reaching the *third age* is for example volunteering work. The volunteers in NVVE told me they started volunteering when entering retirement age because they need to something with all their spare time. However, when reaching the *fourth age*, the aging body can become a hinder. Van Wijngaarden et al. (2015) show through their study that the participants do not wish to feel as *a hindrance* to their children (p. 4). When a person feels as a hinder to loved ones, she might also feel as burden. A parent becoming old can feel in the way of their children’s everyday life. In addition, the offspring will have to adjust to their old parent’s needs. The wish not to bother one’s own children was something I discussed with my informants. Paul said “*I do not wish my children to take care of me, I don’t want to bother them*”. Jane Andreasen et al. (2015), argues that becoming ill and dependent on loved ones can be stressful. The sensation of anxiety and guilt can lead to feeling like a burden to family and friends (p. 6). In McPherson et al. (2007) study, the participants felt they put on extra stress of their family members who already had their hands full with both childcare and work commitment. In addition, the participants did not like needing help from others as this meant they had lost control and their former self as strong independent people. These factors made the participants feel like a burden (pp. 420, 422). To be helped by loved ones is no longer seen as a positive matter, it is rather a feeling that one is creating trouble for the people around (C. J. McPherson et al., 2007, p. 424).

Can the feeling of being a burden lead some elders in the Netherlands choose to die by the autonomous route? Several research has concluded that feeling like a burden is associated with the wish to hastened death (C. J. McPherson et al., 2007, p. 418). Cicely Saunders (1992) argues that fear of old age, brain failure and helplessness has led to a gradual pressure to get euthanasia legalised. Even though assisted dying is legal in the Netherlands, it is not legal to receive it only based on old age. My informants expressed their fear of being old and incapacitated. As we know, being *tired of life* is a Dutch phenomenon, which is often used on the elders who has reached the *fourth age*. The participants in van Wijngaarden et al. (2015)

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11 (Brouns, Beer, & Ganzini, 2004; Ganzini, Silveira, & Johnston, 2002; Amy D. Sullivan, Hedberg, & Fleming, 2000; A. D. Sullivan, Hedberg, & Hopkins, 2001)
study expressed they felt lesser and lesser involved in life and therefor had a desire to end their life. This can be seen as a form of escaping life, where death is the only way out (p. 6). There can be consequences of inventing a new term, as it can lead some to become tired of life and an anticipation towards the elders that they will at some point feel tired of life. The patient choice and autonomy are the main arguments to legalise assisted dying (Saunders, 1992, p. 4). To be able to choose and be autonomous are main factors to why my informants give guidance in the autonomous route. Furthermore, Saunders claims there is a lot of pressure on the hospitals and nursing homes, little or no support for elders living a home and generally an indifference and negativity toward elders. As I have mentioned above, many of the Dutch nursing homes are being closed and relatives and neighbours are expected to take care of the elders. This can reinforce the feeling of being a burden since many elders in the fourth age don not want to bother their children. Saunders (1992) argues that when legalising assisted dying, it will not take a lot of time before voluntary euthanasia goes from voluntary to not voluntary. She questions whether a society that allows assisted dying will apply some sort of pressure on dependent people and make them feel like a burden. The due care criteria are, as I explained in the introduction, meant for people who have unbearable suffering, but the Dutch government is opening up for those who are tired of life to be able to receive assisted dying. NVVE have already given this option to this group of people. This might make the members more aware of their age and its disabilities, thus it can reinforce the feeling of being a burden. Furthermore, Saunders argues that the elders and suffering will feel responsible to hasten their death or beg the medical personnel to help them die (p. 4). When I asked my informants if they had an influence on a members death, most of them said yes. Paul said, “When a member needs to talk and hear options on dying, I get a closer relationship. Especially if the client do it [die by the autonomous route] himself with my advisement, then I feel more responsible”. The NVVE guide those who wish to die and by doing so, they might be responsible for the death of their members.

By legalising a “right to die”, many vulnerable people can feel a “duty to die” (Saunders, 1992). When creating the autonomous route, NVVE has legitimised a death for the people who feel like a burden. This feeling of being a burden can lead some of NVVE’s members feel a duty to choose death. Hence, by making an option for those who is not able to receive

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12 I will discuss this below.
assisted dying, the NVVE can be a contributor to why elders feels like a burden, which can lead them to hasten death.

THE NEW SOCIETY:

So far, I have argued that the feeling of being a burden in old age can lead some elders to die by the autonomous route. In this section, I wish to investigate from a biopolitical perspective whether assisted suicide and the autonomous route can lead to a sorting society. In order to this, it is necessary first to describe the biopolitical regime.

Biopolitic has been a part of the Western societies since the 18th century. Nikolas Rose defines biopolitic as, “political authorities, in alliance with many others, have taken on the task of the management of life in the name of the well-being of the population as a vital order and each of its living subjects” (Rose, 2001, p. 1). Through biopolitic, the state shapes human body and by doing so, the individuals change the way they look at normality and abnormality (Foucault, 1977; Higgs et al., 2009, p. 692). Contemporary politics focus on the fundamental parts of being human, “the size and quality of the population; reproduction and human existence; conjugal, parental and familial relations; health an disease; birth and death” (Rose, 2001, p. 1). A way for the political authorities to shape the citizens body in today’s societies is through what Armstrong (1995) identify as surveillance medicine (p. 395). By monitoring the body through regular health checks and screening, the regime control the body. As a result, public health campaigns are made, to control and encourage good health practices (Higgs et al., 2009, p. 692). Biopolitic supports the new techniques within the medical world, technologies, experts and new apparatuses (Rose, 2001, p. 1). These new factors have made it possible to monitor and control the human body and consequently the body has become one of the most essential site for ethical judgment and techniques (Rose, 2001, p. 21). These new technological practises will be a contributor how we judge human worth. We can for example see this in the euthanasia debates or termination of a new-born with a severe disease (p. 21). However, Rose argues that we also have to look at the everyday practises to be able to see how humans judge the quality of life. Rose exemplify this by pointing to inconvenient genetic testing or doctors who carelessly prescribe anti-depressants to their patient (p. 22). There are different ways of being human, all humans are composed differently, and with biomedical techniques, we are in a position to decide the worth of different human lives. This means that our present and future depends on the quality of our individual biological lives and with whom we identify. As a result, we are in the position of making choices and decision based on our own judgment.
Expanding the law:
The Netherlands legalised assisted dying in 2002 because doctors wished to help their suffering terminal patients to die. However, as I have explained in chapter one, many people in the Netherlands wish to receive euthanasia, but is not able to because not meeting the due care criteria. The people who feel tired of life and people diagnosed with dementia are the two main groups who wish to be able to receive assisted dying. This means that by making a law that let some benefit from it and others not, people may feel discriminated (Schuklenk & Vathorst, 2015). Old age has moved from something that is a normal part of life to become abnormal. Consequently, the Dutch government is currently considering changing the law on assisted dying when it comes to the people who are tired of life. The health and justice ministers stated in October 2016: “[Those who] have a well-considered opinion that their life is complete, must, under strict and careful criteria, be allowed to finish that life in a manner dignified for them, ” (Forster, 2016). In addition, health minister Edith Schippers informed “because the wish for a self-chosen end of life primarily occurs in the elderly, the new system will be limited to them”(Forster, 2016). Instead of reassuring that, the elders are welcomed and a part of the society, the Dutch government wish to change the law on assisted dying. We must not forget that same government has closed many of the nursing homes. This can be a contributor to why the elders do not feel prioritised and therefor wish not to be a part of the society anymore. In addition they might become dependent on their family, thus feel like a burden. Another consequence of the biomedical regime is through surveillance medicine. When the aging body in continually monitored, the elders will constantly be reminded of their health situation. With the help of new technologies, experts and apparatuses, the aging body is constantly judged and this judgment tend to lead people the experience of being old is not a worthy way of living.

The other group of people who was not included when the law permitted a doctor to take life was the people diagnosed with dementia. Dementia is a difficult disease because the patients mind will slowly drift away. The criterions to receive assisted dying are clear, the patient must state a well-informed request voluntary; the doctor and the patient must have concluded mutually that there is no other reasonable solution for the patient; Euthanasia must be conducted with great care (NVVE, 2016c, p. 11). All of these criterions are difficult to meet for a patient with dementia. Even though the people diagnosed with dementia feel unbearable pain, the doctors are reluctant to perform euthanasia because the criterions are not met. Because of the Dutch citizens discontent and the doctors uncertainty the Dutch government
have loosen some of the criterions concerning dementia. In January 2016, the Dutch justice and health ministers proclaimed that “the guideline for performing euthanasia on people with severe dementia have been relaxed a little so that patients can be helped to die even if they are incapable of making their current feelings known” (DutchNews.nl, 2016; Netherlands, 2017). The Dutch government have made it clear that a person with dementia can receive euthanasia if having written request before the dementia has become too progressive. Hence, even though the person is not able express his own will by words or gestures, the doctor can help the person die (DutchNews.nl, 2016). Dementia is a common diagnose to receive when reaching old age, especially since people in Western societies are growing older and older (Kaufman et al., 2004). This is a result of the biomedicalisation of the human body, as technics, medical experts and apparatus is an essential factor the increasing age among elders. Nevertheless, these techniques lead to a new way of perceiving human worth. Hence, dementia is perceived as an abnormality and something that is viewed as outside of the normal body and contemplated as an unworthy life.

A sorting society:
So far, I have argued that biopolitical regimes considers dementia and old age as an abnormality and as consequence, believes it is an unworthy life. I will now discuss if these assumptions can lead to what is denoted as a sorting society. The Dutch government is discussing whether they should legalise assisted dying for the people who feel tired of life. Elders tends to be considered a vulnerable group, they are often exposed to ageism and have a tendency to be neglected by the society and loved ones. The question is whether the discussion on assisted dying for this group can signalise that they are not welcomed by the society. To consider that elders should be able to receive assisted dying, can effect, and influence not only how they perceive themselves, but also how the societies see them. We can see some of the similarities in the ongoing debate in Norway on whether parents should be able to sort out children born with a disability, as they do not fit into what the society considers as normal or wanted. Some considers these children do not live a worthy life and therefore should not have the right to live. I am especially referring to Aksel Braanen Sterri’s article where he assumes that children born with Down syndrome cannot live a happy and meaningful life (Sørvig, 2017). His assumptions and the debate may lead some to choose to abort a child with a disability. Just as the current discussion on assisted dying in the Netherlands, the debate signalise that children who do not fit into what is considered as normal are not desired citizens. The ongoing discussion in the Netherlands may lead some
elders to feel like a burden because it reinforces their assumptions of not being desirable citizens. Hence, it is not only by putting this law into action that might signalise that the society do not desire these citizens, but also the actual discussion.

Aging and dying is associated with the loss of the self where the loss of the mind is especially feared by the elders, as it is difficult to maintain social bonds (Seale, 1998, pp. 150-151). Being diagnosed with dementia is according to my informants the worst thing that could happen to them. Eric expressed this to me:

Dementia is the worst that could happen to me (Eric) because I will lose control. I hope the doctors will not have a choice but to accept that people with dementia should be euthanized. There is only a matter of time. The medical world is always moving, people get older and older and with this comes dementia. The doctors will sooner or later be positive to euthanizing demented people. (Fieldnotes, April 2016)

Eric’s statement shows some of the fear and prejudice the volunteers have against dementia. The Dutch and international press have been filled with a Dutch dementia case. An elderly woman diagnosed with dementia was held down while receiving euthanasia. The woman made a euthanasia request before becoming too ill. Her written request stated that she wanted euthanasia when the time was right. The woman moved into a nursing home and after living there for a while, the doctor decided the time was right. The doctor secretly slipped sleeping pills into the woman’s coffee, so she would be a sleep while performing euthanasia. Unfortunately, the woman woke up and was confused. The relative had to hold her down, so the doctor could give her the euthanasia. The Regional Review Committee cleared the doctor. However, her case is up for trial in the Dutch courts (DutchNews.nl, 2017; Newton, 2017; Roberts, 2017). It can seem that the woman wished to die before becoming too ill, but then did not want to die once the dementia was too progressive. The doctor did everything to honour her wish, but ended up doing the opposite. This case demonstrates some of the negative consequences of changing the due care criteria, so people with dementia can receive assisted dying. The prejudice and fear against dementia as well as loosening the guidelines on dementia can influence people to ask assisted dying and the doctor’s willingness to perform it.

The biopolitical regimes and its technologies, experts and apparatuses can change the way we look at the most fundamental parts of being human. The perception of birth, life, and death is considered according to who has a worthy life or not. The emergence of these new technologies, experts, and apparatuses can lead to a sorting society, were only a certain type
of people are welcomed. Norway’s former minister of health Dagfinn Høybråten defines *sorting society* the following way:

> With the concept of a “sorting society”, we think of a society where one sorts out and chose away something that is not in line with what society refers to as *normal* or *wanted*. With the help of techniques such as preimplantation diagnosis, one can sort out fertilised eggs that do not have the wanted genetic attributes. (...) This will lead to a society we do not want, that signalise we do not have room for everyone…the fight against the sorting society will be a fight for human worth and a fight for the right to be different. (Melhuus, 2012, p. 37)

Høybråten base his definition on genetic testing and amniocentesis as way to sort out the individuals who does not fit into a *normal* society. By doing so, there is a change in how we perceive individuals place in the society and which life is considered worthy. To become a *sorting society* means to become a society that is less tolerant to people with physical difference, to people with disability and to weakness (Melhuus, 2012, p. 43). When a society legalise prenatal diagnosis, the society will sort out the foetus with “undesirable genetic trait” (Melhuus, 2012, p. 33). Can we say the same about a society that legalise assisted dying for people with dementia and elders who feel *tired of life*?

Technology will form a gap between nature and culture (Eriksen, 1993; Melhuus, 2012, p. 35). This means the technology will change what originally is considered as natural into being perceived, in some cultures, as abnormal. Veena Das (1990) argues that old age is seen as a disease (p. 33). If we treat old age as a disease, then the only “cure” is death. Perceiving old age as an illness, where the “cure” is death, can lead to a *sorting society*. Can we consider the autonomous route as “cure” for old age? As we know, the autonomous route is primarily for people who feel *tired of life*. Through the autonomous route, NVVE legitimise and justify the wish to die for the elders in the *fourth age*. Hence, we can consider the autonomous route as “cure” for old age. In this sense, NVVE might function as contributor to a *sorting society* who sorts out the elderly. Eric said above that people are growing older and older and consequently there will be more cases of dementia. The fact that people are becoming older, that dementia is a consequence of old age, and the large number of elderly can be a contributor to why the *due care criteria* in the Netherlands has changed. Dementia causes a lot of fear because it tends threatens peoples identity, independence, autonomy and control,

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13 My translation.
which tends to be important factors for the baby boom generation. The worry of losing these factors, attitudes against dementia in addition to changing the due care criteria can indicate the beginning of a society that will sort out the people with dementia. Even though there is a lot of research done on dementia, there has to be more studies on how to take care of this group of people in the best ways possible. A lot has already been done in this department, for example “healing gardens\textsuperscript{14}” and own communities for people with dementia\textsuperscript{15}. I believe the solution is not to “euthanize” these people, but find ways to make them feel safe and cared for. Nevertheless, the most significant change must take place within the Western perception of old age, where having dementia is associated with being a burden and shameful behaviour.

Biomedicalisation makes humans become older and older. However, the paradox of wanting to become old, but not be old change the way we relate to old age and dying. In this, chapter I have argued that the autonomous route is a consequence of the perception of old age and can therefor as a new form of death ritual. I addition, I have argued that since the autonomous route is a ritual, it can ultimately be seen as a sacrifice where the elders sacrifice themselves in order to become a burden. I have showed that biomedical regimes defines what is considered an normal or abnormal human, and this effects how old age and dementia is perceived as well as what it means to live a worthy life. What we considers as normal influence the way we look at old age and dementia and this can ultimately lead to a sorting society.

\textsuperscript{14} Sanse hage in Norwegian
\textsuperscript{15} See: http://dementiavillage.com/
CHAPTER 4: CONTROLLING DEATH

“The new generation will die the autonomous route and that will be the new dignified way of dying.” Tim, April 2016.

I wish to open this chapter with a description of a video played every morning at the euthanasia 2016 conference:

The video opens with joyful, spirited music. A blue river runs into a pool of clear water. A calm male voice starts to speak, “When life is bright, you find joy.” Bright colours and bubbles draw to the surface. “Passion,” fire consumes the scene. The voice continues, “you party,” as yellow ink dances in dark green water. “You paint the town red … or green.” Another two colours fill the screen. “Or even blue,” blue tinted bubbles float around gently. The words “You choose love” are uttered as a rocket of bright colours explode. Suddenly, the music grows increasingly dramatic and we sense something unknown, ominous, approaching. “But should life darken…” Black ink consumes the water as the beautiful colours vanish. “…and become unbearable,” the same dooming voice vaguely echoes. Black ink gradually becoming more palpable, almost as plastic bubbles caught in a current. “Should the suffering become hopeless,” black figures and a gloomy atmosphere. “People deserve the right to die with dignity.” “Use your knowledge. Use your influence, choose euthanasia 2016.” Empty rings linger in the water (NVVE, 2016b).16

The colours used in the video describe the positive feelings in life. The music, water, dancing colours, bubbles, and rocket colours make the viewer feel good. But, then the video shifts and black ink invades the screen and the music gets sombre, which means that if life gets tough, painful and become unbearable one should choose to die with dignity. This does not just imply illness, but also becoming old, feeling depressed or being diagnosed with dementia. NVVE argues through this video, that life is not worth living when being in this state. Hence, dignity for NVVE only happens when a person dies before life gets too dark, too painful, and too unbearable.

The video above describe the essence of what NVVE considers as a dignified death. I will explore this topic further in this chapter, but fist I will describe some of the perspectives on

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16 To see video go to: https://www.nvve.nl/euthanasia2016
what constitute a good or a bad death. Then, with the help from my informants, I will demonstrate and discus what NVVE considers as a good and dignified death.

WHAT IS A GOOD DEATH?

If there is one thing in life we can be certain about it is death (Lambeck, 2016). Most people have some sort of experience with death. Either by having someone close who has died or having thoughts about one’s own death. By showing news from around the world where horrible deaths and suffering are displayed, the media plays an important part in how humans perceive death (Desjarlais, 2016). One the other hand, most of the deaths in this world happens under normal familiar circumstances and not by terror or violence (p. 648).

Furthermore, Desjarlais argues that the experiences of a normal death is a common factor all humans share, such as consciousness, identity, memory, desire, bodiliness and rationalities. In addition, these experiences are achieved through social and ritual practice (p. 648). As for example funeral rituals. Most of the Western societies today, believes a person will not return when being dead (Lock, 1996, p. 211). Even though all humans experience death, we can have different opinions on what constitute a good or a bad death.

Desjarlais (2016) draws on the ethnography from the Yolmo Buddhists to show us what constitute a good death for the Yolmo Buddhists. When dying a good death the Yolmo Buddhists achieve liberation or a good rebirth. In order to obtain a good death, they have adapted a number of methods and technics to help them “die well.” Surrounded by loved ones the remaining weeks before death, the dying person finds an inner peace (p. 651). The Yolmo Buddhists dies at home just as most people who die a euthanasia death in the Netherlands (Norwood, 2009) or the people choosing the autonomous route. If we considerate dying at home as a good death, it can be because one feel calm and at peace when being in familiar circumstances. The atmosphere might not be as stressed as it can be in a hospital and the people around are present out of love. The person can feel more in control over the situation and sense that her autonomy is intact. The dying person has decided to die at home, in his way and pace. However, it is important remember that dying at home is not always possible.

People often die in hospitals and nursing homes. Nevertheless, does this mean they die a bad death? The Yolmo Buddhists thinks that dying in a hospital is what constitutes a bad death. They believe that when admitted to a hospital, nature cannot take go course because of medication and machines. This means that death is hindered by the hospitals desire to cure. When the person dies, it is not by nature but by the hospitalisation (Desjarlais, 2016).
Furthermore, the Yolmo Buddhists believe that new technological ways of dying will make death “delayed”, managed and timed instead of natural (p. 656). We can see this is the case with patients who are terminally ill, but is still on medication or life support. When admitted to the hospital, the patient is obliged to wait before the hospital staff decide when it is time to die (Kaufman, 2006). This does not only deprave the patient’s autonomy, but also takes away the patients control over own body. As we will see further down in this chapter, control is an important matter when dying a good death for my informants.

Margaret Lock has done several studies on persons who are diagnosed as braindead. She asks whether a braindead can be considered as dead, this is especially relevant when it comes to organ donation (Franklin & Lock, 2003; Lock, 1996, 2002). Lock investigates whether a person is dead when being socially dead or biological dead. Socially death means that the physical part of the body is functioning, however the brain is not functioning and therefor the person cannot perform socially. While, biological death means that both the physical and mental parts of the body is not functioning. Bartlett and Youngner (1988) argues that the loss of personhood should be defined as death rather than the collapse of the physical body. The questions around what it means to be dead become problematic when discussing harvesting of organs from people who are braindead. Lock (1996) has conducted fieldwork in both USA and the Japan where she has investigated this topic. According to Lock, the majority of the North American hospitals recognize a braindead person as dead. Therefore, the harvesting of organs has become a routinized act. The Japanese on the other hand, believes that people who are braindead are not yet dead, as the Japanese think controlling death is against nature, thus dying as a result of removal of all organs is considered an unnatural death (pp. 212-232). Lock (2002) argues that a person diagnosed as braindead dies twice. The first time the accident occurs and the person becomes braindead and therefor socially dead. The second time when the harvesting of organs is completed and the body is biologically dead. This type of death can be considered as both a good and a bad death. The person does not experience any physical or psychological pain; additionally he helps another human being by donating organs. Hence, it can be perceived as a good death. However, this can also be acknowledge as a bad death because the person has lost his voice, meaning that he cannot express himself verbally or physically. In addition, the person has lost control over his own body, thus his autonomy has been destroyed. Not just by the medical staff, but also by the family members who agree with the removal of organs. For these reasons, dying by donating organs can be a both good and bad death. It is a good death because the person is doing something for the
greater good. It can be fruitful to question whether people with dementia can be considered as socially dead as the people diagnosed as braindead. People with dementia still have a “functioning” brain compared to people who are braindead. A braindead person is not able to express any emotions or thoughts since the brain are dead. While, people with dementia are still able to express themselves even though they have a tendency to feel confused and afraid. However, as we will see further down, the volunteers in NVVE will see this as a bad death because those diagnosed with dementia are not able to control what happens to them and therefore has lost their autonomy.

Involuntarily loneliness is a social problem. Even though we wish it were not the case, many people die alone. Ann Allison (2016) studies a new phenomenon in Japan, where the elders die all alone in their home. Allisson question why people lose track of the elderly and leave them to die alone. As I described in chapter three, she believes the elderly are seen as social waste, which means human leftovers that no longer fit into the society (p. 665). A person feeling lonely at deathbed can constitute a bad death. Most people are afraid of dying alone and the majority of people wish to have someone sitting by their deathbed. Whether it is a family member, a friend or a nurse doing her work. Dying alone can reinforce the feeling of not belonging and not being cared for, since no one is there when it really matters. This is a feeling the elders who are tired of life can relate to because they do not fit into the ideal society. The feeling of insignificance can provide to the perception of dying a bad death.

People who commit suicide often die alone, the difference between this and the case where lonely people die alone is that the suicided is voluntarily alone. Suicide is considered as an autonomous act, where the person is in control, which is a factor that is regularly used by my informants when describing a good death. So, why is suicide often treated a bad death? As I have already discussed in chapter two, suicide is often associated with shame and taboo. When a person intentionally takes his own life and give into the “death wish” he die a bad death (Broz & Münster, 2015, p. 6). Maurice Bloch and Jonathan Parry (1982) classify suicide as a “supreme example of a bad death” (p. 16). Bloch and Parry claim that when a person chooses to end his own life it is seen as the as the most horrible act in many cultures and especially in Christian cultures. The reason for this is that their soul will not be included in the society of the dead, in the Christian sense this will be Paradise. In addition, Bloch and Parry assume that the dead wanders the earth as a lonely and destructive ghost. And that the corpse of the person who committed suicide cannot be buried according to the traditional rites (p. 16). I have discussed this matter in chapter two, so I will not go further with this. There are
other reasons to why suicide is considered as a bad death. First is the part where the person
dies alone. Secondly, the feelings the person has when dying: desperation, loneliness,
depression, insignificance… all of these are negative feelings who contribute to a bad death.
Thirdly, it is in the manner the person dies, either it is by jumping, shooting oneself or
swallowing tablets, these types of deaths are violent acts. Fourthly, the people who are left
behind can struggle with the feeling of helplessness. In addition, to the feel they could have
played a role to prevent the suicide. As we now, my informants consider suicide as bad death,
they claim suicide is an abrupt act where the person who commits suicide affect the people
left behind. In addition, the suicidal person does not have control over his doing since the act
is impulsive.

According to Seale and van Der Geest (2004) bad death are socially disruptive. This occurs
for example when death happens violently, when a person commits suicide or a death away
from home (p. 883). A good death on the hand, occurs when the dying has lived a long and
meaningful life, have children and grandchildren and is dying at home surrounded by loved
ones (Seale & van Der Geest, 2004, p. 884). According to Bradbury (1996), a good death is
painless and happens in old age in a peaceful place surrounded by loved ones (p. 94). This
picture painted by Bradbury is similar Norwood’s description of an ideal euthanasia death.
The person who receives euthanasia lies in a bed in the living room, looking out on the garden
and is surrounded by loved ones. The death illustrated by Bradbury and Norwood can be
described as the ideal death. Most people are in a way attached to their homes, the saying
“there is no place like home” is an example of how important a home can be. The home
reflects the personality of the inhabitant, in addition to be a reminder of autonomy and
independence. Still, dying at home is not the only way to die a good death. Patient who is
admitted to a hospital or being at a nursing home can also experience a good death. To have
someone beside the deathbed is essential to experience a good death as most people wish to
feel they matter and be cared for until the end. Dying alone is associated with lonesomeness
and the feeling of not mattering. People, who live alone and do not have anyone close, can
experience to die a bad death by themselves in their own homes. Therefore, dying in a
hospital or nursing home can constitute a good death for this group of people. On the other
hand, not everyone is lucky enough to experience this type of death. Death can be painful,
either it is psychologically or physically. Not everyone has loved ones surrounding the
deathbed, are old or at peace when dying. It is difficult to put labels on what constitute a good
or a bad death because we all have different opinions on how we wish to die. Nevertheless, all
humans have a common wish for their own death, the desire to die a dignified death. According to Rendtorff (2008), dignity “expresses the basic worth and fundamental equality of all human beings” (p. 76). Rendtorff point out to an essential factor about dignity. However, dignity can also be seen as a subjective matter and is experienced differently from person to person depending on what she defines as dignity. Dignity is an individual matter and is therefore represented differently from person to person. When it comes to death and dignity, there are common factors for all people, to feel respected, heard, and significant. As long as a person experience dignity on his deathbed, he will have a good death.

**NVVE’S PERCEPTION OF A GOOD DEATH:**

“A dignified life, deserves a dignified death” (NVVE, 2016a)

Throughout my fieldwork, dignity was a word commonly used by my informants. The quote above is NVVE´s motto. I find it interesting because my informants have a clear opinion of what constitute a dignified death. In this part, we will explore and discuss how the NVVE defines a good and dignified death. According to Seale (1998), taking control over ones dying is seen as an alternative “dignified death” instead of dying in a hospital or hospice (p. 166). In the Netherlands, the public in general is becoming more open towards the possibility of a self-directed death, therefor to determine the time and manner of death has become more common (Wijngaarden et al., 2015, p. 1). In addition, Wijngaarden et al. (2015) claim that a planned death are considered as good death in Western countries (p. 1). This is also the case for NVVE, where being able to plan one’s own death is an essential part of dying a good death.

**Preparing death:**

As I have discussed in chapter two, the autonomous route can be seen as a process towards death. To be able to prepare death was a central topic when I discussed what constituted a good or bad death for the people in NVVE. By doing so, they gained control over the manner and place of death. During my fieldwork my informants stressed the need to prepare one’s own death. Either by filling out the directive documents or by planning to die by the autonomous route. Sophie expressed, “people become more peaceful when the will is taken care of. It is like a burden has been lifted from their shoulders.” The Yolmo Buddhist preparation of death, can be compared to my informants need to plan death. As Desjarlais explains, they have adapted a number of technics to be able die a good death. The same can be said for NVVE and the autonomous route, where the person who wishes to die prepares himself by for example practising the plastic bag method or ordering pills from China or
Mexico. It can seem that the autonomous route is not just about being autonomous; it is also about the need to be in control. Tim explained to me:

Tim thinks the autonomous route is a way of controlling death. According to Tim, we control everything in our life; therefore it is important to control death as well. Tim adds that we are in control of our entire life, except at the end when the doctor takes the decisions for us. Tim thinks this will change. The older generation is used to listening to the doctor. However, the new generation think more their body their decision. According to Tim, the autonomous route is about making his own decision. He wants to do it (die) himself and not go through the doctor. (Fieldnotes, April 2016)

As we can see, Tim thinks it is important to control our death because we are in control of our entire life. In addition, Tim states that his generation, the baby boomers, wants to be in control over their own body. The fact that he wants to be responsible for his own death confirms some of the baby boomers' ideals, to be independent and autonomous. Mary Bradbury (1996) claims that control is what differentiates a good or a bad death and with this control one would be able to influence the time and place of death (p. 94). Daan, who we have met in the previous chapters explained, “With the autonomous route you organise your dignity, you prepare your own death. You don’t do that with suicide.” Daan and Tim emphasise the importance of preparing one’s own death, by doing so the person is in control and is then able to die a good death according to NVVE.

The Pill is also a way of preparing and controlling death in order to achieve a good death. Yet, as we know, the Pill is not legal in the Netherlands, but if it were an option, my informants would not hesitate to use it. Nina explains, “I wish the Pill would be legal. With this Pill, people could end their life in a respectful way and not die alone.” Paul believes that “The Pill will make people take care of their own destiny.” Being respected when dying is closely linked to dignity. By taking the Pill, the person does not only die in a respectful way, but he also takes care of his own destiny. Hence, the person keeps his independency.

When a member of NVVE decides to stop eating and drinking, he not only will feel in control over the situation, but also over his body. Clive Seale (1998) argues that some see the loss of appetite as losing control over the body but it can also be seen as the ultimate control. In the sense were the person controls the manner and timing of death (p. 165).

Seale (1998) claims that taking control over the manner and timing of death is a way to secure a meaningful death (p. 166). However, when people start to expect and hope to control when
and how to die, it can have ethical implications (Seale & van Der Geest, 2004, p. 883). There are about 160,000 members in the NVVE, many of them are in the final stages of life. In chapter one, I argued that the volunteers can influence the members, especially in a home consultation setting. NVVE believes that by controlling death one dies a dignified death. Hence, by assuming that their way of dying is the most dignified, the NVVE can affect the member’s opinion and ultimately how they chose to die. The purpose of the autonomous route is not only to help those who wish to take control over own death, but, it is also to teach the members how to die a good and dignified death.

**Die a good death in old age:**

I have argued that my informants perceive control and preparation as important matters when dying a good and dignified death. I will now discuss my informants view on a good and dignifies death in old age. Getting older signifies that death is getting closer and that this leads to numerous losses (Seale, 1998, pp. 151-153). As I have explained in the introduction, old age is associated with loss of identity, dependency, a failing body, and discrimination (Agich, 2003; Allison, 2016; Das, 1990; Higgs et al., 2009). To be able to control the timing and manner of dying can help to keep self-identity (Seale, 1998, p. 172). To die by the autonomous route is a way for my informants to keep self-identity until the end, which tends to be especially important to the elders of the baby boom generation. Eric, explained to me what a dignified death implies to him, “Going my way...a way that goes with my personality. I want to have control. Emotion and retiro has to be intact. As long as I can listen to music, talk, read...” For Eric it is important to be able to keep his personality. Anthony Giddens (1991) claims the need to control the body is associated to the maintenance of self-identity. Elders can often feel they lose themselves in different ways. For example by moving into a nursing home, where the loss of their home can be difficult to process. To feel that one’s own home is taken away is not just a loss of privacy and intimacy but also a feeling of losing self-identity since many in the Western world decorate their home after their own personality. While I was working in a nursing home several years ago, I recall that this was especially difficult for the women. Not to be able to use their own kitchen, make food or have something to offer the guests. Another significant loss for an elderly person is the loss of mobility, as this can lead to being dependent on others. The decaying body and health in old age tends to be a significant loss for the baby boomers, as their health and body is an important part of how they perceive themselves (Slevin, 2010). To be able to perform the daily activities is necessary in order to experience a good retirement. When no longer able to do this, the baby
boom generation can feel they lose their purpose in life. As we can see in Eric’s example, he wishes to be able to read and listen to music, when he cannot do this anymore he wants to die. NVVE means that a person of old age who dies before losing the self, health and mobility will preserve his personality and experience control and autonomy until the end. In this sense, the autonomous route is way to die a good death in old age.

Sophie told me about her positive experience with assisted dying and dementia. Sophie is a retired woman working as a home-consultant for NVVE welcomed me into her home. We sat down in her office which was it was filled with books from the roof to the floor. Sophie served me some of her homemade Dutch cake and a cup of tea.

I had a friend with dementia. She was a fighter for euthanasia. When she was diagnosed, we (her friends) helped her with what we could. We also helped her find a doctor who was willing to perform euthanasia on people with dementia. The night before she died, we had a big dinner party in her honour. I (Sophie) was there when she died. (Fieldnotes, April 2016)

When asking Sophie if she could describe a good and dignified death, this was one of her examples. Her friend died before the dementia was too progressive. This woman died while she still had control over her mind and therefore her self-identity was preserved. In addition, the woman had control over manner and place she died by dying a euthanasia death. This classify as a good death to my informants because the woman kept her autonomy until the end. As we remember from chapter three, Eric believed that dementia was the worst thing that could happen to him, which is expected because a person with dementia slowly but surely loses control. In the case above, Paul was worried that the member he consulted would die a bad death because the dementia was too progressive. To be diagnosed with dementia is associated with the loss of control and the self. Hence, my informants consider it as a bad death if the illness has gone too far. However, if the diagnosed is able to receive assisted dying or die by the autonomous route before the dementia has become too progressive, the person keeps control, identity, and autonomy, and can therefore die a good death.

**Uncontrolled death:**

Until now, I have argued that a good death for NVVE is associated with having control, keeping autonomy and preserve the self. A bad death will then be to be deprived of control, autonomy and the self. If we go back to the video described in the introduction, we can understand what NVVE defines as an undignified death. They seem to believe that if life gets
tough a person should be able to end his life while his dignity is still intact. So, if becoming too ill, life would no longer be considered as worth living. Hence, one must control death to be able to die a dignified and good death.

When discussing what constituted a bad death for my informants the answers where consist: to die with a lot of pain or suffering, by suicide, dementia, or palliative care17. Palliative care is used on patients in a terminal stage, these can either be terminally ill because of a disease or because of old age. The pain-relieving treatments (as morphine) makes the patient feel painless in the final stage of life but the patient often slip into a coma and is unconscious until death. When receiving palliative care, the patient is often unconscious and is therefore bereaved of control, autonomy and the self. When discussing death and dying with Sophie she told me about a friend of her who according to her died an undignified death:

She was a strong independent woman diagnosed with breast cancer. She wished to die a euthanasia death. She had asked her doctor if he could help her die by euthanasia when the time would come, which he had accepted. When she reached the terminal stage, she was in a lot of pain. According to the plan, she should now get euthanasia. However, her doctor was on vacation. Another doctor was there and she was not willing to give euthanasia. She was religious and against it. Instead, the doctor gave a lot of morphine. This drew her into a coma and she died about 20-24 hours later.

(Fieldnotes, April 2016)

When discussing her friend Sophie was mostly angry with the doctor for not honouring her friends wish. When telling about her friend, Sophie was not only furious that her friend did not get her euthanasia wish fulfilled, but also because it took her friend so long to die. Even though she was not in any pain and unconscious, Sophie was sad on behalf of her friend. Her friend did not only get her wish ignored, she also lost her autonomy and control by being in a coma due to too much morphine. This issue can remind of the people who are diagnosed as braindead. Lock argues that these people dies twice, the first time socially and the second time biologically (Lock, 2002). Maybe Sophie felt this way because her friend experienced both of these types of death. Socially dead is associated with the loss of voice, control and autonomy, factors my informants tends to think of as negative. If Sophie´s friend had died before experiencing these circumstances, she would have died a good dead.

17 Palliative care: “symptom control, effective communication and measures to support the quality of life for a dying person and their family” (Saunders, 1992, p. 1)
Frances Norwood conducted fieldwork in the Netherlands at the beginning of the 21st century. She explores the social and communicative aspects of euthanasia. Norwood used the term *socially dead* on those who had slipped into a coma or was not present mentally because of an illness. She describes *socially dead* as, “*It is probably best describes as a series of losses-loss of identity and loss of the ability to participate in social activities and relationships that eventually culminates in a perceived disconnection from social life*” (Norwood, 2009, p. 7).

My informants describe dementia as losing control, autonomy, and identity. Following this logic, we can assume that they consider people with progressive dementia as *socially dead*. The question is whether they legitimise assisted dying and the autonomous route because they consider the person with dementia as already dead. People with dementia might experience pain in addition to losing voice, control, and autonomy, which tends to be negative factors to my informants. Hence, the person with dementia dies a *bad death*. Paul, who we have met many times, told me:

Paul tells me about a man he is currently consulting. His wife contacted Paul when he was diagnosed with dementia. In the beginning, the man was very positive to get help to die. However, as time passed by, he withdraws himself from the conversations. He did not want to talk about it anymore and left it to his wife. Paul thinks this is a shame because it will soon be too late for that man. I said that people with dementia could be happy even though they have the diagnosis. He abruptly asked me if I wanted to have dementia. (Fieldnotes, March 2016)

It is clear that to die dementia is not a good way of dying according to Paul. We can see that he wishes the man would act before it was too late. *Too late* means the diagnosis has become too progressive. Dementia is an unpredictable illness, which make it difficult to handle. The person loses control over his mind and self and this can be a burdensome process for both the family and the diagnosed. During the fieldwork, I heard similar stories of family members who wished their relative with dementia could receive assisted dying. Since the Western world tends to be built on individualisation and independency, it can seem that some would believe it to be a burdensome experience to take care of the people with dementia. To suddenly put one’s own life to the side and become a caregiver, can lead some to push their relatives towards assisted dying.

As we know, my informants consider suicide as a *bad death*. They describe suicide as an abrupt and impulsive act, which is not a controlled act and often characterised as *jumping in*
Frank believes that “jumping is a not dignified way of dying.” According to my informants, the autonomous route takes place in a controlled environment. It is either practised (plastic bag method) or a volunteer provide guidance to the member (lethal pills, stop eating, and drinking). Suicide on the other hand happens in an uncontrolled environment. The person does not know the outcome of his action and there is no guidance. Since suicide tends to happen within an uncontrolled environment and this is seen as undignified, it is an undignified death to my informants.

In this chapter, I have argued that NVVE have an urge to prepare and control their death in order to achieve a good death. In addition, it is essential that a person have his autonomy intact, and preserve his self. I have argued that NVVE redefine what constitutes a good death and in this way influence their members. I have discussed what it means to die a good death in old age. I have shown that to be able to preserve the self into old age are an important factor for dying a good death. I have suggested that a bad death for NVVE is an unprepared an uncontrolled death. Hence, suicide and dementia are defined as bad deaths. I have also discussed whether my informants see people with dementia as socially dead and if this is a way to legitimise assisted dying or the autonomous route for this group of people. NVVE wish to throw away the old assumptions, were the doctor is in control until the end. They yearn to be the ones in control and define their own death after what is important to them: to preserve autonomy, control and the self. To die a good death means the person take control over the body, and not the opposite, that the body controls the person.
CONCLUSION

The battle for assisted dying in the Netherlands emerged in the sixties, where the main argument for assisted dying was a wish the doctors had to help those who suffered from terminal diseases. Consequently, NVVE emerged, and was built on values of freedom, individuality, independency, and identity. The baby boom generation who prided themselves in throwing away ancient morals and ideals were behind these values. As time passed, this generation grew older and after thirty years, the law of euthanasia was a fact in 2002, but it was not enough. Some of the ageing baby boomers wanted more; they wanted autonomy until the end. At the same time, many elders felt lonely and did not find a meaning in late life. Some felt like a burden and that they could not contribute to the society they helped build. Growing old the same way as those they rebelled against in sixties was not tempting. Suddenly, old age and being in the fourth age evolved into something to be feared. Feeling tired of life became a term the elders used when having lost the lust for life. This group of people wished to end their life when they wanted. After all, they had controlled their life, so why not control death. For many the need to control death became a necessity and as we have seen, NVVE fronted this view.

The fact that the due care criteria needs to be fulfilled means that only a small part of the Dutch population will be able to receive assisted dying. To feel unbearable pain is one of the main criteria to get assisted dying, but most often, doctors only apply assisted dying on those with physical pain. As a result, many feel discriminated because their subjective sensation of pain is not taken seriously. Pain needs to be experienced, thus the law cannot decide who feels unbearable pain and not. The Dutch citizens interpret the law differently and therefor think they can receive assisted dying when becoming ill. As we have seen, many are not aware of the due care criteria and consequently think assisted dying is a right for everyone. As a solution, NVVE have invented a new concept for their members: The autonomous route.

The autonomous route is the “new” cause, a battle for autonomy and control until the end. The Pill emerges as the ultimate idea of autonomy and is a symbol for independence, control and independence. Those who are tired of life or feel that their life is completed might want to end their life in a dignified way. The Pill, on the other hand, is not yet legal and therefor the NVVE has to offer other options to their members. The NVVE home consultant and the member form a complicated relation in which boundaries tend to be pushed. The volunteers
and NVVE affect the choice and the member´s perception of death. The plastic bag method and ordering lethal pills from China and Mexico are the main methods used and make the members dependent on the volunteer. The autonomous route might be considered suicide, but as I have explained, informants strongly argue the case that it is not. The autonomous route is planned and well thought out, whereas suicide is the opposite. We can see that the autonomous route fits Durkheim´s definition of suicide. NVVE underlines that the autonomous route is talked about and does not affect anyone in the same way as suicide. The ones left behind will have a better experience than those who experience someone close to them committing suicide. In this sense, the autonomous route is good alternative for the elders who wish to die.

Six years ago, the Netherlands went through a political change, where the right-wing took over after the left-wing. This affected the healthcare system, the increasing number of elderly and a change in the economy, lead to a closing of many nursing homes. The elders had to rely on their family and neighbours, which left some feeling like a burden. At the same time, many elders do not have anyone else to rely on outside of nursing homes and immediate family. As we have seen, the NVVE functions as a reassurance for these people and can help restore some of their social ties. The autonomous route can be seen as a new type of death ritual that has emerged as a consequence of social changes- a death ritual that essentially is a form of sacrifice, where the elderly sacrifice themselves in order to alleviate society and to achieve a socially accepted death.

This might lead to the perception that the aging body is an abnormality rather than a natural process. Aging is more of a disease than a causative of life. The bodily functions change dramatically, possibly leading to anxiety against old age, leading elders to choose death. The autonomous route can then be perceived as a “cure” for old age. The discourse in the Netherlands on whether elders should be able to receive assisted dying has contributed and confirmed the negative feelings the elders have about themselves. These factors can lead to a society where we sort out the elders. As the Dutch government has changed the due care criteria concerning people with dementia, this might be seen as a sign that this group of people are not desired citizens. People suffering from dementia might see themselves as unwanted or at the very least unproductive members of society.

The medicalisation of the human body has allowed people to grow older, making illnesses such as dementia more common among elderly. At the same time, the baby boom generation
is now growing old and bring their values into the *fourth age*. The Western society’s view on old age has led some people from this generation to want to be in control over their own death. Lonely and isolated, elders might opt out of life. NVVE has emerged as an organisation that fronts and legitimizes these values and feelings.

The need to control and prepare death in order to die a good and dignified death was something my informants tended yearned for. As we have seen, the Autonomous route is a way to achieve a controlled and *good death*, where autonomy and identity is preserved. A *bad death* on the other hand happens when a person does not have control or the chance to prepare. NVVE claims that amongst other suicide, dementia and palliative can be defined as *bad death* because of the lack of preparation and control.

By comparing the abortion debate to the assisted dying debate in the Netherlands, some of the problems that can occur when legalising assisted dying crystallise. Abortion was originally for women who did not wish to have a baby. Assisted dying was primarily meant for the terminally ill patients and those who suffered from a chronic descries. The abortion debate today evolves around parents’ rights in deciding what children are wanted or unwanted. Hence, abortion has changed from being able to abort a child to being able to choose what kind of child one wants. Similarly, assisted dying has moved from the motive of helping the people who were already dying, to encouraging the elders and people with dementia to choose “the dignified way of dying.”

This thesis discusses only a small part of the consequences that can occur when assisted dying is legalised. An aging baby boom generation in combination with a reluctance against old age can change the society we live in. There is a danger that some will continue to push the boundaries, thus it is difficult to say where it can end. It is necessary to conduct more research on the consequences of assisted dying and how it potentially changes a society morally and ethically. It could be fruitful to investigate consequences of assisted dying in larger scale, to look more in depth on the biopolitical or economical aspects, or at other countries who legalise assisted dying. Just as NVVE, the others “right to die” organisations can influence an affect many people, it is essential to conduct more research on these organisations to see in what way they contribute to a changing society.
AFTERWORD

Conducting this fieldwork has been an emotional process. To listen to my informants opinions on death and dying has made an impact on me. An episode that captured how I felt was the first time I saw NVVE’s promotional video for *euthanasia 2016* (which I described in chapter four). The conference was at the end of my fieldwork, I was tired and emotional. To be honest, at this stage of my fieldwork, I was tired of talking and thinking about death and dying. At the same time, the NVVE had become an organisation that represented many arguments that I was against. When seeing this video, these feelings were reinforced and I felt anger and fear for what kind of world I was living in, a world that teaches the elderly not to value and be proud of their old age and a world that sorts out those who do not fit in.

Just as the fieldwork was difficult, the writing process was similar. Not just because of the subject, but also because of the emotions that awoke in me. It has been a struggle to maintain focused and nuanced while being so conflicted in my opinion of the research area. I have been frustrated, confused and low in spirits at times. It all peaked when Aksel Braanen Sterri stated that children born with Down syndrome could not live a life worth living (Sørvig, 2017). The debate on selective abortion reminded me of the current debates in the Netherlands. What kind of world would my son would grow up in, a world that becomes more and more concerned with who has the right to live, a world that does not include everyone? As a result, I chose to write as clinically as possible, remaining neutral, so that my own opinions would not overshadow the central thesis.

During this process, I have thought a lot about the residents in the nursing home where I used to work. The elders might have stopped to contribute economically to the society, but their life experience and knowledge can teach us many things. The elders I was fortunate enough to know have all contributed to my life and has made an impact on how I relate to them and vulnerable others. I remembered those who died at the nursing home, with the help of palliative care. I remembered how these patients died what I at the time considered to be a dignified and good death with their family around, even though they did not have control or autonomy.
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