

## Chapter Two

# **Anticipating an Unwanted Future: Euthanasia and Dementia in the Netherlands**

### **Abstract**

This chapter presents an ethnographic exploration of the dynamics of anticipation. Drawing on ethnographic fieldwork with people with dementia and their families in the Netherlands, I examine how requests for euthanasia among people with dementia offer insight in the work of anticipation, as a temporal mode through which the future is made tangible. While the imagined future with dementia is for many a reason to request euthanasia, timing euthanasia with dementia is extremely difficult and often results in the deferral of established boundaries. Hence, contributing to an emerging anthropology of temporality, I argue that anticipation is a process of establishing, collapsing, and renegotiating the temporal distance between present and future, in which the imagined future demands action now, while also being a continuous “not yet.”

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The current version of this chapter has been submitted for publication.

## Introduction

“I do want euthanasia, but not yet,” said Ms. Verbeek, after she had taken a sip of her coffee. We sat at her dinner table by the window, looking out onto the street in a small town in the south of the Netherlands. We had been talking about her experiences of living with dementia, her outlook on the future, and the end of life. The topic of euthanasia came up in our conversation, as it often did during my research on the end of life with dementia in the Netherlands, namely as a process of anticipation of an unwanted future that came to inhabit the everyday lives of people with dementia and their family members. This unwanted future often was not there yet but actively occupied the present as people sought the “right” time to prevent it from happening. The simple phrases “but not yet” and “not now,” often uttered in the conversations I had with Ms. Verbeek and others with dementia who were in the process of requesting euthanasia, were indicative of the difficulties of deciding when euthanasia should happen. This difficulty of finding the *when*, I argue, reveals that anticipation is a continuous process of negotiating the temporal distance between present and future, in which the future is both brought into the present, as demanding action in the now, and pushed away, as something that is not yet there.

Analyzing euthanasia in dementia through the anthropology of time, then, can serve to disentangle the concept of anticipation. Anticipation takes on particular importance as people with dementia who are requesting euthanasia, orient themselves toward a future of inevitable cognitive and physical decline that they fear and wish to avoid. The prospect of decline is what motivates the request for euthanasia, but it is also precisely what threatens the possibility to receive it, as the request has to take place before one loses the ability to understand and confirm the request. The problem with this is that in this moment in time, the person most often has not (yet) reached the point they consider not worth living. In public debates this is often referred to as the “five-to-twelve-problem,” the need to request euthanasia “too early” before it is

“too late” (The 2017, 65-6).<sup>14</sup> In this sense, dementia not only forms an exceptional condition with regard to euthanasia (Bolt et al. 2015; Snijdewind et al. 2014) but also shows some of the difficulties of and hard work done in anticipation as a particular way of relating to and acting upon an unwanted future.

The question of timing death through euthanasia has sparked intense ethical debates in the Netherlands as well as in many other societies. While taking into account these often highly polarized debates, in this chapter I do not advocate for or against euthanasia. Rather, I suggest that a careful analysis of the process of requesting euthanasia provides important theoretical insights into the workings of anticipation. As I will continue to demonstrate, this anticipatory practice both brings the unwanted future into the present as it is already lived and acted upon, and pushes the future away from the present as decisions are postponed and boundaries shift.

The discussion presented in this chapter is based on eighteen months of ethnographic fieldwork, conducted in 2014 and 2015 in nursing homes in The Netherlands. Although participant observation in the daily life of closed wards included many hours of “being there,” I focus here on observations made during meetings of people with dementia, their family members, and general practitioners (GPs) wherein requests for euthanasia were discussed. I also draw on in-depth interviews with people with early stage dementia, who were living at home and in the process of requesting euthanasia, as well as with their family members, professional caregivers, and spiritual counsellors. I further build on a focus group session with volunteers of the Dutch Association for Voluntary End-of-Life (NVVE), one of the principal advocates for euthanasia in the Netherlands, which is mainly committed to consultation and lobbying.

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<sup>14</sup> Regularly, newspaper articles appear with titles such as “If I Become Demented, Put Something in My Coffee” (Matthijssen 2017), referring to life with dementia as not worth living and thus justifying euthanasia, while others highlight the legal and ethical challenges, for example, “Euthanasia for Mentally Incompetent Dementia Patients Is Impossible to Defend” (Kreulen 2018) and “The Woman Who Forgot That She Wanted to Die” (Reerink 2012).

In the next section, I begin with an overview of the recent scholarship in the anthropology of time, in order to give insight into the workings of anticipation as a way of bringing the future into the present. Highlighting that anticipation is embedded in local value systems, I then briefly consider the Dutch cultural and legal context. Next, I proceed to unravel the concept of anticipation, through ethnographic accounts, in three steps. Firstly, I discuss the image of an unwanted future that dementia evoked for many of my interlocutors. I connect this anticipated future to culturally rooted notions of dignity and control, and the prospect of its loss, and show that it builds strongly on previous experiences with dementia. In this sense, euthanasia emerged for Ms. Verbeek and many of my interlocutors as an anticipatory response to, and a way out of, an apocalyptic future. Secondly, I turn to the question of how anticipation is “done,” by detailing how the unwanted future is acted upon in the interactions between people with dementia and their family members and professional caregivers. In doing so I show the negotiated nature of this anticipatory process. Finally, by paying attention to deferral, how boundaries of what people consider “worth living” shift in the process of anticipation, I conclude that anticipation should not only be understood as bringing a fixed moment from the future into the present but also as a continuous renegotiation of the temporal distance between that future and the present.

## **Anticipation and the Anthropology of Time**

While the concept of anticipation has mainly been addressed within future studies, as well as in planning and engineering disciplines (e.g., Poli 2010, 2014), it only recently caught on in anthropology with the so-called temporal turn wherein anthropologists increasingly paid attention to time and temporalities (Bear 2016; Fabian [1983] 2014; Munn 1992) and have taken on the future as an object of focus (Appadurai 2013; Bryant and Knight 2019; Pels 2015; Salazar et al. 2017). In focusing on time, anthropologists have shed light on alternative ways of being in time that challenge linear thinking, emphasized temporal diversities and inequalities, and attended to temporal forms of agency (e.g., Ringel 2014,

2018; Nielsen 2011, 2014). The present, in these lines of thought, is always already infused with both pasts and futures, in the sense that future orientations as well as past experiences are integral to the meanings of present experiences (Bryant and Knight 2019; Crapanzano 2004; Mattingly 2014; Munn 1992). In light of this recent scholarship, I find that anticipation presents a particular dynamic in which the future is made tangible, making it a valuable conceptual tool through which the relationships among past, present, and future can be further illuminated.

Appadurai (2013) has called attention to the need to take imagination seriously when studying the cultural processes of future-building. The power of imagination becomes clear when considering that a person may request euthanasia in response to an imagined unwanted future with dementia. However, anticipation is more than a temporal imaginary: where a temporal imaginary offers a certain horizon, anticipation involves action (Bryant 2016; Bryant and Knight 2019). Anticipation is a mode of being in time, “a way of actively orienting oneself temporally” through which the future comes to inhabit the present (Adams, Murphy, and Clarke 2009, 247). Anticipation establishes meaningful relations among the past, present, and future, whereby past experiences and future orientations both inform how the present is navigated. Adams, Murphy, and Clarke (2009) emphasize that in anticipatory practices, the future is engaged in such a way that it shapes present actions and states of being. The anticipated future, they state, appears as already formed, and accordingly legitimizes certain actions in the present. Giving the example of pre-emptive war, where violence is justified as preparedness, Adams and colleagues make clear that this legitimizing force of anticipation may include acts in the name of a future that otherwise could not be legitimized. They further conceptualize anticipation as an “affective state” (Adams, Murphy, and Clarke 2009, 247). As the future comes to inhabit the present, it not only informs actions but is also lived and felt. As such, it can generate urgency, anxieties, hopes, and fears, both at the level of individual subjects and collectively (Bryant and Knight 2019). Ahmed’s (2004) work further illuminates how anticipation, as an affective state, can generate possibilities for action in the present. Ahmed argues that emotions are essentially about movement: to be affected is

not only to be moved but also to be moved in a direction. Emotions, she writes, “involve (re) actions or relations of ‘towardness’ or ‘awayness’ in relation to . . . objects” (Ahmed 2004, 8). To state that anticipation is an affective state, then, means recognizing that the future can move and legitimize certain actions in the present.

In the following, I build on this body of literature in the anthropology of time, futures, and anticipation to explore the process of anticipation as it emerges in the request for euthanasia among people with dementia in the Netherlands. To approach anticipation as affective allows me to look into the fears of the imagined, unwanted future with dementia, and how these inform and legitimize the request for euthanasia in the present. As Clarke (2015, 90) writes: “one largely ignored facet of anticipation is how much work it actually takes to “optimize,” to “live in preparation,” to anticipate—to gather information, calculate, consider, plan, foresee, decide, act, and so on.” I take this cue to look in detail at *how* the future is anticipated through a euthanasia request, to study the hard work and the complexity of orienting oneself toward a future that is finite. Taking this approach shows that anticipation is not done individually but collaboratively, and—even though finitude is actively pursued—deferral plays as a crucial role. Hence, I do not only demonstrate how the unwanted future is brought into the present through a euthanasia request, but also the negotiations and struggles through which it is kept at bay. This research makes clear that anticipation is not an event that relates to a clearly demarcated moment in the future, but is rather a process in which perspectives change and boundaries shift in relation to a future that is always in flux. Before elaborating on this, I address in the next section some of the local values and norms that inform euthanasia, as a culturally specific form of relating to the future, in the Dutch context.

## **Euthanasia in the Netherlands**

Anticipating the end of life and requesting euthanasia can be understood in relation to the values of autonomy and control that are central to Dutch society (Buiting et al. 2012; Norwood 2009; Pool 2000, 2004). The

Dutch terms *zelfredzaamheid*, *zelfbeschikking*, *eigenregie*, *onafhankelijkheid*, *controle*, and *autonomie* all refer, in subtly different ways, to what would translate in English as “control” and “autonomy,” and each of these terms is frequently heard in contemporary euthanasia debates. This can be traced back to a paradigm shift that took place between the 1960s and 1980s, when the ethics of the medical prolongation of life were questioned and the self-determination of the patient became increasingly valued (Kennedy 2002, 67; The 2009, 153; Van Wijngaarden et al. 2017).

Pool (2000, 2004) argues that euthanasia in the Netherlands is ultimately about control. In addressing the Dutch context, he demonstrates that having control over the timing and manner of death contributes to a large extent to its discursive framing as “good.” Norwood adds a level of nuance by arguing that control is exerted not so much through the act of euthanasia, but is rather established and maintained in what she calls “euthanasia talk”: “a discussion for the purpose of planning a person’s euthanasia death” (Norwood 2009, 30). The fact that euthanasia is discussed, she suggests, reconfirms the value of control and autonomy, even if the person does not go through with euthanasia. Further, the cultural value of control does not only emerge at the level of individual patients who seek to control their own death. In his thorough historical and cultural analysis of how euthanasia policy emerged in the Netherlands, Kennedy (2002) argues that attempts to deconstruct the taboo around euthanasia and make it *bespreekbaar* (literally “speakable,” or allowed to be openly discussed) have been a way to control the phenomenon through state regulation. The legalization of euthanasia in the Netherlands, then, has made it possible to anticipate the end of life through a euthanasia request. However, it also becomes clear that doing so happens within institutional, legal, and cultural frames.

This cultural focus on autonomy and control also resonates in the Termination of Life on Request and Assisted Suicide Act, commonly known as “the Euthanasia Law.”<sup>15</sup> The “criteria of due care”

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<sup>15</sup> By law, euthanasia in the Netherlands is not a right but a request that can also be denied. Legally, euthanasia can only be carried out by a medical doctor, and must be

(*zorgvuldigheidseisen*) as formulated in the euthanasia law, and to which a euthanasia request must comply, presume and require a rational subject. This creates tensions in the context of dementia. Firstly, the requirement that “the request by the patient was voluntary and well-considered”<sup>16</sup> can become problematic due to cognitive decline. It is likely to become difficult or even impossible for the person with dementia to confirm the euthanasia request. The GP can then no longer be certain that the request is well-considered and if the person with dementia still wishes euthanasia. In this sense, dementia poses a challenge in the Dutch paradigm of self-determination (The 2009, 156). Secondly, the legal requirement that “the patient’s suffering was lasting and unbearable”<sup>17</sup> is difficult to assess in dementia because suffering is often related to as a condition in the future that would become unbearable, which might lay beyond the loss of cognitive abilities to confirm the request (Bolt et al. 2015; Hertogh et al. 2007).<sup>18</sup>

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confirmed by an independent medical specialist. All cases of euthanasia must be reported to a Regional Euthanasia Review Committee (*Regionale Toetsingscommissies Euthanasie*, RTE) that reviews whether the criteria of due care (*zorgvuldigheidseisen*) have been met. The euthanasia law includes the possibility for people to prepare a written statement that, in theory, makes euthanasia accessible for people with dementia. However, in practice, physicians find it difficult, or refuse to consider, to end someone’s life when the person cannot confirm the request (Bolt et al. 2015; Rurup et al. 2005). The question is to what extent a statement written in the past continues to reflect a person’s wishes (Borst-Eilers in Smit and van Gelder 2013, 11–2; Hertogh et al. 2007).

<sup>16</sup> Requirement from Wet toetsing levensbeëindiging op verzoek en hulp bij zelfdoding, Hoofdstuk II. Zorgvuldigheidseisen, Artikel 2.1.a. Translation to English in Norwood (2009: 238–9).

<sup>17</sup> Requirement from Wet toetsing levensbeëindiging op verzoek en hulp bij zelfdoding, Hoofdstuk II. Zorgvuldigheidseisen, Artikel 2.1.b. Translation to English in Norwood (2009: 238–9).

<sup>18</sup> Nevertheless, both the total number of cases of euthanasia and the specific number of cases with dementia have been rising sharply. In 2012, the RTE received 4,188 notifications of euthanasia, including forty-two notifications concerning people with dementia. In 2016, it received 6,091 notifications. The number of cases with dementia had risen to 141, and accounted for little over two percent (RTE 2013, 2017). While, in numbers, dementia may then seem a minor concern, public debates on euthanasia in the Netherlands have revolved primarily around euthanasia for people with dementia. Note that these numbers do not include cases wherein euthanasia was requested but withdrawn or denied.

In this context, as I discuss in the next section, the evaluation of suffering is inextricably tied to images of a future with dementia—the anticipation of an unwanted future associated with a loss of control and dignity. By showing what people are afraid of in this future, I demonstrate how anticipation establishes a future imaginary that demands action in the present.

## **An Unwanted Future**

“He is a zombie. He doesn’t respond to anything anymore. Nothing remains of your former self. My husband used to work; he is a historian, has a university degree. He can’t even read the newspaper anymore,” said Hanneke, as she turned and pointed at the wall behind her:

These paintings are his, but now he cannot paint, he cannot read. He used to be active in sports, ran marathons. He cannot do any of that any longer. [There’s] A long list of things that have been lost. All he has left is billiards, for what it’s worth, but he does seem to take some pleasure from it. But that’s all that’s left, and if that falls away, he won’t have anything.

Hanneke and I sat at the long, wooden table in her spacious, country-style kitchen. She had poured us two large cups of tea. She talked fast, sometimes without finishing her sentences, which made me think she had a lot to say. Every now and then she got up and rushed to the living room, and came back with a newspaper article she had saved or a book to show me. She reflected on the last ten years in which her husband had been living with dementia, from the initial diagnosis to their current trajectory toward euthanasia. Besides narrating what had been lost over time, her story also conveyed losses that she anticipated were still to come. She lamented:

If I don’t put him in the shower, he does not bathe. If I don’t tell him to shave, he won’t. And there will come a time when he will no longer be able to do it himself. Well, I absolutely do not want that, because I find it unworthy of a human being. And he would also not have wanted it. We have talked about this, and I told him,

‘you are slowly sliding off toward Bloemenhof.’<sup>19</sup> He then said, ‘I don’t want that.’

She looked back at the paintings and said, “I don’t think that is dignified. A human being is not meant to end as a lump of misery.”

It was common for those with whom I spoke, both those with dementia and their family members, to address a future with dementia in terms of a loss of control, which was often equated to a perceived loss of dignity. Like Hanneke, interlocutors foresaw the future as a grim and ever-worsening scenario. A loss of dignity was imagined as even worse than death by some (cf., Behuniak 2011). This was also strongly voiced during a focus group conversation with NVVE volunteers who informed and guided people in their efforts to request euthanasia. When I asked “What is it that makes you consider that life unworthy?” I received a series of answers that quickly followed one another. “I think you are not a worthy human being anymore. Almost animal-like,” said Ben, followed by Harold: “I don’t see it as a human-worthy existence. My former boss was always a gentleman. At some point I saw him drooling in a wheelchair, being pushed around town. I was certain: he would have never wanted this. And I would never want it either.” Dorien nodded, adding, “The emotion and frustration. He would not have wanted that.” Ben sighed, and explained: “And then we are not even talking about the changes in someone’s character. So it is not only about self-composure and losing your mind, but ending up in a different atmosphere and becoming a different person.” Julie immediately confirmed: “Yes. Not knowing how I will become. Because you don’t know that.” “Yes. And becoming a burden for another. That is really difficult,” concluded Tina.

These responses, even though each referring to different aspects of what it would be like, according to them, to live with dementia, all pointed at an anticipated loss of dignity, autonomy, and control. As such, life with dementia presented an unwanted future to which interlocutors protested: “I don’t want that!” Such a view of dementia resonates more broadly, as well, since negative imaginaries of the disease are dominant

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<sup>19</sup> Fictional name of the nursing home where he received day care three days a week.

in media representations and dementia is widely considered one of the most frightening diseases in Western societies (Johnstone 2011, 2013). For example, commenting on how dementia is narrated and imagined in the United States, Basting (2009) distinguishes multiple fears: of being a burden, of the unknown, of being out of control, of losing one's self, and of a meaningless existence. Hellström and Torres (2016, 1571), in a Swedish context, highlight how couples living with dementia viewed the future as “predetermined and rather gloomy.” The anticipation of this unwanted future is further infused with strongly held, (neo)liberal values that prize individual autonomy and rationality, as well as socially desirable forms of behavioral and bodily containment. This resonates with a worldview, wherein certain lives corresponding to these values are deemed dignified while others are not, creating a norm for a “life worth living” (Lemos Dekker 2018). Anticipating the future with dementia as a life not worth living, can, in many cases, be considered a driving force behind the request for euthanasia.<sup>20</sup>

Herein the nursing home plays a key role (van Wijngaarden, Leget, and Goossensen 2015). Even while institutionalization during old age is common in the Netherlands, for many of my interlocutors the nursing home symbolized the loss of independence and control, and thus came to materialize the ultimate tragedy (cf., Leibing, Guberman, and Wiles 2016). Ms. Verbeek for example, during a conversation with her GP about her wish for euthanasia, said:

Actually, I wish to stay at home as long as possible, until I don't know it anymore and need to move to a nursing home. Then I want euthanasia. If I cannot stay at home, it's done. To be closed in, in a ward, what kind of life is that?

The prospect of moving to a nursing home, for Ms. Verbeek, Hanneke's husband, and many others, threatened their life and autonomy to such

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<sup>20</sup> Here, I wish not to reinforce the negative imaginaries of a future with dementia. Rather, I draw attention to this often powerful image of an unwanted future as a crucial element in my interlocutors' narratives and in the process of anticipation.

an extent that several interlocutors insisted that “euthanasia is the only alternative.”

Such images of losing independence and dignity circulate in the public domain and media (e.g., Johnstone 2011, 2013), but were often also infused with personal experiences from the past. “Both my father and brother used to live in a nursing home, so for me that is a limit, then it is enough,” said Ms. Verbeek, reminding us that how we perceive the past can guide how we anticipate the future (Bryant 2016, 26; Munn 1992, 115). Interlocutors shared stories of having witnessed dementia among acquaintances, which influenced their outlook on a future with dementia. Harold, for example, was very outspoken about this, explaining that people opt for euthanasia:

because too often we have seen things we don't want to be exposed to ourselves. That is why I want to maintain my self-determination. I have made that very clear to my GP. I have volunteered in a nursing home, and I would not wish what I saw there on anyone. Even though they are being cared for with love. But, well, that's not for me. I never want to be encountered like that.

A similar sentiment was expressed by Dorien, who, one year after her mother's death, reflected on the final year of her mother's life and her process toward euthanasia. She told me that her mother had witnessed her two older sisters, Jet and Cor, developing dementia and eventually moving to a nursing home. Dorien recalled: “the shocking image that she kept was how, during family dinners, Jet and Cor were unable to join in conversations. So she knew what awaited her. And she always said: “I do not want to become like Jet and Cor.” That was her doom scenario, becoming like that.” For Hanneke, the memory of her father's death and her husband's current condition together influenced her image of the future and whether she would want euthanasia if she were to develop dementia:

At some point I started seeing things I recognized from my father. My father went to the bitter end, curled up like a fetus, bedridden for half a year. The only time you could see he was alive was when

putting candy in his mouth. That image. I have always said, if I get Alzheimer's and I get to the stage my husband is in now, I want to be long gone. I refuse to do that to my children and grandchildren. And especially not to myself.

For those seeking euthanasia, this unwanted future haunts the present through fearful anticipation, threatening the worthwhileness of life itself. Euthanasia appeared to be an answer to this unwanted future. The possibility of euthanasia became associated with the possibility of a death without further degeneration and without becoming undignified. This conception of the future, together with experiences of loss in the present, places prospective suffering both in the future and present, collapsing these temporalities into a single experience. Here, Munn's (1992, 115) insight that "people operate in a present that is always infused, and which they are further infusing, with pasts and futures" further allows us to understand how the fear for a future with dementia that is experienced in the present already evokes that future and its associated suffering. Ahmed (2004, 65) makes this link between fear and anticipation more explicit, writing that "while the lived experience of fear may be unpleasant in the present, the unpleasantness of fear also relates to the future. Fear involves an *anticipation* of hurt or injury. Fear projects us from the present into a future" (emphasis in original). To anticipate a future of suffering, then, means not only to imagine it, but to engage that suffering in the present, as Dorien, Ms. Verbeek, and many others sought to fight it, to postpone it, and, ultimately, to put an end to it before it arrived. Anticipated suffering may become suffering in itself.

Through its affective force, anticipation demands action in the present, bearing a responsibility to strive for the best possible future.<sup>21</sup> The options available to my interlocutors seemed limited but also clear. Ahead of them they saw a choice between the nursing home or euthanasia. However, as I will show in the following section, while the request for euthanasia can become a way to position oneself as an active agent in pursuing one's well-being toward the end of life with dementia,

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<sup>21</sup> Adams, Murphy, and Clarke (2009, 256) term this imperative to strive for the best possible future "optimization."

this process of retaining control still encompasses many uncertainties and is subject to negotiations among the person with dementia, their family members and medical professionals (Norwood 2009). By elaborating on how the unwanted future comes to be acted upon through such negotiations, I argue that anticipation is a collaborative process.

## Negotiating the *When*

While anticipation establishes a future imaginary, I underline here that acting upon this future requires work and negotiation. Anticipating the end of life through a euthanasia request, requires establishing the *when*. It asks of the person with dementia, their family, and professional caregivers, to plan, book, and agree on the timing of death, which means it cannot remain a vaguely formulated reference to an unwanted future. The practical work of anticipation includes filling out forms, meeting with medical professionals, and, more generally, navigating the legal and medical systems of euthanasia and dementia.

In most cases, meetings between the GP and the person with dementia and their family members take place on a regular basis (cf., Norwood 2007, 2009).<sup>22</sup> While Ms. Verbeek, her niece Hannie, and I waited for her GP before one of these meetings, Ms. Verbeek seemed restless, rubbing her hands together and shuffling in her chair. The GP, Maarten Terbrugge, arrived and after greeting each of us we entered a small meeting room. Terbrugge was a young and jovial man. He wore a striped shirt and jeans and gave an approachable impression that, I found from witnessing his interactions with nursing home residents, often enabled him to create open conversations with his patients. He sat down at the head of the table with his back to the clock on the wall. I checked to see if he was wearing a watch, but he was not. He seemed not to be preoccupied with clock-time. On the table was an entirely different temporality: the timeframe of a request for euthanasia. In the

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<sup>22</sup> Usually, people with dementia who live at home have their own GP, while most nursing homes have an in-house elderly care physician, or an external GP who is affiliated with the nursing home.

conversation that followed, Ms. Verbeek, Terbrugge, and Hannie sought to clarify at what point the time for euthanasia would arrive. Ms. Verbeek repeated what she had told me when I had visited her at home: she wanted to stay at home as long as possible, and she wanted euthanasia if she would have to move to a nursing home.

“Why is having to leave your home the limit for you?” Terbrugge asked Ms. Verbeek. “Well,” she answered, “that I might walk onto the street and not find my way back home. You hear that sometimes, of people who start wandering. I would not want that.” Terbrugge tried to rephrase her answer: “So for you, admission to a nursing home means you will have degenerated to a point where you think you will be doing things you don’t want to do?” “Yes,” she answered, “then life has no point anymore, has it?” “So what makes that the limit?” Terbrugge repeated his question, seemingly trying to get a more concrete answer from Ms. Verbeek. “What are you afraid of? Is it the fact that you would have to leave your home, or further degeneration?” “Well, those two come together,” said Ms. Verbeek, and, after a short pause: “This situation will only get worse. I am sometimes a bit forgetful, and then I will not be able to discuss it anymore. So I felt I had to start this on time.” Terbrugge took a deep breath and said: “The point is that when the moment arrives when you would no longer be able to live at home, you will likely have regressed cognitively to a point where it will be hard to oversee the request.” To which Ms. Verbeek answered: “Well, I do want euthanasia, but not now.”

Meetings in which a request for euthanasia is discussed, such as this one, often revolved around the motives for the request, as well as the moment at which suffering would become unbearable. The anticipated, unwanted future that, as I have discussed above, is fundamental to the request for euthanasia in the context of dementia, and was often expressed in rather ambiguous and subjective terms, such as “when it becomes undignified” or “when I am no longer myself.” When meeting with the GP, however, the person requesting euthanasia needs to make these notions explicit and establish the boundaries of what they consider a life not worth living and unbearable suffering. These need to be described in concrete terms to the GP in order to comply with the legal

criteria that the physician holds the conviction that the patient's suffering is lasting and unbearable. In this light, Terbrugge was urging Ms. Verbeek to state concretely at what point, and why, she would want to receive euthanasia.

The repetition of such meetings makes it possible for the general practitioner to evaluate the consistency and continuity of the request. This is to comply with the legal criteria that the patient's request be voluntary and well-considered. As such the focus on temporal dimensions, such as consistency and continuity, contributes to the legitimacy of the request for euthanasia. Dorien described to me how her mother's GP had initially been hesitant, "but by now the GP has come to a point in which he says he may eventually do it. But that is only because we have had a meeting every month for the last half a year, and my mother is persistent in what she wants." During this period, Dorien had been proactive, realizing her mother would not have been able to navigate the process of requesting euthanasia by herself. She told me her mother was able to engage in conversations, but afterwards could not remember what had been discussed and agreed upon. Dorien said:

She can no longer do this by herself. She needs someone who can structure the process so as to give her a chance to, when the time comes, receive euthanasia. And, with hindsight, that has been crucial. Because I remembered what had been discussed, and made sure that a new appointment was made and that she would attend it.

Taking her role as the one responsible for "structuring the process" seriously, Dorien sought to have many medical professionals involved who would be able to confirm that her mother had indeed expressed a wish for euthanasia, an approach she referred to as "building a portfolio."

Similar to Dorien, Hanneke also made an effort to compile a track record of the euthanasia request. She explained, "We agreed with the GP now that my husband and I will meet every four weeks with her, to guide him through that difficult process." Hanneke then got up from the kitchen table and came back shortly with several documents: euthanasia request forms for her husband and herself. Two forms, dated 1990,

showed signs of folding and unfolding, one of them torn halfway at the fold, which made the page barely hang together. “These forms are falling apart as we speak,” Hanneke said,

So this spring we have filled out and signed new forms. It is not as if you can say, “I want euthanasia tomorrow.” It’s a long trajectory. It sounds strange, but it is about providing evidence – the burden of proof that this is what I want and have wanted for a very long time.

Anticipating the future through a request for euthanasia thus encompasses a complex negotiation of legal and social structures, involving the person with dementia, family members and friends, and medical professionals. In order for a euthanasia request to be considered, people with dementia and their family members have to demonstrate that their choice is deliberate and well-considered, and not a hasty thought. Here seems to lie an assumption that repetition over a longer period of time reflects a well-considered decision. Discussing the euthanasia request multiple times, as well as with multiple people, forming a collaborative reiteration, adds up to its legitimacy. Clearly, euthanasia is not requested in social isolation, as Norwood (2009, 183) emphasizes, “euthanasia is a family matter” (cf., Snijdewind et al. 2014). Anticipation is not merely an individual process of envisioning and acting upon a future; it involves building upon knowledge of how to navigate a specific system, in this case requesting euthanasia.

And yet this pragmatic approach, though necessary for a request to be considered by a GP, cannot cover the personal and social complexities of preparing for euthanasia. “In my mother’s case,” Dorien said, “it is ideally prepared. The only thing is that my mother has not said “yes” yet. If she would set a date, it would happen.” As I demonstrate in the following, and final, section, it is one thing to establish the timing of one’s death on paper or in conversation, but it is quite another to have to decide when that point is reached in daily life.

## Deferring the Future

In building a portfolio as part of the request for euthanasia, and in repeatedly discussing the topic with medical professionals, anticipation emerges not only as a future imaginary but also as an active, and interactive, process that brings the unwanted future into the present where it is acted upon. Yet it also became clear that this future was made distant: rather than fully collapsing future and present, the process of anticipation also involves the reiteration of their conceptual separation. Some anthropologists, such as Nielsen (2011, 2014) have sought to dissolve the conceptual distance between past, present, and future, dismantling its supposed linear sequence. In seeking to understand how change may, counter-intuitively, occur in non-linear and non-progressive ways, Nielsen (2014, 170) writes that “in a peculiar inversion of conventional linearity, the present becomes the effect of the future rather than vice versa.” However, while focusing on anticipatory practices underlines the entanglement of past, present, and future, it also demonstrates the importance of maintaining distance between present and future: the future is coming but not yet here. So while I agree with Nielsen that moments that are chronologically distanced from the present moment can be tied together and internally related in meaningful ways, I also find that the (sometimes repetitive) affirmation of the temporal distance between present and future can be one of the ways in which both are made meaningful. In the conversation between Ms. Verbeek and Terbrugge, for example, she appeared not so much preoccupied with convincing Terbrugge of her wish for euthanasia, as with demonstrating that she was still capable of living by herself at home. Ms. Verbeek emphasized repeatedly that she was only a little forgetful at times, with statements like “It’s not that I cannot function.” In this way, she sought to hold off the future.

This dynamic of deferral is fundamental to anticipation in this context, as it establishes the unwanted future as “not yet” through its engagement in the present. In many cases, The (2011, 3) writes, “people shift their boundaries as circumstances change” (author's translation). At one point, the person with dementia can envision certain future circumstances as “unbearable suffering,” but once these circumstances

are reached, their outlook on the situation may change and they may wish euthanasia to be postponed. Initially, Dorien reflected, her mother had been quite decisive as to her wish for euthanasia and the moment she wanted it. She recalled:

We were celebrating her birthday, in August, and she said, “I want to have a conversation with you all.” At the end of that day it was very clear. We were all startled—she told us she wanted to die before Christmas. She did not want to live for another winter. That was the worst, the winter. She also did not want to buy a new winter coat. Economical as she was.

Dorien chuckled, then, more seriously, she continued: “We then went to the GP, and there she repeated this. Not another winter. That was very clear.” However, even though Dorien’s mother voiced a moment in the future *before which* she would prefer to receive euthanasia, establishing a concrete moment for death would turn out to be challenging. Dorien continued:

So we proceeded to make appointments. However, in the meantime my daughter went traveling and would return mid-December. So we all assumed the euthanasia would take place while she was away. But then the postponing started. She wanted to wait for my daughter to come home. Then it was almost Christmas. And so she continued postponing. Then, the 6<sup>th</sup> of January was my son’s birthday and she did not want to die just before his birthday. Right after his birthday we had another appointment with the GP, so we thought, now she will set a date, but then she said my birthday was coming up. The intervals became shorter each time, but she kept saying “not yet”. Eventually she lived until the next summer.

The story related by Dorien reflects the difficulty of establishing the moment to end life through euthanasia. In trying to find the “right” time for euthanasia to take place, people generally do not mention a concrete date, but at first tend to refer to a broader timeframe or relate it to particular (future) events, whereby boundaries shift. As one NVVE volunteer said: “my experience is that people always hold on to life and always shift their boundaries.” Many interlocutors also indicated that,

even though they were requesting euthanasia, they would prefer a “natural” death, which in this context refers to a death before the imagined, unwanted future has become a reality, but one that does not require an active intervention. Such a death would relieve the burden of knowing the timing of one’s death. Ms. Verbeek, while we were having coffee in her living room, once said she would find it hard to know if that would be her last cup of coffee. She continued by saying: “I would prefer to be sitting there on the couch and just go.” Quite similarly, Dorien reflected on how her mother had struggled with this, and remembered her mother saying: “I cannot decide. I find it so hard because it is a decision to be made. I wish I would just get the flu, so it would just happen.” For many, the idea of being “taken away” by a “natural” death seemed much less demanding than actively planning and deciding on death – the difficult work of anticipation.

While deferral can take the form of people actively and self-consciously postponing decisions and shifting boundaries, one recurrent aspect, specific to dementia-related euthanasia requests, is that the person with dementia oftentimes is not exactly aware of how the dementia has been progressing (The 2017; Keizer 2003). This lack of insight into one’s own illness can result from cognitive losses, whereby the person for example assumes she is still able to perform daily tasks as she was used to, because she is unaware of having lost the capacity to do this. As NVVE volunteer Tina commented: “When *wilsbekwaamheid* becomes insufficient, then you are too late.” However, the thin line of losing cognitive capacity might pass unnoticed. One of the uncertainties in establishing the timing of euthanasia, then, is that it may not be evident when previously established boundaries of unbearable suffering are reached, when life is considered not worth living anymore. This line, further, is not definite. Dementia does not progress linearly, and moments of clarity can alternate with moments of disorientation, and while dementia confronts us with certain losses, life is not lost all at once (Hellström and Torres 2016). As the request becomes increasingly dependent on what family members referred to as “good” or “clear” days, moments when the person with dementia could have and

understand coherent conversations, the temporal distance between the unwanted future and the present becomes increasingly vague.

Ms. Verbeek had established boundaries for when she wanted to receive euthanasia, but might not have been aware that she had reached, or was close to reaching this point. When Terbrugge asked Ms. Verbeek about the things that were becoming more difficult in her daily life, she answered: "I am often forgetful but usually it does come back, you know." Her niece Hannie frowned disapprovingly. "Well," Hannie intervened, "some things are becoming more difficult, like hygiene. I find it difficult to confront her with that, but I find that I have to. Otherwise she thinks everything is fine, and it is not." At a certain stage Hannie and the GP might find it irresponsible for Ms. Verbeek to continue to live at home and deem it necessary for her to move to a nursing home, even though that was the line she had set for going through with euthanasia. Without full awareness of her illness, Ms. Verbeek may not realize whether she has progressed "too far."

Similarly, Dorien's mother made it clear she did not want to become like her sisters Jet and Cor when they had dementia. "Becoming like" encompassed a future she did not want to end up in. "We know she always said: 'I don't want to become like Jet and Cor,'" reflected Dorien, "but the funny thing was that Cor's children would say to me, 'When I see your mother, she looks so much like our mother when she was in that phase.'" While Dorien's mother placed "becoming like" her sisters in the future, her family members already linked her present state to that image. This raises the question of when such a subjective boundary is reached. It also demonstrates that Dorien's mother was not aware to what extent she had already "become like" Jet and Cor, and thus how her condition had already degenerated. Hanneke similarly commented on her husband's limited awareness of his illness: "This summer he was telling the neurologist that he was going to pick up Greek again, reading Greek books." She said. "But the books are gathering dust on his table. He cannot read anymore. And then he has been telling people about starting a Spanish course, which he has been saying for seven years now."

At some point, it may become "too late" for euthanasia, as the person with dementia may become unable to confirm the request as the disease

progresses. This brings me back full-circle to the ethical dilemma I addressed in the introduction, wherein a person with dementia who wishes to receive euthanasia has to request for it “too early” or else it becomes “too late” (cf., The 2017). If the person with dementia can still confirm the request, this means it may be too early for euthanasia—too early for the person with dementia herself, because she is still enjoying life, and too early for the GP, who will not perform euthanasia if the person with dementia is still doing well, or before she is convinced the person with dementia is suffering unbearably. Hanneke quoted her husband, describing his biggest fear: “if I decide now, I will die too early. And who knows how many years or months I still have.” Hanneke continued: “He keeps saying, “What if I still had half a year left, then I would die too soon.” But he has shifted his boundaries so many times now. Soon there will be nothing left.” Hanneke realized that, as her husband kept postponing the moment for euthanasia, there could come a point where it would no longer be possible.

Family members were often aware of this possibility, as they witnessed the degeneration in the person with dementia. They often worried that the temporal window for euthanasia would be missed. For Dorien, this raised another element that she found “very complicated”:

My mother had explicitly asked me to warn her if she declined too far. And I said, ‘yes mom, I will.’ But how to do that? It’s an impossible promise to take on. Afterwards, I regretted so much that I said that. For years, I have thought, when am I going to tell my mother, ‘mom, I think you’re declining too far?’ But then that moment came, it was before Christmas, and I said, ‘I think you will need to start thinking about setting a date.’ Well, to say something like that to your mother, who you love. I thought perhaps mid-January, and told her I believed it would be too late if she waited longer. She agreed with me, but Christmas was fun; she didn’t want to die yet.

What interlocutors wished to avoid was a future that was considered undignified, thus life would need to end before this point is reached. Referring to this, NVVE volunteer Jan said: “On time is one minute to twelve. A quarter to twelve is too early. It’s impossible, because you

never know when it's one minute to twelve.” One of the difficulties, then, is that the “right time” can in many cases only be evaluated with hindsight. Exactly *when* the time for euthanasia has arrived—a moment wherein the person with dementia is still able to confirm the request and considers her suffering unbearable—is in many cases extremely difficult and impossible to anticipate.

## Conclusion

Acting in the present upon an imagined future establishes a tense relation to the future as a time that is yet to come. In anticipation, the future is already lived but it is also held off, relegated to the possible or the imminent. Ms. Verbeek's remark that she wanted euthanasia *but not yet* echoed not only how difficult it appeared for many people with dementia to establish the *when* for euthanasia, but also how anticipation did not unilaterally bring the future into the present, but worked to establish temporal distance between the future and the present. This process was delicate: it entailed an intimate, though often uneasy, correspondence between actions and affects in the present and the imagined future, each continuously reforming the other. Involving thus both the constitution of a future imaginary and the process of acting upon it in the present, I suggest that anticipation is a process in which perspectives change and boundaries can shift. This is important for the anthropology of time more generally because it gives insight into how the temporal distance between future and present can be established, collapsed, and renegotiated.

Further, this research makes clear that anticipation is not an isolated, psychological process, but culturally embedded. Anticipation, as the dual process of establishing a future and acting upon it, is done collectively and in negotiation. Not only the person with dementia requesting euthanasia anticipates: their family members were in all cases deeply involved, as were GPs and volunteers. This process involved the reiteration of established wishes and boundaries as well as their reformulation and deferral. Collaboratively, then, people with dementia, family members, and medical professionals sought to navigate the

agonizing trade-off between being “too early” for euthanasia and the fear of being “too late,” continually testing out images of the unwanted future against changing circumstances in the present.

Euthanasia in the Netherlands is shaped by local notions of autonomy and control, the loss of which is associated with a loss of dignity. But among people with dementia, the loss of autonomy as the motivation for requesting euthanasia also becomes the main factor threatening its possibility. The foresight of an unwanted future wherein control will be lost, for many interlocutors, stressed the importance of acting in advance, to prevent the unwanted future before it became a present reality. In the highly affective process of anticipating the end of life through euthanasia, the person with dementia, their family members, and GP together search for an ideal moment, which should consist of overlapping timeframes wherein she can still state her wish for euthanasia at a point in time when life is deemed not worth living anymore. Often, these timeframes exclude one another.

For Dorien’s mother, despite a long process of deferral, the timing of euthanasia eventually became clear. In early spring, she fell and broke her hip. She had established a written statement that explicitly stated she did not want to be hospitalized in the case of a broken hip, but wished to be cared for at home where she would be allowed to die. Nevertheless, in that moment she made it very clear to Dorien and the attending medical staff that she wanted to proceed with surgery. Dorien quoted her saying, “If I do not have the operation, I would be choosing death, and I cannot do that now.” Following the surgery, Dorien’s mother moved to the recovery unit in a nursing home. In the first few weeks after the surgery she was delirious, and reacted anxiously to the dark paintings of a giraffe and a lion that were hanging in her room. Yet little by little, and contrary to expectations, her condition improved. Dorien told me that her mother became very clear about her wish for euthanasia:

When I visited to tell her, ‘Tomorrow we will have a conversation with the physician,’ she said, ‘In that case I will tell him I want to die and that I want euthanasia. I have been letting it all sink in, and I don’t want this. I am now like Jet and Cor and that’s exactly what I didn’t want.’

The next day, the elderly care physician broke the news that she had to move to a psychogeriatric nursing home unit. Dorien's mother remained steadfast, and Dorien quoted her saying, "But that is not what I want. I want euthanasia." Knowing that her GP was willing to proceed with euthanasia, Dorien's mother went home, where eventually her wish for euthanasia was granted.