



Departing Together, Leaving Alone:  
A Situated Philosophy of Hospice Care

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## Prelude

*I hopped on my bicycle and pushed hard on the pedals. As I biked off the college campus and onto the road, I made my way through the dewy park, then the residential area, and finally, into the buzz of the commercial city center. Cars honked, children yelled, salespeople loudly advertised their goods, and acquaintances bumped into one another on their way to the grocery store. A crescendo of life welled up and just before it reached its boiling point, I rang the bell next to a big green door.*

*Upon entering, the hospice's tranquillity washed away the bustle of the streets. I heard chatter coming from the rooms, the coffee machine gurgled away, filling the hallway with its earthy aromas. The sounds of 11.00 am on a Saturday. After hanging my jacket up, I went out back. There, I found David sitting on a lounge chair with his eyes dreamily looking up at the apple tree. A slight smile of contentment on his face. I am still not sure what he was thinking about that morning. It might have been his brother, who came to visit later. Perhaps he was thinking of his next meal or what the weather would do. Maybe he was guessing the outcome of that day's football match. He might have thought about his parents. Would they be proud of the life that he had lived? Did he think about the mountains he had scaled or the regrets he carried with him? Did both mountains and regrets appear small in hindsight? Did he think about what his daughter might do after her study? Was the bird song taking him back to his 1986 summer trip in Barcelona, when he lost his shoe on a nightly skinny-dipping excursion?*

*All of these thoughts might have gone through his head. Simultaneously, his smile revealed a profound presence. He was there, his feet firmly planted on the ground. He must have felt the wind on his skin and the sun on his head. He must have been lost in that Birdsong, so ruthlessly spreading him between Barcelona and the hospice's garden. He must have thought about what he had in common with this little creature that would outlive him.*

*He must have felt the weight of his body in the chair, fully present in a now that encapsulated his entire past and future. He must have felt at home.*

When I started my participatory fieldwork for this thesis in a small hospice in a Dutch city, I thought I would write about a dark and dreadful place where hospice inhabitants agonizingly ponder about their own mortality. What I found couldn't be further removed. As many hospice workers told me: 'the hospice is more about life than it is about death.'

But what is 'life' to the hospice? It is but the *shaping* of our world while our world *shapes* us. To be present with all those connected to us.

# Introduction: Arriving

*"That's the door through which you entered." Jasmijn, the hospice volunteer coordinator, was already showing me around the building after our initial meeting. While I pictured the hospice as a dark place, I now found myself almost blinded by the sunlight pouring through the stained-glass windows. I would spend many days running back and forth in that hallway with bowls of soup, cups of coffee, cleaning supplies, or freshly cut flowers.*

The goal of this thesis is to present a situated philosophy of hospice care that I have come to enact as a volunteer in a small hospice in a Dutch city.<sup>1</sup>

From February 2020 until December 2020, I spent roughly two 4-hour volunteering shifts in the hospice per week, with the exception of a few breaks and holidays. During these shifts, I tried to be entirely present with the tasks at hand.

Back home, however, I reflected on my inter-actions during the shift in two to five pages of field notes. Additionally, I conducted six in-depth qualitative interviews, each 40 to 70 minutes long and three walk-along interviews. The transcribed interviews and field notes helped me reflect on my interactions in the hospice throughout the writing process. I distilled the current philosophy from these reflections.<sup>2</sup>

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<sup>1</sup> I have already presented early conceptions of some of the ideas present in this thesis in "When Silence is the Expected Answer" with regard to the loss of communicative faculties in the final stage of life. The current work goes beyond communication loss, draws deeper philosophical conclusions, and presents more complete versions of these early explorations. Sam van der Lugt, "When Silence is the Expected Answer: Maintaining Personhood in the Last Phase of Hospice Care" in *Students of Cultural Anthropology Journal* 2, no. 1 (November 2020): 103-114. [https://27bda672-d8c6-4aed-838b-075b69debc85.filesusr.com/ugd/f00c4a\\_2e31d0edfff94a249bce156dbcf271e.pdf](https://27bda672-d8c6-4aed-838b-075b69debc85.filesusr.com/ugd/f00c4a_2e31d0edfff94a249bce156dbcf271e.pdf).

<sup>2</sup> 'Distilling' is the word I chose here, because 'distillation' mediates the substance in such a way that its valuable characteristics become more palpable.

As 'situated philosophy,' this thesis is firmly positioned between the social sciences and philosophy. The traditions of social science and philosophy (ontology and metaphysics in particular) have long been treated as separate domains.<sup>3</sup> It is the primary task of the philosophers to ponder the universal nature and logic of reality from their reading chairs, while social scientists generally steer clear from ontological musing when presenting findings from the field.<sup>4</sup>

However, Mol argues that different systems of everyday practice construct their own, highly particular ontology and logic.<sup>5</sup> When we see objects of medical practice (e.g., 'the body,' 'good care,' 'the patient') as *enacted* rather than pre-existent before any action, they take up highly diverse characteristics depending on the situation they are enacted in.<sup>6</sup> The next task for social scientists is to join philosophers and draw the full ontological conclusions from their findings in the field.

Similarly, the phenomenological tradition has argued that any understanding of reality is contingent on embodied and situated modes of relating and attuning to the world.<sup>7</sup> Also here, the understanding of reality is shaped by concrete activities. Heidegger demonstrates how Descartes' rather unnatural activity of staring at candle wax and pondering its essence, enacts an entirely different ontology from someone who lights the candle so they can see.<sup>8</sup>

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<sup>3</sup> Bruno Latour, *Reassembling the Social* (Oxford: Oxford University Press, 2005), 13, 117

<sup>4</sup> Clive Lawson, John Latsis, and Nuno Martins, "Introduction: ontology, philosophy, and the social sciences." in *Contributions to Social Ontology*, ed. Clive Lawson, John Latsis, and Nuno Martins (New York: Routledge, 2007), 1.

<sup>5</sup> Annemarie Mol, *The Body Multiple: Ontology in Medical Practice* (Durham, NC: Duke University Press, 2002); Annemarie Mol, *De Logica van het Zorgen: Actieve patiënten en de grenzen van het kiezen* (Amsterdam: Van Gennep, 2006)

<sup>6</sup> Annemarie Mol, "Embodied Action, Enacted Bodies: the Example of Hypoglycaemia," *Body & Society* 10, (2004): 43-62, <https://doi.org/10.1177/1357034X04042932>.  
Mol, *The Body Multiple*, 5-6.

<sup>7</sup> Martin Heidegger, *Being and Time*, trans. Joan Stambaugh (Albany: State University of New York Press, 2010)

Maurice Merleau-Ponty, *Phenomenology of Perception*, trans. Donald A. Landes (New York: Routledge, 2012)

<sup>8</sup> Heidegger, *Being and Time*, 53-62.

The sitting, reading, and pondering 'scholar's body' implies a peculiar mode of relating to the world.<sup>9</sup> The next task for phenomenological philosophers is to abandon their arm-chairs, that even Heidegger and Merleau-Ponty inhabit, and join their social science colleagues in letting situated, embodied, activities shape their ontologies.<sup>10</sup>

This project stands between philosophy and social science, trying to describe hospice practice without assuming its objects are pre-determined and exploring the fundamental nature of hospice care's objects without assuming their ontology and logic is universal and accessible prior to engagement in concrete situations.

*"To the left here, right next to the main entrance, there is the volunteer room."*  
*Standing in this room, I could hear the outside's traffic in my left ear, while my right ear received the coffee machine's gurgling and the nurse's washing of the inhabitant in room 4.*  
*"We currently have about 60 volunteers who all meet here at the beginning and end of their shifts during handover. This is when the volunteers ending their shift discuss what happened with those starting. We often close this intermediate door, cause these conversations can get sensitive. All the file folders also stay in this room." The faces of all 60 volunteers smiled at me from the blackboard. Most of them appeared to be well over retirement age, with the addition of some students and a handful of volunteers in their 30s and 40s. This room, with*

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Kalpana Ram and Christopher Houston, "Introduction: Phenomenology's Methodological Invitation," in *Phenomenology in Anthropology: A Sense of Perspective*, eds. Kalpana Ram and Christopher Houston (Indiana: Indiana University Press, 2015), 3.

<sup>9</sup> Paul Stoller, *Sensuous Scholarship* (Philadelphia, PA: University of Pennsylvania Press, 1997), ix-xviii.

<sup>10</sup> *Phenomenology in Anthropology* includes great examples of how this can be done. Some noteworthy chapters:

Monica Dalidowicz, "Being 'Sita': Physical Affects in the North Indian Dance of Kathak," 90-113; Greg Downey, "Beneath the Horizon: The Organic Body's Role in Athletic Experience," 114-137; Robert Desjarlais, "Seared with Reality: Phenomenology through Photography, in Nepal," 197-223, in *Phenomenology in Anthropology: A Sense of Perspective*, eds. Kalpana Ram and Christopher Houston (Indiana: Indiana University Press, 2015).



*its large table and framed poetry covering the walls, would be where I would reflect at the beginning and end of all my shifts. A true 'backstage' area.*<sup>11</sup>

The 'situated' aspect of 'situated philosophy' comes from Haraway's 'situated knowledges': systems of knowledge that gain their substantiality from their connection to particular and partial embodiment within situations.<sup>12</sup> Historically, claims to solid knowledge have precisely been based on shedding 'subjective' biases stemming from particular situatedness in exchange for 'objective' knowledge, attained from a 'view from nowhere'. Haraway calls this claim to unmediated universal 'objectivity' the God-trick.<sup>13</sup> Only individuals with a specific type of embodiment have historically been allowed to claim, like gods, that they had no embodied situatedness at all.<sup>14</sup> Therefore, the God-trick helped universalize a particular set of modernist ideas which were valid for upper-class, white men, occupied with constructing thoughts (an activity highly particular to scholars). These ideas become debilitating if, under the guise of 'universality,' they cover over knowledges from different situations, such as hospice care. In short, 'there is no metalanguage.'<sup>15</sup> Solid knowledge should recognize itself as particular, limited, and situated, its feet firmly planted on the ground it is born out of.<sup>16</sup>

I decided to switch the 'knowledges' part of 'situated knowledges' with 'philosophy' based on Mol's 'empirical philosophy' works, in which she extracts philosophies from

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<sup>11</sup> Erving Goffman, *The Presentation of Self in Everyday Life* (London: Penguin Books Ltd., 1959), 114.

<sup>12</sup> Donna Haraway, *Simians, Cyborgs, and Women: The reinvention of Nature* (London: Free Association Books, 1991), 183-201.

<sup>13</sup> Haraway, *Simians, Cyborgs, and Women*, 189.

<sup>14</sup> Haraway, *Simians, Cyborgs, and Women*, 183.

<sup>15</sup> Jaques Lacan, *Ecrits: A selection*, trans. Alan Sheridan (London: Tavistock, 1977), 311, quoted in Timothy Morton, *Hyperobjects: Philosophy and Ecology after the End of the World* (Minneapolis: University of Minnesota Press, 2013), 4.

<sup>16</sup> Haraway, *Cyborgs, Simians, and Women*, 183-201.

Timothy Morton, *Hyperobjects: Philosophy and Ecology after the End of the World* (Minneapolis: University of Minnesota Press, 2013), 81-95.

concrete medical practices.<sup>17</sup> *The Body Multiple* focuses on the ontology of atherosclerosis patients in a hospital, while *The Logic of Care [De Logica van het Zorgen]* centers around the logic of GP care for Diabetes patients.<sup>18</sup> For the purpose of this thesis, I did not want to split the hospice's 'ontology' and 'logic,' so I settled on 'philosophy': how hospice care enacts its objects, and how these objects are meant to interact with one another.

This situated philosophy of hospice care adds nicely to Mol's works for two reasons. Firstly, all these works are based on practices in the Dutch care system. Their philosophies work alongside one another and grant some careful comparison. Secondly, the hospice's palliative philosophy contrasts with the more curative and biomedical philosophies in Mol's works. The hospice facilitates the shift from life to death, while trying to involve as many of the guest's relations as possible. This distinct mandate, characterized by its transitoriness, gives rise to distinct terms and boundaries.

*"These are our four guest rooms." Jasmijn had already explained how the hospice referred to its terminally ill inhabitants as 'guests.' The term 'guests' still seems dissonant to me, given that guests merge with their rooms so intimately that hospice volunteers occasionally use guests' names and the numbers of rooms as metonymy for one another.*

*I would see these rooms change many times. Each of them already has a distinct quality - room 1 and 2 are in direct sight of the kitchen, perfect for those who need some more help, room 3 is the biggest one and has a beautiful panoramic view of the garden, and room 4 is more privately located on the other side of the hospice - but the guests would fill the room with their own character. One of the things that hospice workers value most about*

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<sup>17</sup> Explanation of 'empirical philosophy' in Mol, *The Body Multiple*, 4-7.

Relevant works: Mol, *The Body Multiple*, *De Logica van het zorgen*, *Enacted Bodies*, and *Embodied Action*.

<sup>18</sup> Mol, *The Body Multiple*.

Mol, *De Logica van het Zorgen*.

*this hospice is the diverse set of people who come here. The only thing hospice guests truly have in common is their life expectancy below three months and their diseases - mostly cancer or other diseases with predictable trajectories - that this expectancy is paired with. The general age range of hospice guests is anywhere from 45 to 95, and they come from vastly different backgrounds: Dutch, Turkish, German, English, Rich, Poor, without formal education, attained a PhD.*

What do I refer to when I mention 'the hospice'? The hospice consists of a multitude of parts which subscend the whole.<sup>19</sup> These parts make it possible to encounter the hospice while never encountering 'the whole.' The hospice workers (meaning 'volunteers, nurses, and coordinators'), guests, GPs, family, and friends are 'the hospice.' I am 'the hospice.' The hospice building is 'the hospice.' Even the pills, oxygen machines, cookies, pens, and file folders are 'the hospice.' In Latour's terms, the hospice's parts *inter-act* in such a way that they assemble the actor-network of 'the hospice.'<sup>20</sup> I got to know 'the hospice' and its philosophy by *inter-acting* in this actor-network, thereby, becoming an actor in the network myself.

Simultaneously, I take up a highly specific position within this actor-network. I worked in the hospice as a volunteer and communicated with the hospice network based on my particular habits and background. My positioning within the hospice network, therefore, mediated my understanding of the network, creating a situated, partial understanding.

This thesis is fully mediated by my personal history and embodiment.<sup>21</sup>

Simultaneously, the hospice shaped me during my time as part of the network. When I started

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<sup>19</sup> Timothy Morton, *Humankind: Solidarity with Nonhuman People* (London: Verso, 2017), 199.

<sup>20</sup> Latour, *Reassembling the Social*, 202.

<sup>21</sup> I borrow the terms 'mediator' and 'intermediary' from Latour, who describes 'mediators' as entities that 'transform, translate, distort, and modify the meaning or the elements they are supposed to carry,' while an intermediary 'transports meaning or force without transformation. (Latour, *Reassembling the Social*, p. 39)

this project, I thought it would be about existential dread at the end of life. Gradually, however, my outlook on life and death shifted through my attunement to the hospice. The more I lived through hospice care, the more I got acquainted with a philosophy that hospice care lives by. As Morton writes about interobjectivity: "*The human anthropomorphizes the cup and the cup cup-omorphizes the human, and so on.*"<sup>22</sup> In my engagement with the hospice network, I Sam-morphize the hospice, while the hospice hospice-morphizes me. I then thesis-morphize this process in this philosophy. Since this philosophy is a collaborative effort constructed through attunement between me and the hospice it stands in interobjective solidarity with both me and the hospice.

I should make my particular embodiment and history specific, given that it plays a large role in the construction of this situated philosophy of hospice care. Simultaneously, presenting a list of personal characteristics that affected my account, creates the illusion that these characteristics are exhaustive.<sup>23</sup> According to both the phenomenological tradition and Actor-Network theory, *everything* about my situation mediates my experience. The fact that I am one of the youngest hospice volunteers changes the way that the hospice network interacts with me. I am also able-bodied, white, male, and a student. All these aspects mediated my experience. But it doesn't end there. I forgot to brush my teeth once, and consciously stood further away from all others in the hospice. Did they interpret my distance as aloofness and treat me differently for it? Did reading literature on the philosophy and anthropology of care change the way I cared for guests in the hospice? Does it matter that I am both Dutch and American, grew up in the Netherlands, but mostly speak English in daily life? Surely it did, because other volunteers commented on my slight accent almost every shift. All of these characteristics mediate my account. Yet, it is not possible to trace any single aspect in my

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<sup>22</sup> Morton, *Hyperobjects*, 89.

<sup>23</sup> Haraway, *Cyborgs, Simians, and Women*, 186.

philosophy back to any single characteristic. Situated reality is too multifaceted and messy to adhere to clean dissection. Still, it might be helpful to gain a general sense of my personal historicity, through which I inter-acted in the hospice. In chapter 1, I suggest that the descriptions of guests in the hospice's file folders don't coincide with the guest or exhaust them, but they do grant a sense of the hospice guest.<sup>24</sup> This inspired me to make a file folder for myself to give any curious reader a general sense of my positioning.



<https://docs.google.com/document/d/1hzh7mmpy152cacwD2oHcdThKS3tUihZqJQk3mzutPU/edit?usp=sharing>

*The kitchen evolved around a large round table. "This is where you'll spend most of your time during the shifts. It's really the center of the hospice." From here, one could hold all four rooms on the perimeter of one's field of vision, providing a comfortable overview of the hospice. I would spend much time here cooking, folding laundry, checking up on guests, sharing meals with people in the hospice, and reading when there was no chore left on the kitchen's to-do list.*

As all language not only communicates, but also mediates and shapes the actions it refers to, I consciously chose which vocabularies were suited to explore the hospice philosophy. The first is phenomenology, mostly from Heidegger and Merleau-Ponty.<sup>25</sup>

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<sup>24</sup> I use Merleau-Ponty's concept of 'sense' here as an affective, experiential apprehension that extends beyond the qualities of its perceived parts.

Merleau-Ponty, *Phenomenology of Perception*, 4, 13.

<sup>25</sup> Heidegger, *Being and Time*. Merleau-Ponty, *Phenomenology of Perception*.

Phenomenology and the hospice's philosophy interlink because they are both oriented towards the complexities of (human) experience. In the end, the hospice's goal is to shape the guest's experience at the end of life. In hospice care practices, Cartesian and modernist binaries that are perpetuated in everyday language - such as body and mind, individual and collective, and subject and object - become difficult to justify.<sup>26</sup> Many of these binaries are co-responsible for the idea of a mind transcending all embodiment in a view from nowhere.<sup>27</sup> For Descartes, the distinction between 'res cogitans' and 'res extensa' might have been obvious, situated in his armchair by the fireplace. In hospice care, on the other hand, these distinctions are far from obvious if they are not presumed *a priori*. Is helping a hospice guest to turn in their bed so they can face their daughter one last time care for the body or care for the mind? Hospice care is located in the liminal intertwinement of these binaries. Mediating the hospice's philosophy through phenomenological terms (e.g., 'attunement,' 'mood,' 'care,' 'body schema,' 'sense,' and 'intentionality'), as opposed to terms from everyday language, allows me to construct a philosophy that stays with this intimate intertwinement without reducing it to either side of a binary. Simultaneously, hospice care will give these terms a new sense, mediating phenomenology through concrete care practices.

*From the second floor, I could still hear some voices and clattering of dishes coming from downstairs, but they were less immersive. Simultaneously, the sounds of the busy street outside seeped through the windows. There is some distance between the second floor and the literal groundwork of the hospice.*

*The first room she showed me was the nurse's office. It was centered around a single laptop through which the nurses connect to online platforms with medical records.*

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<sup>26</sup> Haraway suggests some of these binaries in *Simians, Cyborgs, and Women*, 177.

<sup>27</sup> Haraway, *Simians, Cyborgs, and Women*, 183-201.

*Then, there was the coordination room, often referred to as simply 'the office.' "This is where I work." Jasmijn announced proudly. There were three working spaces for the three different coordinators: the volunteer coordinator, care coordinator, and facilities coordinator.<sup>28</sup> Files upon files surrounded these desks, neatly tucked away in drawers. Documents about previous guests, contact information for outside institutions, information about volunteers, checklists of materials that need to be fixed or bought, financial records, and memories of previous guests. Information constantly flowed in and out in this office through emails, digital files, post-its, phone calls, and online portals. This is where the hospice's various connections beyond the big green door were sustained.*

While hospice care is geared towards human experience, I will also try to bring in as many non-human actors as possible, inspired by Actor-network theory (ANT).<sup>29</sup> There seems to be a tension between ANT and phenomenology, one focussed on human centered experience, the other trying to get as far away as possible from any whiff of anthropocentrism.<sup>30</sup> Within the scope of this project, however, this marriage is justified, firstly, because both vocabularies circumvent Cartesian binaries.<sup>31</sup> Secondly, the hospice's philosophy is oriented towards experience from a human situation, but this human experience teems with non-human entities and is possible only through its subsistence into these non-humans. The morphine pump and the human intertwine in an ever-shifting relationship. Throughout the thesis, I will try to include the intimate roles that non-human actors play in the logic of a system oriented towards human embodiment, how these actors come to merge,

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<sup>28</sup> The director also works in this office, but during my time at the hospice, she was not often present due to illness and other personal circumstances.

<sup>29</sup> Latour, *Reassembling the Social*.

<sup>30</sup> Latour, *Reassembling the Social*.

<sup>31</sup> Tihomir Mitev, "Semiotics and Phenomenology in the Social Study of Science: About Some Limitations of Actor-Network Theory," *Sociological Problems* special, (2006): 69, <https://www.cceol.com/search/article-detail?id=32804>.

and how they constitute new forms of cyborgs, challenging strict demarcations of the human/object binary.<sup>32</sup>

*"The main purpose of the family room is to give families a space where they can meet and have difficult conversations in private. If they want to stay close at night, the family can also sleep in the attic." The family room contained both a large conference table and a more casual couch area. It was also the only room that had a door which could only be opened from the inside, ensuring full privacy.*

Since embodied experience is an integral part of this thesis, I will also try to engage the senses in my writing. Wynn shows that both the traditions of philosophy and early anthropology have been particularly poor at engaging embodied emotion in writing.<sup>33</sup> The hospice, however, is a place of emotion. It is where lives come to end, relationships break off, and some of the most precious connections are formed. I will be content if I can not only convey the hospice's 'formal logic,' but also a sliver of its sense and emotion.

This embodied sense will primarily be included through vignettes of my interactions with a hospice guest called 'David.' In fact, David is not a single guest, but an assemblage of my interactions with a handful of hospice guests. He serves two purposes. Firstly, centering the entire project around one character enables me to describe a single hospice trajectory in more depth than I could if I split the reader's attention between multiple characters. Secondly, he enabled me to write about hospice practice without compromising confidentiality of actual interactions I had with the guests. In pursuit of the latter, I also modified specificities of my

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<sup>32</sup> Haraway, "A Cyborg Manifesto: Science, Technology, and Socialist-Feminism in the Late Twentieth Century" in *Simians, Cyborgs, and Women*, 181.

<sup>33</sup> L. L. Wynn, "Writing Affect, Love, and Desire into Ethnography", in *Phenomenology in Anthropology: A Sense of Perspective*, eds. Kalpana Ram and Christopher Houston (Indiana: Indiana University Press, 2015), 224-247.



interactions with David, as long as they increased anonymity while leaving the nature of the interaction intact. To keep integrity, I ensured that I could trace every event that I described with David to a specific interaction with a real hospice inhabitant, and that the interaction fulfilled a similar role in David's story and that of the particular guest that I had this original interaction with.

David's character is based on a group of guests in the hospice who were relatively young, had strong family relationships, and were highly successful in 'making the hospice their home.' He represents a group of guests who made this hospice philosophy most salient.

*Finally, Jasmijn led me to the garden. The terrace, bordering on the kitchen, looked out over the adjacent church, a grass field, and pine trees. It was hard to remember we were still in the middle of the buzzing city center. It was a perfectly serene place, where I would often sit outside and ponder what exactly made the hospice so valuable.*

Chapter 1 argues that hospice care is oriented towards the guest's relations to their surrounding world (the in-between). Then, chapter 2 explores how these relations are brought into the hospice and continuously re-enacted to create a sense of 'feeling at home.' The hospice network attunes to the guest's relations and enacts them together with the guest, so these relations can be maintained in the face of decline (chapter 3). Throughout this process, direction of how these relations are enacted is distributed in different ways, which are explored in chapter 4. Then, I argue that the in-betweenness of hospice care dissolves certain clear-cut boundaries and actively works to constitute new boundaries between networks of relations (chapter 5). Chapter 6 explores the questions that arise when various values of hospice care stand in conflict with one another. Then, I argue that the hospice never creates the same degree of homeliness as the guest's house before arrival but falls short in some

aspects while exceeding it in others (chapter 7). Finally, I conclude that these aspects together enable the hospice network and the guest's network to intertwine intimately for a short period of time, generating a strong presence before untangling once again.

# 1. File Folders

In *The Body Multiple*, Annemarie Mol argues that hospital practices reveal who the 'enacted' atherosclerosis patient is.<sup>34</sup> The hospital's medical files enact the patient in a highly specific way. These files contain everything that happened to the patient's anatomical body, that might be of importance for treatment. What were their previous reasons for visiting the hospital? What was the outcome of the blood measurement?<sup>35</sup> The *enacted* patient in the hospital files is an anonymous human body, which malfunctions in such a way that it requires medical treatment. It is also in the hospital's interest to keep these files as brief as possible. Adding facts that are not essential to treatment might undermine efficiency.<sup>36</sup>

The hospice's file folders couldn't be more different. They show everything:

*At the start of the shift, one of the volunteers told me there was a new guest in room 2: David. After 'handover,' I stayed in the volunteer room to glance through his newly created file folder.*

*First, there was a general overview of personal information:*

Name: David Bergens  
Address: Kerkstraat 17  
Date of birth: 06-07-1965  
First contact: Gerard Bergens  
Relation: Brother  
Diagnosis: Lung cancer with melanoma

Character: David has a calm and laid-back presence. He is quite independent, but also enjoys a nice chat.

Family: David's parents are still alive and come to visit regularly. He has an ex-wife, who he hasn't had contact with over the past ten years. After the divorce, his daughter,

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<sup>34</sup> Mol, *The Body Multiple*.

<sup>35</sup> Mol, *The Body Multiple*, 56-58: part of medical file sent from the hospital to a GP. Additionally, hospice workers (nurses, volunteers, and coordinators) who worked in the hospital prior to the hospice, commented on the difference between the hospice's files and the hospital's/GP's in interviews and throughout my fieldwork.

<sup>36</sup> Brit Ross Winthereik and Henriette Langstrup, "When patients care (too much) for information" in *Care in Practice: On Tinkering in Clinics, Homes and Farms*, eds. Annemarie Mol, Ingunn Moser, and Jeannette Pols (Bielefeld: Transcript Verlag, 2010), 209-210.

Emma, mainly lived with him. He has a strong relationship with Emma. His current partner, Monica, will come to visit almost daily. Gerard, his brother, lives close to the hospice and can come by in case of an emergency.

Religion: raised Catholic, but not particularly religious.

Hobbies: David loves music and played guitar in a band for years. He also likes the local football club, Hiking, and painting. He used to be a big traveller.

*Then, there was a section termed 'around dying' [rondom overlijden]. Normally, this would be where the family and the guest put all their preferences about what happens after the guest's death. Would they want the hospice volunteers to remove jewelry from the body? Who will organize the funeral? Does a family member want to wash the body themselves? As David had just arrived, however, it was not yet the time to ask these sensitive questions and forms remained blank.*

*Next up, there was the 'points of attention' [aandachtspunten] section:*

David gets opioids when he is uncomfortable, but he is not allowed to have access to them himself, because his GP fears he has addictive tendencies. When he wants painkillers, he should inform a nurse, who will manage them. His cancer might make him feel nauseous and ruin his appetite, but generally, he has a real sweet tooth and enjoys desserts. He will often go out to smoke cigarettes on the terrace. Generally, he can walk to the terrace himself. Sometimes, however, he prefers that someone walks with him to decrease the danger of falling.

*The next three dividers were empty. In the past, nurses kept their updates and medical records, similar to those in the hospital, here. Now, however, they kept their own (online) records separate from the volunteer folder.*

*Then, the sections 'Standard medication sign-off' and 'when necessary medication sign-off' included a sheet of paper for every type of medication that David received.*

*Whenever he would receive medication, at least two hospice workers would have to sign, stating that he received the right substance and dosage.*

*Finally, there was the most important part for volunteers: the 'Report' section. After every shift since David had arrived in the hospice, one volunteer would jot down a brief message of interactions that they had with David throughout the shift:*

Shift 1; Sharon and Nellie

David was fast asleep throughout the entire shift

Shift 2; Rick and Andrew

David woke up around 11.00. He then had his breakfast (a sandwich with egg and cheese) and sat outside. Later, his sister came to visit. They went for a little walk in the wheelchair. He mentioned that he was slightly nauseous around 12.00.

Shift 3; Jessica, Beth, and Dylan

David had a nice visit from his sister and sat in the kitchen during dinner. He enjoyed his pancake, but he could only eat half, due to nausea. The other half is next to his bed. He is now watching the football match with a friend of his. Apart from the nausea, he seemed to be in a cheerful mood.

Shift 4; Jorik and Rebecca

After his friend left, David slept for an hour. He woke up again around 22.30 and said he was cold, so we turned the heater up.

Shift 5; Joanna and Dirk

David had a bad night. He was up worrying and fidgeting until 2 am. He asked for painkillers, so we gave him extra fentanyl nose spray, and this calmed him down. He is still asleep now. It looks like his plants need some more watering.

*These updates from volunteers were written in blue, while nurses jotted down their updates between them in red. As a volunteer, however, I didn't read the nurse's updates, which mostly included medical terms I wasn't well acquainted with.*

*Finally, there was a section with extra forms in which volunteers noted down all events relating to David's food-intake and stool. I skipped these for now.*

*I hadn't actually met David yet, but still, I thought I had a sense of who he was, and what his current mood would be. I felt ready to be there for him during the shift.*

Who is the receiver of hospice care, as described in the volunteer file folders? Where, in the hospital, only facts to do with the bodily state of the patient were let into these folders, the hospice lets in an astonishing range of information. Few interactions are too insignificant to jot down in the folder.<sup>37</sup> Hospice care is geared towards the inter-actions that the guest has: the relations between the guest and their world (inter) and how they enact those relations (actions).<sup>38</sup> It takes place *between* the guest and the many actors their world is composed of. Simultaneously, the guest and their world constitute each other. Hospice care is situated between the two sides of this same coin.

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<sup>37</sup> This description of the 'anatomical body' might hold for the medical files specifically, but Mol explains how the body is enacted in the hospital in a variety of ways, depending on the site and activity (more than one, less than many).

<sup>38</sup> I split up the composite parts of the word 'interaction' to stress the nature of actions always taking form between entities. I did this before in an article (Lugt, "When Silence is the Expected Answer"). Later, realized Latour (*Reassembling the Social*) did the same when describing how actor-networks are formed through inter-action.

## 2. 'Feeling at home'

Jasmijn has been the hospice's volunteer coordinator for a few years now. Before coming to the hospice, she worked in a hospital for over two decades, taking up diverse roles. During our interview, she beautifully described the hospice's purpose:

[The hospice set-up] actually comes from the ideal that someone can die at home. It all started with the 'Foundation for Dying at Home' [Stichting Thuis Sterven]. Hospices in the Netherlands were created because, for some people, dying at home wasn't tenable anymore for various reasons. But when it isn't possible at home, I think a hospice is the best place after that. Because it mimics the feeling of being at home. So you're not in a hospital or a nursing home, where you might have your own room, but the care is different. There is a lot of running in those places. There, you are dependent on 'cleaning times' and many other procedures. Here, it is really almost like you're home. So when you can't go on at home, we are a nice place because you do have your own room. We knock before entering, so you literally have your own private room as a guest. Yes, I think that means a lot. That we mimic the home here. It's not called an 'almost at home house' for nothing. It's just not exactly your home, but you're allowed to bring your own chair, your own paintings, your own things. 24/7, you only need to press a button and caregivers are there to assist you. Caregivers. We actually take over the role of someone's usual caregivers when they are overburdened. Because that is often the reason someone comes to the hospice. Perhaps they only have few caregivers, or their caregivers are overburdened. A partner is also allowed to just be a partner again. They're not a caregiver anymore and don't have to help with turning and cleaning and don't have to stay up entire nights. They're allowed to sleep at home again and to be in the hospice as much as they desire. And they don't have to do anything. They only have to sit with their loved one and drink a cup of coffee.<sup>39</sup>

*Ding, dong. David's bell rang, indicating that he had pressed the button around his neck and was in need of help. I hadn't met him yet, as it was my first shift after he had exchanged his hospital bed for the one in the hospice. Slightly nervous, I knocked on the door. He told me to come in, and I introduced myself: 'Hello, I'm Sam. I'm one of the volunteers and I'm also here for a thesis project as part of my study. Is there anything I can*

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<sup>39</sup> Interview Jasmijn

*help you with?' After shooting me a warm smile, he told me that he needed help going to the toilet. I asked Joanna, the other volunteer on shift, to help us out. David slowly made his way to the bathroom, with Joanna and me supporting him from both sides. Then, we closed the door so he could pee without undue intrusion. While waiting in his room, I was drawn to his photos, vignettes into a different time. At the top, there was David standing on top of a snowy mountain, beaming with pride. The one below showed what I assumed to be a kindergartened-aged David, sitting on his dad's shoulders, surrounded by evergreens. The adoration in his father's eyes was almost tangible. Then, there was a picture of him and Monica, his partner, huddled up over coffee cups in a road-side cafe, and a picture of his old band on a stage, rocking out what I could only imagine to be Led Zeppelin. There was David, waving his then still dark hair while jumping on the stage. His desk held about a dozen cards from friends and family, wishing him well, three house plants, a scale of chocolates, rolling tobacco, and dried prunes. Finally, I saw a stuffed animal turtle on his pillow, looking right at the door of the bathroom, as if he was waiting for his friend to come back. I stared out of the window as cars on the street passed by, unaware of the astonishing amount of life concentrated in this room.*

*When I started my Sunday morning shift, David was in his room, sharing breakfast with Emma. Normally, I would knock on the door and ask whether they wanted any coffee or tea, but something told me not to disturb their moment together. After a few hours, the door creaked open, and Emma came out, cradling a tray of used dishes.*

*"Have you two had a nice visit?" I asked.*

*"Yeah." She responded. "My dad always used to make a special breakfast for me on Sundays. I tried to bake up some scones myself today. I think he liked them. Thanks for the coffee and all your help, by the way."*



*I told her not to worry about it and stacked the dishes. She donned her spring coat and left with a familiar thump of the green door. Gently, I pushed David's door open after three soft knocks. There he was: sleepily lying in his bed, hands resting on his stomach, crumbs scattered across his chin, and that contented smile beaming from his lips.*

*"Thank you." he whispered as I cleaned the crumbs off his face and let him doze off. A bag with one and a half untouched scones remained on his table, serving as a reminder of the type of father David was.*

In Heideggerian terms, the feeling of being at home in the world (the 'authentic' mode of existence) relates to a specific mode of temporality in which the 'ecstasies' of time enfold one another. One realizes how the entirety of one's past inter-actions in the world has led to the present situation, and how one can actively anticipate the future from the present.<sup>40</sup> In this mode of temporality, one actively shapes and is shaped by their surroundings instead of passively and unreflectively awaiting (an 'inauthentic' mode of being).<sup>41</sup> Similarly, Merleau-Ponty's concept of 'intentionality' describes how our past inter-actions shape the ways in which we relate to the world, and, subsequently, the way we relate to the world shapes our inter-actions. The hospice aspires to enable the inhabitants to be their fully intentional selves, making them feel at home. Guests are encouraged to bring as many of their relations as possible into the hospice and to allow their past to shape the space they inhabit and carry these relations into their future. Describing these relations through *enactment* reveals how the hospice and guest continuously work to maintain and manifest these relations through concrete action. Hanging up the picture of his father *enacts* David's relationship with his

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<sup>40</sup> Heidegger, *Being and Time*, 65-68.

<sup>41</sup> Heidegger, *Being and Time*, 65-68.

room and his father. Going to the toilet enacts David's relaxing bladder, which allows him to relax during his breakfast with Emma, enacting him as a caring father.

Additionally, Heidegger argues that the natural human mode of existence is through care for one's surroundings. 'Care' [sorge], in Heidegger's terms is the inter-acting with surroundings with the goal of developing future relations to those surroundings in specific ways. Through this lens, David's present relations and inter-actions, based on his past, shape the new ways in which he will relate to his world in the future. Even something as simple as watering his succulent, which he received as a present from Monica, allows him to inter-act with healthy plants in the future, and inter-act with Monica as a grateful partner.<sup>42</sup>

To care for the surroundings and intentionally shaping one's future, based on the historicity of experience, it is necessary to be able to *do* things. This is where Gibson's concept of 'affordances' comes in handy. Gibson (along with Merleau-Ponty) argues that we do not see the world as 'objectively present' objects, but as opportunities to enact future states of relating.<sup>43</sup> The chairs in the hospice's garden, for instance, do not appear to me as constructions of wooden beams, but as a place to sit. The same goes for my body, which is the mode through which I make contact with the world around me. My body's ability to sit is what allows the chair to reveal itself as sittable. *Affordances* are these opportunities to inter-act that the world is filled with, as long as one can afford to engage in them.

My fieldwork in hospice revealed how disease can dissolve affordances which enable one to intentionally enact their relations to the world. The pictures of David flashing a smile

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<sup>42</sup> This relating to the world through action geared towards one's future state of being, is what Heidegger refers to as 'care.' This mode of acting is characteristic of the human state of being through existence: the state of being in which one is concerned about one's own state of being.

<sup>43</sup> James Gibson, *The Ecological Approach to Visual Perception* (Boston: Houghton Mifflin, 1979), 127-137.

Greg Downey, "The Organic Body's Role in Athletic Experience" in *Phenomenology in Anthropology: A Sense of Perspective*, eds. Kalpana Ram and Christopher Houston (Indiana: Indiana University Press, 2015), 119.

Merleau-Ponty, *Phenomenology of Perception*, 139-140, 464.

on top of a freshly scaled mountain made it painstakingly clear that the world held a different set of opportunities for him prior to the onset of his cancer. He used to go for morning jogs, have breakfast with Emma daily, and pee whenever he wanted. In these moments, I doubt that he consciously thought about his lungs, limbs, or bladder. When functioning smoothly, the body slips away into the background of inter-action.<sup>44</sup> When one falls ill, however, the body makes itself known in painful, 'world-destroying' ways.<sup>45</sup> Where, previously, even mountains were climbable to David, journeys to the bathroom now seemed treacherous. David's world filled up with the nagging presence of ailing feet, breathless lungs, brittle bones, and the impossibilities they implied.

David, like most hospice guests, went through a phase in which he needed to adjust to these declining affordances while living at home. There was a time when David wanted to get out of bed to pee, but there was no one to accompany him on this now dangerous journey. He lost the ability to get out of his bed to sit outside with Emma, or to water his own plants. Slowly but surely, there are fewer and fewer possibilities to enact one's relations with their surroundings.

Simultaneously, friends and family members increasingly become caregivers, shifting the nature and direction of care in their inter-actions with the sick or dying person. When David was still living at home, Emma was his main caregiver. She was the one who helped him go to the toilet, shower, make his food, and all other care activities, when she could find the time between her college classes. Squeezing this newfound role as a caregiver into her already busy daily routine carved out a path towards a burn-out. Furthermore, something changes in a relationship when connecting over breakfast makes way for administering

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<sup>44</sup> Merleau-Ponty, *Phenomenology of Perception*, 100-105.

<sup>45</sup> Jason C. Throop, "Sacred Suffering: A Phenomenological Anthropological Perspective" in *Phenomenology in Anthropology: A Sense of Perspective*, eds. Kalpana Ram and Christopher Houston (Indiana: Indiana University Press, 2015), 68-89.

medication, washing, and accompanying to the toilet. The nature of the relationship and the (reciprocal) direction of care shifted. David could not enact himself as a caring father in the same way when he ran out of ways in which he could care for Emma, and Emma could not receive care from David in the same way as before his decline.<sup>46</sup> Norwood shows how, in the worst cases, this inability to enact relations can even cause family relations to disintegrate entirely.<sup>47</sup>

In severe sickness, patients transfer to the hospital, which is contrasted with the hospice's philosophy in its different goal and temporal focus:

The big difference is that in the hospital, there is often still a trajectory in which people have hope. They come to the hospital hoping that the operation will still help, hoping that the Chemo will be effective, hoping that the radiation works... I always thought that the people in the hospital had a lot of fighting power or were in denial. Still willing to sacrifice anything for it [recovery]: 'if I follow this diet..', 'if I do it like this..', 'if I start exercising from now on..', 'if I stop smoking.' And you don't notice that here. Here people only smoke more or eat more, and that doesn't matter anyway. So I think that's the big difference. Hospital or here? The hospital is more focused on recovery, and that's not the case here.<sup>48</sup>

The hospital has a clear service in mind for the patient: to treat as efficiently as possible, with the hope of future recovery. The mode of relating to surroundings based on one's past, making one feel at home, is largely abandoned in pursuit of potential recovery. The ultimate goal of the hospital is to return to 'home' (i.e., the familiar state of relating) in the future. In the present, one has to wear an anonymous hospital robe, sleep in an unfamiliar

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<sup>46</sup> Ram and Houston, "Introduction," 44-45.

Side note:

Relationships are multifaceted and flexible enough to develop new modes of care and interaction when old ones dissolve (for a beautiful example when this happens for the better, see Janelle S. Taylor, "On Recognition, Caring, and Dementia in *Care in Practice: On Tinkering in Clinics, Homes and Farms*, eds. Annemarie Mol, Ingunn Moser, and Jeannette Pols (Bielefeld: Transcript Verlag, 2010), 27-56). The 'caregiver' and 'daughter' role are not mutually exclusive. Still, these changed modes of care and inter-actions, often paired with a changed direction and painful confrontations, mediate the relationship and can shift its characteristics in unwanted ways.

<sup>47</sup> Frances Norwood, *The Maintenance of Life: Preventing Social Death Through Euthanasia Talk - Lessons from the Netherlands* (Durham, NC: Carolina Academic Press, 2009).

<sup>48</sup> Interview Jasmijn

bed, choose from three bland meal options, suffer through chemotherapy, sacrifice privacy, and forcefully stop smoking (David took this last item with a grain of salt). Perhaps one could place a handful of cards wishing for a 'speedy recovery' on the bedside table. However, an extended breakfast with freshly baked scones and all the tea he could wish for while sitting on his father's old reading chair would have been a distant fantasy in the hospital. Taking the changing nature of relating to one's surroundings through an aching body with tumor-ridden lungs and liquid-filled limbs into account, the hospital creates an even more alienating situation.<sup>49</sup> Its white wards don't try to make patients feel at home. This alienation is often worth enduring as a transitory stage towards recovery and return home. When this recovery is out of the picture, however, the hospice forms a better alternative.

In contrast to the hospital, the hospice does 'mimic the feeling of being at home.' This is done by inviting as much of the guest's network of relations in as possible, and ensuring that these relations are continuously enacted, despite the limitations of a terminal illness. When David first moved in, the care coordinator wrote his introduction in the file folder after a long conversation with him. Then, his own objects were moved into his room, and his friends and family got to know the hospice. Finally, he became familiar with the volunteers and nurses. His network of relations was brought into the hospice in the same way as it was present in his home. The guest's room becomes the locus of an entire life, a personscape, taking up the character of its inhabitant and developing together with them.<sup>50</sup>

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<sup>49</sup> For more works on how hospitals can shape an alienating end of life, see: Sharon Kaufman, *...and a time to die: How American Hospitals Shape the End of Life* (Chicago: The University of Chicago Press, 2005). Clive Seale, *Constructing Death: The Sociology of Dying and Bereavement* (Cambridge: Cambridge University Press, 1998).

<sup>50</sup> Strathern and Stewart coined the term "personscape" to refer to the "co-evolution between person and landscape."

Andrew J. Strathern and Pamela J. Stewart, "Personhood: Embodiment and Personhood" in *A Companion to the Anthropology of the Body and Embodiment*, ed. Frances E. Mascia-Lees (Malden, MA: Wiley-Blackwell, 2011), 393.

When standing in his room, I could sense what David's life was about, from being placed on his father's shoulders, to standing on mountaintops, to sitting in wheelchairs. It was almost astonishing how fast 'room 2,' inhabited by a different guest only a week prior, had turned into 'David's world.' Life in hospice was no break from his previous life, but an extension of it. He seemed at ease in the hospice. 'At home.'

### 3. Enacting relations together

*Throughout the weeks of his stay, David gradually became weaker. His tumors grew and his limbs filled up with fluid. A catheter made his walks to the bathroom obsolete and waves of nausea now followed his breakfasts with Emma. On the bright side, he moved from room 2 to room 3, the latter of which had significantly more windows and easier access to the garden, David's favorite spot. The birds were now audible from inside his room.*

*Still, he was more than happy to roll his wheelchair out into the garden for a good smoke during the sweltering summer days. One Saturday in particular, I was on shift while Emma and Monica let us know that they were coming over for lunch. David wanted to be cleaned and seated outside before they arrived. His inability to move his legs, combined with his high bodyweight, however, meant that nurse Mary, David, and I had to engage in the long task of washing and getting him into the wheelchair.*

*I supported David's back with my right arm, while David tightly clenched my left arm for security. His face displayed visible discomfort while nurse Mary and I helped him turn around multiple times. Mary traced his body with a washing cloth, one side soaped up, the other only damp. Visiting all areas, making sure to include the folds in his skin. When the time had come to clean his genitals, she swiftly lifted up the towel that had veiled them, wiped, and covered them up again.*

*"There, that way you get some privacy, David. You're all clean now."*

*I rubbed lotion into his skin, and with some tugs and turns, we were able to clothe him while in his bed. Then, it was time to put him in his wheelchair.*

*First attempt. Try to slide the mat under his body. Bed set to my hip-height.*

*"Alright, David, we are gonna roll over, okay?"*

*3,2,1...*

*"AAaahh"*

*I guide his hand to the bed's rail.*

*"It'll be okay."*

*I support his weight while Mary puts the mat under his back.*

*"Oh, I see you need to go to the toilet."*

*The shift of his body allowed David's intestines to relax.*

*"Oh yeah? I'm sorry."*

*"Nothing to worry about."*

*A small pile of brown tissues made its way to the bin as Mary tried to catch all excrement.*

*"Keep on pressing, David. Better to get this over with now."*

*Mary changed her gloves. Turn to the other side. Supporting his hand, I pulled the mat under his body. Mary rolled it up so that I could easily pull it through. Lying on his back again, with the mat tucked below his torso. The clips of the mat clicked together, folding David up in a package. I rolled the hoist in from the hallway. Nurse Mary attached it to the mat. Check, check, double check. Everything in its proper place? We didn't want David to fall. Mary operated the buttons on the hoist. The machinery hummed as a 160-kilo man was lifted into the air. I guided his back end into his chair until I saw his weight securely settling into the cushion. Make sure that his posture seems okay (we wouldn't want to cause undue back injuries). Tune into his body. Everything alright?*

*"Does that feel okay, David?"*

*"Yes. Thanks."*

*Unfasten the clips and pull the mat out from under his body.*

*"Alright, we'll let you rest now."*

*The three of us were exhausted after a good 30 minutes of intense physical labor. David took a nap in his chair, in anticipation of his visit, Mary went upstairs to write a report, and I went back to the kitchen to refuel over a cup of coffee.*

*When I later looked into the garden, I saw David, Monica, and Emma sitting at the table. There was music playing. Bowie. His wife's hand rested on his, as she helped him eat his grilled cheese sandwich. His drowsy eyes and single-word responses had made way for an energized sermon about one of his favorite songs.*

*"This one. This is one of his best songs. Just listen to the bass and the drums complementing each other."*

In pursuit of maintaining the guest's ability to enact their relations, the hospice's network of actors (e.g., the building, volunteers, nurses, communicational devices, coordinators, flowers, medical technologies) ties in with the guest's network of relations (e.g., their relation to their body, friends, family, hobbies, living space, food). When a guest cannot enact their relations on their own, actors in the hospice network do it together with them.

On the part of the hospice workers, this requires a great deal of presence and the ability to attune to the guest's network of relations. As one volunteer put it: "You need to attune and search for that connection without words."<sup>51</sup> The more I interacted with David, the more I got to know him. The brief description in his file folder was the first step. After that, the pictures on his wall, the scones that Emma made, the soft-spoken manner in which he asked for help to go to the toilet, his peculiar habit of drinking tea comprised of 75% milk in

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<sup>51</sup> Interview Charlotte



early mornings, and the way his hand grabbed my forearm when turning, all added up to a sense of how he related to his world, a sense of who 'David' was.<sup>52</sup> Some volunteers have specific modes inter-action they use to attune to the guest. One volunteer told me they had an introductory conversation with every new guest, while another preferred to clean the guest's room while making calm, silent eye contact every now and then. All volunteers got to know how to interact with David intuitively. We knew that he enjoyed our company when we vacuumed his room and cleaned his toilet. We also knew not to disturb him when Monica or Emma were in the room, as they might have intimate conversations or even snuggle up in his bed. All of these preferences were explicitly mentioned in David's file folder, but they also built up to a sense beyond concrete statements, which enabled volunteers to intuit how to interact with David.

With the sense of how the guest inter-acts with his world, it also becomes salient in which ways it is difficult for them to enact relations. This reveals where hospice workers can give them a leg up and enact relations together. Is it, for instance, important for David, Monica, and Emma to connect over long talks, preferably in the outside air? Let's offer David to bring him outside for lunch. Music played a large role throughout David's life? Let's make sure his stereo works. His nausea keeps him from connecting to his surroundings? Let's offer metoclopramide. This way, David was able to do what he wanted despite his disease.

One of the most important aspects of the guest's relation to their surroundings that hospice workers enact together with them is the guest's body.<sup>53</sup> All of the guest's experience is mediated through their body, making it crucial for them to relate to their body in familiar ways, despite changes due to disease. Mol and Law propose to describe bodies as *enacted*

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<sup>52</sup> I use Merleau-Ponty's concept of 'sense' here as an affective, experiential apprehension that extends beyond the qualities of its perceived parts.

Merleau-Ponty, *Phenomenology of Perception*, 4, 13.

<sup>53</sup> In chapter 5, I argue that the hospice deconstructs the body/mind dichotomy. In hospice care, the guest does not 'have' a body, but *exists through* the body as the starting point of all relations.

rather than existing independent of action to reveal the processes behind the body's constitution.<sup>54</sup> Throughout his life, when David had to pee, he walked to the toilet. When he was dirty, he showered. When he was hungry, he ate. When he wanted to sit outside, he pulled out a garden chair and sat. He *enacted* his body as relaxed, clean, satiated, and sitting.

His disease made these processes significantly more difficult. His bladder had decided on its own regiment, his limbs refused to carry his weight, and his tumors covered his body schema in an oppressive layer of nausea and pain. Previously, only David enacted his body's getting out of bed and sitting. He was the only one who had to be in tune with his body schema: where his ankle was positioned, how he shifted his weight, how he wanted to stand, and where he wanted to go.<sup>55</sup> This was second nature, a mere habit.<sup>56</sup> Now, on the other hand, there were at least two other bodies and a multitude of technologies required to enact his sitting body. Mary and I constantly attuned to his body schema. Heidegger describes 'attunement' as the encountering and understanding of things in the surrounding world through being affected and moved by them.<sup>57</sup> Mary and I couldn't move David's body as a passive object. We open ourselves to be affected and move *together* with his body, actively trying on his 'body schema' to detect any sticking points. We felt where his center of weight was when supporting him, made sure there were no creases in the mat. "Would this position feel natural to me?" We kept an eye on his catheter bag, which would pull on his bladder if tangled. "How would he try to turn around if he could move?" When he tensed up out of fear, we stopped what we were doing, calmly looked into his eyes, and reassured him. A network

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<sup>54</sup> Mol and Law, *Embodied Action, Enacted Bodies*.

<sup>55</sup> 'Body schema' is a term that Merleau-Ponty uses to refer to the experience of the body actively inhabiting time and space in inter-action with the world. Merleau-Ponty, *Phenomenology of Perception*, 100-105.

<sup>56</sup> Merleau-Ponty defines habit as 'the motor acquisition of ... signification,' which 'resides ... in the body as the mediator of a world.'

Merleau-Ponty, *Phenomenology of perception*, 143, 146, respectively.

<sup>57</sup> Heidegger, *Being and Time*, 133-134.

of able bodies and technologies attuned to David's body to enact the turn together with him.<sup>58</sup> Simultaneously, David attuned to the network. He got used to the feeling of hands gripping his arm and back, holding his breath when we slid him higher in the bed, and squeezing out his last bit of fecal matter so Mary could clean it with a wet cloth.

Getting David out of bed forced him to relate to his body and surroundings in previously unknown ways. His tumors hurt, he was not used to being cleaned by a woman he did not know a few months ago, and he definitely was not pleased by the feeling of a miniature crane ripping him out of bed. On the other hand, sitting in his chair enabled him to inter-act with his body, his favorite music, his partner and daughter, the fresh air, and his food in familiar ways, re-establishing his familiar relationships. These are the things that make life worth living.<sup>59</sup>

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<sup>58</sup> By 'able' I here only mean 'able to turn David.'

<sup>59</sup> Chapter 6 contains more on balancing suffering and familiar relations.

## 4. 'Directing'

Enacting relations together with the hospice network changes the character of the guest's inter-actions. In chapter 2, for instance, I described how David had to ask for my help when he wanted to pee. What he previously did on his own now involved communication with at least two others. Similarly, getting him out of bed and into his chair, in a later stage, took attunement and communication between Mary, David, me, and all non-human agents involved.

Many such non-human actors are involved in enacting the guest's body, requiring the guest to enact their body in new ways. Even before we started cleaning and lifting David, for instance, his body had already attuned to the catheter, opioid band-aids, and many different kinds of pills, drinks, and nose sprays. Additionally, intravenous morphine pumps and oxygen machines are also commonplace in the hospice.

These technologies reveal the leakiness of the body.<sup>60</sup> All bodies are inherently dependent on their environment, but medical technologies make bodily processes that were previously a silent agreement between the body and its surroundings, explicit and tangible. Breathing with an oxygen machine is no longer an activity that lungs and invisible air engage in silently. It involves a machine that rattles and clicks 24 hours a day, tubes leading from this machine in the hallway to the nostrils, and large metal tanks. The breath can be seen, touched, smelled, adjusted. Breathing is still possible, but it has become a different activity. As soon as it is externalized, it involves consciously managing and tinkering with the relations in a network of human and non-human actors.<sup>61</sup>

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<sup>60</sup> Alex M. Nading, "Local Biologies, Leaky Things, and the Chemical Infrastructure of Global Health" in *Medical Anthropology: Cross-Cultural Studies in Health and Illness* 36, no. 2 (June 2016): 142, <https://doi.org/10.1080/01459740.2016.1186672>.

<sup>61</sup> Dick Willems, "Varieties of Goodness in High-Tech Home Care" in *Care in Practice: On Tinkering in Clinics, Homes and Farms*, eds. Annemarie Mol, Ingunn Moser, and Jeannette Pols (Bielefeld: Transcript Verlag, 2010), 257-275.

Guests in the hospice continuously engage in managing *how* they merge with actors in the hospice network to enact their relations together. The hospice's term for this process (used during 'handovers' or 'palliative consultation') is 'direction' [directie], mostly in the sense of the director of a movie or a play. Hospice workers often expressed that they saw it as a virtue when the guest can keep as much 'direction' as possible, by communicating how they want to relate to the hospice network. In certain situations, however, 'direction' is more dispersed across the guest's and the hospice's actor-network. The following examples display different directorial situations:

*Three weeks after David's arrival:*

*Ding-Dong, ding. A green number '2' flashes on the room bell display. I know that this is David, so I walk over to his room to check what is the matter. After three knocks, he yells 'Come in!' and I enter. He is lying on his bed, reading the newspaper.*

*"Hi there. Over there." He points to the desk. "There's the remote for the thermostat. Can you make it a little warmer? I like it at 22 degrees."*

*I adjust the air conditioner likewise.*

*David explains "They always turn it to twenty, but I like it a little warmer. Can you make sure everyone knows?"*

*"Of course I can. Do you need anything else?"*

*"Yes, can you bring me soup at 13.00? That would be amazing. Thanks so much."*  
*I wrote about this inter-action in the file folder and told the volunteers on the next shift that David likes to keep his room at 22 degrees.*

*"Ooh yeah, David loves to keep the direction. Beautiful, isn't it?" the other volunteer responded.*

This vignette is a salient example of the guest taking up the 'director' role. He seamlessly tells me what his intention would have been. Attuning to the guest's intentionality is easy in these cases. It involves only a few levels of communication.

*Two months into David's stay in the hospice:*

*The previous volunteers informed me that the GP wanted a small sample of David's urine. Apparently, David had been fidgety for the past days, and made trips to the toilet every 30 minutes. When one volunteer asked him about this unusual behavior, David mentioned that he was experiencing discomfort in his bladder. A nurse notified the GP, who wanted to know whether David had a bladder infection. 'Ding-dong, ding.' David's bell rang. When I walked over to his room, he told me that he had to pee. I got the commode and helped him get in. Then, I left the room awaiting a signal that he was done. This signal didn't come. His eyebrows formed a disappointed frown as he panted. Failed attempt. 20 minutes later, his bell rang again. Second try. I turned the faucet on this time, and Miriam, the other volunteer on duty, massaged his back. Still nothing. The care coordinator called to check how it was going. I reported that David tried to pee, but it didn't work. The nurse noted this down in their medical records. I put it in the three-sentence summary in David's file folder. Later, when Monica came to visit, I asked her to let us know when David wanted to pee, so that we could take a sample, and that he might seem uncomfortable because he might have a bladder infection. During the 'handover,' I informed the next volunteers that David was struggling to pee and was visibly uncomfortable.*

*The next time I was on shift, I read that David eventually provided the GP with a urine sample, and he indeed had a bladder infection. He now received antibiotics with his standard medication and seemed much more comfortable.*

In this example, 'directorhood' is more dispersed. David's intention is to get rid of the discomfort in his bladder and be able to pee normally again. The road to get there, however, is unclear. This puts an entire chain of communication in motion, involving David, the room bell, volunteers, his commode, the sink in his room, Miriam's massaging hands, file folders, a sampling cup, morning urine, an external lab with equipment and workers who analyze the sample and report back, the hospice's landline, file folders, medical records, and antibiotics. When there is no straightforward line of action based on the guest's intentional wishes, all actors muddle through the uncertainty together, and tinker with relations until a solution is found.<sup>62</sup> In this case, the process resulted in tinkering with David's standard medication by bringing in antibiotics as a new actor in David's network.

The following example comes from an article I published in 2020, called 'When Silence is the Expected Answer.' In this article, I described how Nurse Rachel asked Anne, another hospice inhabitant, which shirt she wanted to wear:

“Which one do you want?” Nurse Rachel inquired. In either of her hands hung one of Anne’s T-shirts: one black, the other white with colorful flowers. Anne stared back vacantly. The three of us waited in frozen anticipation until Rachel broke the silence: “Let’s go for the flowers. It’s a sunny morning, and you like color.”<sup>63</sup>

Rachel was well aware that Anne, who was in the later stages of dementia, could not respond to her question. Still, she gave Anne the option to choose. She then concluded, based on the months of experience with Anne in the earlier stages of dementia, that Anne dressed according to the weather. Therefore, the flowery shirt

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<sup>62</sup> Mol describes this process in *De Logica van het Zorgen*.

<sup>63</sup> Lugt, *When Silence is the Expected Answer*, 103.

was the winner. This allowed Anne to inter-act with her surroundings in her usual clothes, despite her loss of communicative abilities.<sup>64</sup>

This example demonstrates how the 'director' role is dispersed across the hospice network and the guest's social network when a guest cannot communicate. Actors in the hospice network try to piece together what the guest's intentional line of action would have been, based on attunement through past inter-actions. They then try to align their care with these expectations from past inter-actions.

It is important to note that direction is not the same as control. The guest does not 'decide' what other actors do.<sup>65</sup> Rather, the network tries to create connections between all actors in such a way that hospice care is moulded to the intentionality of the guest. Similarly, the director of a play does not control everything the actors do. Actors have their own quirks and ways of filling in their characters. Yet, they attune their style to the wishes of the director. Because the hospice guest's intention and history is constantly changing (in Merleau-Ponty's terms, the guest is engaged in an 'intentional arc'),<sup>66</sup> adjusting the network to the guest's intention requires constant tinkering.<sup>67</sup> The actors in the hospice connect in such a way that they are receptive to the guest's intentionality based on the past of their inter-actions. This receptivity is what enables the guest to 'direct.'

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<sup>64</sup> Lugt, *When Silence is the Expected Answer*, 103.

<sup>65</sup> Latour, *Reassembling the Social*, 58-62.

<sup>66</sup> Merleau-Ponty, *Phenomenology of Perception*, 137-139.

<sup>67</sup> Mol, *De Logica van het Zorgen*, 69-74.



## 5. (De)constructing Boundaries

*I am was rush-hour at the hospice on this day. A myriad of visitors rang the doorbell at 2 minute intervals and all guests woke up at the same time. Dirk, the other volunteer on shift, and I divided up guests. I would take care of David. The first thing on my list of to-dos was cleaning David's room. I entered and saw his half-sleeping eyes light up ever so slightly.*

*"Good morning, David. I'm just gonna clean your room now."*

*"Thanks."*

*At the same time, nurse Mary checked the IV for his morphine. David had consistently complained about his pain over the past week, so the nursing team and the GP had decided to increase his standard morphine dosage.*

*"How is your pain, David? Is the morphine working?" Nurse Mary asked.*

*"Much better. I feel way better than last week."*

*David lightened up as he watched me dust the surfaces in his room, and we chatted. I watered his plants, which were almost growing out of their pots by now, and asked whether he wanted any breakfast or coffee. 'I'll have a little bowl of custard [vla] with whipped cream and coffee with a lot of milk.' David had a sweet-tooth and seemed to gravitate mostly towards staple comfort foods for anyone with a Dutch upbringing. Pancakes with syrup, vla, a type of Dutch custard, and cream of wheat were his favorites.*

*I prepared David's custard and Mary sprinkled a powdered pill into the bowl. 'This will prevent him from feeling nauseous right after eating,' she explained. While I fed him the custard one bite at a time, the door rang. Dirk opened up and a few seconds later, Monica entered the room and took my place feeding David. When I walked back to the kitchen, I saw that Emma was still talking to Dirk at the front door. He later told me that she seemed worried about David's increasing loss of physical abilities. 'Is he going to suffer?' she asked him. He reassured her that people rarely ever suffer for extended periods of time in the*

*hospice. 'We almost always notice when we need to adjust things to prevent extended suffering in the final stages.' This seemed to calm Emma, as she made her way to her father's room.*

In chapter 1, I suggested that hospice care takes place in the in-between of the guest and their surrounding world: the guest's network of relations. This aspect of hospice care implies some important ontological conclusions. Boundaries within the guest and between the guest and their surrounding world dissolve, while the hospice actively tries to uphold boundaries between different networks of relations.

### **Dissolving boundaries**

When describing hospice care through phenomenological terms, 'the guest' and 'their world' are co-constitutive to the degree where they become synonyms.<sup>68</sup> The guest does not precede their intentional relations to the world but is precisely constituted by the entirety of their relations, and vice versa.<sup>69</sup> Care for the guest is simultaneously care for the things the guest relates to, and care for the guest's surrounding world is care for the guest. This results in the dissolving of body/mind, individual/community, and human/object binaries in hospice care.

This dissolving first becomes salient because every care action contains 'multiple goods.'<sup>70</sup> Bringing David his custard serves multiple purposes at the same time. Firstly, David simply likes his custard. It tastes nice, and its nostalgic quality generates a youthful comfort.

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<sup>68</sup> Merleau-Ponty, *Phenomenology of Perception*, 482-483.

<sup>69</sup> Merleau-Ponty, *Phenomenology of Perception*, 482-483.

<sup>70</sup> Annemarie Mol, "Care and its Values: Good food in the nursing home" in *Care in Practice: On Tinkering in Clinics, Homes and Farms*, eds. Annemarie Mol, Ingunn Moser, and Jeannette Pols (Bielefeld: Transcript Verlag, 2010), 215-231.

Simultaneously, it feeds him. While his appetite steadily declined over the last weeks of his life, his sweet tooth remained relatively untouched. This made custard one of the most fruitful avenues of enacting his comfortable, nourished body. Then, there is the medicine. Adding the powdered pill to his custard enabled David not to feel nauseous after eating. Similarly, helping him get into his wheelchair prevented his skin from blistering due to lying in the same position, but it also allowed him to have lunch with his family. Does this mean that feeding or moving was mainly care for his body or his mind? Was helping David and his family share lunch care for David or for his family? Was checking David's morphine pump care for David or the pump? In all cases, the answer is 'both.'

Furthermore, any inter-action comes to mediate all others. As I argued in chapter 2, one's surrounding world is accessed and conceptualized through the body and the affordances that the embodied situation yields.<sup>71</sup> Sitting in his wheelchair grants David an entirely new experience of his surroundings and allows his surroundings to interact differently with him. He can swallow his food more easily, he can interact with Emma and Monica at eye height, he sees new things, he can feel the outside air, and his bodily sensations shift. It also prevents the discomfort of blistering skin to take a hold on his experience. Simultaneously, having lunch with his family re-energizes him, making his discomfort easier to bear even after the visit. Changing his position not only changes one aspect of his situation (mind or body, David or his Family, humans or objects) but the entirety of his situation and the future to come.<sup>72</sup>

Binaries that split the guest and their surrounding world did not even cross my mind while working in the hospice, until I tried to put this work into words. Everyday language implicitly insists on splitting body from mind and the 'individual' from their surrounding

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<sup>71</sup> Gibson, *The Ecological Approach to Visual Perception*, 127-137.

Merleau-Ponty, *Phenomenology of Perception*, 139-140, 464.

<sup>72</sup> If the above example is too subtle, just imagine the devastating impact that a maladjustment on his morphine IV would have on the entirety of David's existence.

world. This makes entities in the world appear as independent, isolated objects instead of in constant processes of inter-acting and relating. When I cleaned David's room, Mary adjusted his morphine, and Dirk reassured Emma, there was no question about whether we were caring for David or his 'room,' 'pump,' 'family,' and 'body' as independent objects. All three activities made all the difference for David's relations and had an immediate impact on his mood.

Heidegger argues that 'mood' is a collaborative attunement between an individual and their surroundings, revealing the intimate connection between both.<sup>73</sup> It is precisely this connection that dissolves binaries. Each side of a relationship makes all the difference for the other. Simultaneously, the guest's various relations are so entangled that a change in one makes all the difference for the others. Hospice care can either be framed as care for the guest, or care for their family, their friends, their mind, their body, the building, their belongings, their medical technologies, and all their possibilities of experience. Each mode of framing is synonymous with all others to the degree where these categories dissolve: "Man is a knot of relations, and relations alone count for man."<sup>74</sup>

### **Constituting boundaries: Relational Hygiene**

Precisely because hospice care is geared towards the 'in-between' of the hospice guest's relations, the hospice works to set up new boundaries between the relations of the guest and other hospice actors.

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<sup>73</sup> Heidegger, *Being and Time*, 130-136.

<sup>74</sup> Antoine de Saint-Exupery, *Pilote de Guerre: Mission sur Arras* (Paris: Gallimard, 1942), 174, quoted in Merleau-Ponty, *Phenomenology of Perception*, 483.

One boundary lies between the guest's relations and the personal relations of volunteers who enact the guest's network together with them. Hospice workers often refer to these boundaries through hygiene metaphors:

[When you become too involved] you can't care for someone. You need to feel that involvement, that sadness, those emotions with your own family. Here, you need a bit of professionalism in the volunteer work. And you are allowed to feel very involved. You're allowed to do everything you want in those four hours of your shift. But, once again, after the shift, I think you should leave it behind. Literally wipe your feet when you leave and close the door. Yes. Also when you arrive. It also goes the other way around. It is also good that when you come out of the hustle and bustle of the day and arrive here in a rush and just on time and there are still so many things to do, that you also take a moment to literally close the door, leave the business behind, and are simply present here for the guests. And grab your email and phone again only after your shift. Only then can you actually be there for the guests. - Jasmijn

'Wiping your feet' and 'closing the door' are some of the hospice's emic terms to delineate the boundaries of where the volunteer's or guests' relations are 'out of place.'<sup>75</sup> On the surface, the volunteer's activities such as bringing soup and turning the guest's body might seem banal, but they comprise a substantial part of life, through which volunteers merge with the guest's network of relations. This is an intimate role that can cause harm when there is no relational hygiene: a protocol for separating various actors' networks of relations.

Firstly, volunteers are expected to 'close the door behind themselves' and 'wipe their feet' when entering the hospice. Carrying the 'hustle and bustle' from one's own non-hospice network of relations in mind throughout the shift will prevent volunteers from doing a good job. The 'volunteer manual' describes the function of a volunteer as 'being there' or 'being present' ['er zijn'] for the guest. Attunement to the needs of the guest is only possible when being present and fully occupied with them. When I worried about my own deadlines, relationships, or health, my shift seemed tedious and difficult. Interactions seemed awkward

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<sup>75</sup> Mary Douglas, *Purity and Danger* (New York: Routledge, 2002), 44.

and other volunteers seemed frustrated with my lack of attentiveness. However, when I took a moment to arrive by closing the door behind me, turning my phone off, and saying 'hi' to the guests, time flew and hospice work seemed like second nature.

Such a 'wiping your feet' also takes place outside of the guest's door. The volunteer coordinator stressed the importance of preventing issues from other guests or one's own relations from mixing with care for the guest. Whereas the guest is invited to bring as many relations as possible into their room, the volunteer is expected to leave most of their everyday relations at the door.<sup>76</sup> This way, the volunteer can be entirely present with the guest's network of relations to enact them.

As all volunteers have their own historicity and intentional arc, meaning that they are also constituted by the entirety of their relations, it is impossible to truly remove themselves from these intentions. What is asked of volunteers is better described as an orientation towards the guest's intentionality. As multiple volunteers mentioned, "you're allowed to just be who you are and all you have to do is attune to the guest."<sup>77</sup> From the situated position that the volunteer inhabits, there should be an opening that allows for full presence and attunement to the guest's intentional relations.

If this doesn't happen, there is a danger that the volunteer uses the guest to enact their own relations. Jasmijn mentioned that during the intake of new volunteers, they pay close attention to ulterior motives. Some people applied to volunteer out of guilt for their lack of care when their own parents died. Such a motive contains the danger of using the hospice guests as a means to enact one's own relation as a caring person, despite their guilt of not caring for their parents. The weight of hospice care then rests on the volunteer's relation to

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<sup>76</sup> Buch's study on elderly care work in Chicago contains a similar argument: Elena D. Buch, "Senses of Care: Embodying Inequality and Sustaining Personhood in the Home Care of Older Adults in Chicago" in *American Ethnologist* 40, no. 2 (November 2013): 637-650, <https://doi.org/10.1111/amet.12044>.

<sup>77</sup> Interview Charlotte (volunteer).

their parents, not the guest's. All volunteers work in the hospice to get something out of it themselves, and this is widely acknowledged. Most do it because they like the work intrinsically, some want to enact themselves as caring people, others, like myself, are there as part of their study. Despite these motives, however, enacting the guest's relations should always take center-stage when inside their room.

On the other hand, volunteers also need to wipe their feet and close the door when leaving the guest's room and the hospice altogether. Volunteers should enact the guest's relations together with them, but also ensure they don't take ownership over them, in which case they would get in the way of the guest's ability to live their own life. A volunteer who talks to the guest too much can get in the way of the time for the guest to connect with their family or themselves. A volunteer who grieves too much can take away space for the family to grieve.

Simultaneously, volunteers have their own lives to go back to. Hospice work isn't sustainable when volunteers try to live their own life and the guest's.<sup>78</sup> It is okay to think about a guest when at home, or grow from the inter-actions with them, but when the shift is over and handover is completed, volunteers should leave the guest's concerns behind.<sup>79</sup>

Simultaneously, hospice workers maintain boundaries between different guests' networks of relations. As I argued above, guests are expected to bring the entirety of their past relations into the hospice by creating their personscape.<sup>80</sup> However, a boundary is drawn where one guest's personscape gets in the way of the possibility of other guests to enact theirs by spreading into the common areas. One time, for instance, a guest started to use the

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<sup>78</sup> Interview Jasmijn.

<sup>79</sup> Similar themes in a thesis about the hospice from a different volunteer:

Leander Overmars, *"Zorgzaam zijn naar jezelf: Over de invulling van zelfzorg bij vrijwilligers in de palliatieve terminale zorg,"* Bachelor Thesis, Universiteit voor Humanistiek, 2020.

<sup>80</sup> Andrew J. Strathern and Pamela J. Stewart, "Personhood: Embodiment and Personhood" in *A Companion to the Anthropology of the Body and Embodiment*, ed. Frances E. Mascia-Lees (Malden, MA: Wiley-Blackwell, 2011), 393.

communal refrigerator for a dozen beers. The volunteers protested, as this decreased the space for food for other guests. The suggested resolutions centered around pushing this personscape back into the guest's room by adding a mini-fridge or asking him to keep all of his beers but six in his room. The same happens when a guest is too loud or brings strong scents into the common areas. Other types of mixing between guest's networks are sought after. Amazing and unexpected friendships have come to blossom over the conversations on the terrace. Some families that met in the hospice decades ago still have close ties. These types of merging between relational networks need to happen spontaneously, however, without one guest being subjugated to another's relations.

Through these boundaries, the hospice network establishes norms for when and where networks of relations merge and are kept separate. When volunteers should coincide with the guest's network of relations and when they should consciously exit this network. When volunteers should be entirely present, and when they should be entirely absent. When guests' networks mingle, and when they need their own domains. This way, the guest always has at least two volunteers present for them who, only when needed, enact their relations together and ensure that there is enough space for the guest to be present with these relations.



## 6. Balancing values

Hospice guests have many multifaceted relations to their world. Maintaining them in the face of decline in disease, while only knowing the guest for a short period of time is a tricky task. Inevitably, relations bump up against each other and difficult choices need to be made. This chapter explores some of the difficult decisions that need to be navigated in hospice care. Each section will end on questions that I will leave unanswered because there are no answers. A large part of hospice work consists of discussing and muddling through these difficulties with every guest anew.

### **Filling in the blanks**

The following vignette comes from my interaction with Jonas instead of David. This is precisely because I did not have trouble attuning to David, while filling in the blanks for Jonas was significantly more difficult for me.

*Jonas was a 96-year-old hospice guest who loved to tell everyone stories about his youth. Especially his experiences during the Korean war had made a big impact on him, and he often didn't shy away from discussing them over the dinner table. During handover, volunteers mentioned his torrent of war stories that a simple question as 'how are you?' could invoke. He did seem to enjoy airing his thoughts out, so we didn't protest.*

*One afternoon, when I was about to start my shift, the previous volunteers told me that it was Remembrance Day for the Korean war. Jonas might do something special. When I cleaned Jonas' room, I decided to give him the opportunity to talk about the war.*

*"Are you doing anything special for the remembrance today, Jonas?"*

*His eyes froze in terror, fixated on mine.*

*"What do you mean?"*

*His voice trembled as he looked like a deer in the headlights. I realized I had made a big mistake asking a traumatized veteran whether he was doing anything for Remembrance Day, like it was a picnic. Given the generational gap, I must have been roughly his age during the war. This might have struck a nerve with Jonas. I also hadn't experienced war. Remembrance days, for me, were times to think about ancient histories or distant places. This caused me to assume Remembrance Day was somewhat of a 'mild holiday,' whereas I now realized that for Jonas it was a gruelling confrontation with his traumatic past.*

*"I'm sorry. I shouldn't talk so lightly about things I know nothing about."*

*"It's okay, boy. You couldn't have known."*

*I left the door ajar, as he liked it.*

As I described in chapter 4, much communicating takes place in the hospice, surrounding the guest's wishes, habits, and preferences. Yet, 'the other is not reducible to knowledge about the other.'<sup>81</sup> The guest's complex relations are not reducible to handovers, file folders and limited inter-actions, which stand in solidarity with these relations, but do not exhaust them. Attunement to the guest, and the guest (as 'Other' in Levinas' terms) always remaining an ungraspable Other, stand in tension.<sup>82</sup> Where should the hospice volunteer fill in the blanks and where should the guest remain entirely Other?

Similar questions arose when a guest with limited verbal abilities entered the hospice (either they could not talk due to their disease or their Dutch was limited). In these situations,

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<sup>81</sup> Emmanuel Levinas, *Totality and Infinity: An Essay on Exteriority*, trans. Alphonso Lingis (Pittsburgh, PA: Duquesne University Press, 1969), 28.

<sup>82</sup> Levinas, *Totality and Infinity*, 28.

Merleau-Ponty, *Phenomenology of Perception*, 373-374.

there was insufficient material to attune to them. Stereotypes of the few scraps of information that hospice workers received then formed the basis for care.<sup>83</sup>

Because hospice care is geared towards enacting the guest's complex relations, blanks need to be filled in to make it successful. This is what differentiates hospice care from the anonymous, standardized care in hospitals. Without precaution, however, filling in blanks can cause harm. When are occasional 'misses' a necessary trade-off of good hospice care, and when do they impede good care altogether?

### **Inevitable loss of affordances**

*When David first came to the hospice, he went to the bathroom by himself. He needed someone to walk with him, to protect him from falling, but he carried his own body. Later, he needed two volunteers to carry him to the toilet and back. This went well for a few weeks, before his ability to carry his own weight declined to the extent where he couldn't support himself at all, and the volunteers almost carried him to the toilet. This turned out to be uncomfortable for all involved, and he soon received urine bottles. He would always have one ready at his bedside, pee in it while seated on the bed, and leave it in the same spot until a nurse or volunteer came to pick it up. This worked fine, until his bladder decided on its own regimen and let urine flow more freely. Then, he received adult diapers. These, however, made him fidgety and itchy. A few days after he started with the diapers, I saw a small bag with yellow fluid attached to his bed. He now peed straight into a catheter. I could even let his pee out of the bag without waking him up.*

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<sup>83</sup> Lugt, "When Silence is the Expected Answer," 108-109.

Hospice guests are able to maintain affordances with help from the hospice network, and, therefore, relate to their surroundings in similar ways. At some point, however, the effort of maintaining the affordance overshadows the relations it maintains. Along the road from toilet to catheter, each step took David further away from his initial mode of going to the bathroom to enact his empty bladder. Standing up and peeing in a separate room is quite different from having a balloon attached to a tube running from your bladder out of your urinary tract, which transports urine without waiting for permission.

Similarly, putting David in his chair seemed worth the effort for a long time. When this caused too much suffering, however, the alternative was to roll his bed next to an open window whenever he wanted to listen to the birds.

Nurses, guests, volunteers, and family spend much time discussing whether it is still worth maintaining affordances, or whether relations need to be tweaked to provide more comfortable alternate modes of enacting. These decisions are almost never straightforward, and they can be painful, as they mark a clear decline in abilities. On the other hand, they are an essential part of minimizing suffering during the inevitable decline into death.

### **Conflicting relations**

The following vignette also describes experiences with a guest other than David, as David's relations did not display tensions as salient as Elizabeth's.

*Elizabeth was a hospice guest with lung and brain cancer. When she arrived in the hospice, she was slightly confused, but she could still communicate. She even loved it when you dropped by her room to have a chat about her favorite dog breeds or what her kids were up to. Later, however, it became increasingly difficult to read her. Her family seemed worried*

*by her random behaviors, and asked the volunteers whether Elizabeth was safe. After she fell a handful of times while climbing out of bed, the family and hospice staff decided to place a camera next to her bedside. This camera, originally meant to be used on new-borns, had a corresponding display, which volunteers could look at from the kitchen.*

*One afternoon, I saw Elizabeth make attempts to climb out of bed through the little display. When I made my way over to her room, so I could support her in case she wanted to get out of bed, she pretended to be fast asleep. I went back to the kitchen, seeing her mischievously crawl out of bed once again. When I went back to look, she crawled back in bed and forcefully closed her eyes again. Rinse and repeat. This happened about ten times throughout the shift. When I brought this up during the handover, it stirred up some conflict. Yes, we had to keep an eye on her, to make sure she was safe. Her family wanted us to do this. No, the camera wasn't nice for her privacy, and if she truly wants to walk, she should be allowed to walk. After all, wouldn't she be allowed to walk if she were at home?*

*The weeks went by, and Elizabeth lost the ability to get out of bed altogether. Her lungs filled up with fluid, and she became increasingly fidgety. I was on shift before she passed away. Her body colored dark red and pearls of sweat covered her forehead. Her breath grinded through the slime in her chest, forcing her to pant and gurgle. When Charlotte, the other volunteer on shift, asked her anything, she didn't respond. She had no space to respond. She could only suffer through one painstaking breath at a time.*

*That's when the doorbell rang. Her family came to visit. We let them into her room and gave them some privacy. Ten minutes later, however, they came out, looking utterly distraught. To her family's dismay, Elizabeth had started ripping all her clothes off her body. I walked into her room just in time to see her colostomy bag flying through the air. In an attempt to get comfortable, she pulled at anything touching her skin. The family, however, did*

*not want to be confronted with the fragility of her bare body. What to do? Leave Elizabeth as she was or try to see if she could get her clothes back on? In this case, it was clear that Elizabeth should be allowed to remain bare in bed, but it was sad to disappoint the family. We did, however, put her colostomy bag back on, lest she filled the bed with feces, and we had to go through the arduous motions of cleaning her sheets while leaving her in bed.*

Both examples above show how, when affordances decline, difficult way-offs need to be made between relations. Is it more important to maintain Elizabeth's relation to her surroundings as someone who has privacy and autonomy to walk whenever she wants, or is it more important that she can relate to the world without the discomfort of a fractured hip? In the end, the coordinators and the family settled on the camera, but this remained controversial among some volunteers.

Is it more important that Elizabeth can lie in bed unclothed if that makes her feel more comfortable, or that her family can say goodbye without a confrontation with her nude, ailing body?<sup>84</sup> As I mentioned earlier, care for the guest is most often care for the family, and vice versa. 'The guest' and 'family,' however, are multifaceted and require many different types and layers of relations that require care. This causes some aspects of hospice care to be in tension with one another.<sup>85</sup> Here, a choice had to be made between Elizabeth's comfort and that of her family. Simultaneously, we put her colostomy bag back on, trading slight added discomfort in the present for the prevention of nearly catastrophic suffering in the future if we would have had to replace her stained sheets or let her sit in her own feces. Such trade-offs have no clear-cut solution and are painful, but they are a necessary part of hospice care.

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<sup>84</sup> Lugt, "When Silence is the Expected Answer," 110.

<sup>85</sup> Lugt, "When Silence is the Expected Answer," 110.

These examples also show how tricky hospice care can be when the guest's relations to their network, which the hospice ties into, are fraught with conflict and discontent. Is it okay to rob a visitor of a chance to say goodbye if the guest doesn't want to see them? When should the family be allowed to make decisions for the guest? Should volunteers help to resolve long-standing family conflicts or stay out of them?

Finally, the above vignette raises another tension between values: what to do when aspects of care are in tension with the value of 'being at home'? Every time a camera is installed, hospice workers discuss this question. The hospice aspires to 'mimic the feeling of being at home.' Yet, these cameras seem far removed from anything homely. Simultaneously, the hospice is responsible for the guest's safety. Where should the hospice mimic the guest's house exactly, and where should it become a different kind of 'home' entirely?

## 7. 'Almost home'

Until now, I have not yet explicated one of the most important questions surrounding the hospice's philosophy: what does the '*almost*' in '*almost* at home house' refer to? Why is the hospice never entirely 'home' in the sense of the home they lived in prior to the onset of their disease? Why did Jasmijn say the hospice *mimics* the feeling of being at home?

Firstly, some obvious differences between the hospice and a guest's home come to mind. At home, the guest's personscape is not limited to a single room, and they don't have to take all other guests and hospice actors into account. The hospice is also not the place in which they have lived a large part of their lives. At most, they spend about six months in hospice. Their children have not grown up in the hospice, they don't pay a mortgage for the hospice, they cannot decide to re-paint the walls or do anything else that is irreversible. Furthermore, at home, there is no team of 60 volunteers and a dozen nurses ready to give them all the care they desire. In light of these differences, it is appropriate to call the hospice guests '*guests*' instead of '*inhabitants*': the 'guest' is similar to a hotel guest.

Additionally, the guest's relations change upon entering the hospice. I have argued that the hospice is able to bring the guest's relations into the hospice as much as possible and maintain the guest's ability to enact these relations by enacting them together with the hospice network. This is not simply 'mimicking' the feeling of being at home. The actual relations that the guest had at home, prior to their disease, are brought into the hospice. Still, the situation is different. The hospice network tying into the guest's network of relations not only maintains, but also mediates these relations. David and Emma's breakfasts at home were different from those in the hospice. At home, no one would offer them coffee, their kitchen at home was different from the hospice room, and there weren't any other people around, right outside the door. Perhaps even more importantly, all of these things remind them that they are sharing breakfast in an institution meant to facilitate David's death.



Simultaneously, other aspects of the hospice facilitate 'feeling at home,' in the Heideggerian sense, even more than their home prior to arrival. For a large part, this has to do with the new temporality that a life expectancy of less than three months creates. Most guests have accepted that their time is limited upon arrival in the hospice.<sup>86</sup> In contrast to the hospital's mandate, which holds up the guise of immortality through treatment, the hospice's mandate leaves no illusion: you are here *because* you only have a few weeks to live.<sup>87</sup> For David, this meant only a few weeks to sit on the terrace, to have breakfast with Emma, to play his favorite music.

Additionally, the activities that fill a hospice guest's time are different from those prior to their arrival. Whatever they cannot do themselves is taken care of, leaving more time to do what they choose. While David spent much of his time cooking and doing groceries at home, I later fried eggs and bacon for him as he listened to the birds on the terrace. While David worked as a consultant before coming to the hospice, there later was no need to work. No need to do anything he doesn't want to, apart from the occasional washing and getting out of bed. What Jasmijn said about the family's position when relieved of their 'caretaker role' also holds true for the guest: *'They don't have to do anything. They only have to sit with their loved one and drink a cup of coffee.'*

In Heideggerian terms, these aspects of the hospice change how guests relate to their surroundings in two ways. Firstly, their actions are not dictated by what anonymous functions they had to fill prior to the hospice (an 'inauthentic' mode of being dictated by the 'they').<sup>88</sup> As one of the volunteers put it in an interview: *'The most honest people are the terminally ill. In the hospice, you are not expected to hide anything. You don't have to like each other. You*

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<sup>86</sup> Interview Jasmijn.

<sup>87</sup> Kaufman, *...and a time to die*, 28-36, 70-71.

<sup>88</sup> Heidegger, *Being and Time*, 114-126, 167-173.

*don't have to get money from one another or pretend to be bigger.*"<sup>89</sup> David, for instance, could take up his specific position instead of holding up the guise of general 'consultant on the job,' his actions determined by clients' expectations. This is not to say that the 'consultant' role is inherently in conflict with 'authenticity.' The Heideggerian mode of 'authentic being' has to do with reflectively letting one's outlook on life be determined by one's specific positionality, rather than blindly getting lost in the roles one thinks they are expected to fill: Being a 'consultant' because one simply is a 'consultant' and wants to get a better salary or a bigger house without asking *why*.<sup>90</sup> As the hospice is the final stage, however, many expected roles and the aspirations connected to them dissolve. *"This is the final station. After this, there is no next apartment and an even bigger house than before."*<sup>91</sup> As a result, hospice guests increasingly seem to connect to their surroundings for the sake of experiencing the specific connections that their situation yielded, being 'at home' with those connections.

Secondly, the awareness of the weeks in hospice being the last, opens up the ecstasies of time.<sup>92</sup> The realization of David's limited time opened up the possibility for his entire network to engage with their activities in light of the past that led up to their connection, the future that David would leave behind, and the present as the meeting point of all temporal ecstasies. David smoked even more, despite his lung cancer. He sat on the porch, had his favorite comfort foods, and listened to his music. His friends from all over the country came to say goodbye. Emma paid some extra attention to her father, visiting the hospice almost every day, sometimes accompanied by scones, almost always crawling up in bed with him. David only had to relate to his surrounding world, experiencing his deep connections. His

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<sup>89</sup> Interview Peter (volunteer).

<sup>90</sup> Heidegger, *Being and Time*, 172.

<sup>91</sup> Interview Peter.

<sup>92</sup> The 'ecstatic unity of time' refers to one's 'being outside of oneself' across present, past, and future. Heidegger, *Being and Time*, 309-349.

visitors only had to stay with their connection to David, being fully present while foreshadowing the inevitable loss.

The hospice is not the same as the guest's home prior to the onset of their disease. In many ways, the guest remains a 'guest.' Simultaneously, the hospice enables its guests, in the most successful cases, to be fully present in the world, thinking of the life they leave behind and their hopes for the future. To remember how their world made a difference for them, and how they made a difference to the world. To be entirely 'at home' in the world. The hospice is *almost* home because it falls short of the guest's house in some aspects of 'homeliness' but extends beyond it in others.

## Conclusion: Departing Together, Leaving Alone

I wrote almost the entire first draft of this thesis before realizing I hadn't mentioned death explicitly yet. This is ironic, as I came to the hospice, expecting that it was a 'place of death' and that I would write extensively about how hospice care harshly confronts guests with their own mortality. What I found, couldn't be more different. The line 'the hospice is actually more about life than it is about death' was mentioned during all my interviews and many of my shifts.

But what is 'life' about? What is the philosophy of hospice care? The hospice's philosophy reveals life as an intimate connection between the guest and their world. Life is about being in the world and of the world, of constituting a world and being constituted by a world. It is about having a history and projecting a future. About caring for those around you and being cared for by those around you. About feeling and making others feel. About touching and being touched. About making a difference for those around you and have those around you make a difference for you. It is about feeling at home in the world, because you are precisely your connections to the world.

The hospice is a place where the guest can connect with their family, laugh, cry, eat their favorite meal, struggle with their decline, see depictions of their past on the wall, get as comfortable as they can be. It is a place where the family and friends can see their loved one, share a meal, vent to the workers, decide how to move on after the funeral, and throw a last birthday party. All of these things are possible despite disease and decline, because the guest brings their relations into the hospice, shaping their personscape, and trying to make them feel at home. Hospice workers then attune to the guest's network of relations and see where they can help out. The guest's network and the hospice network finally enact the guest's relations together, continuously tinkering and muddling through difficult decisions, all the while trying to maintain healthy boundaries of when to merge and when to separate networks.

Together, this intimate intertwining of the hospice network and the guest's is what enables guests to be 'fully alive' in their last weeks.

Hospice care is not primarily centered around death, but departure. Departure, in some senses, is the moment at which one is most present. It is the moment before stepping out the door at a party, when you turn around one last time, see the people you were talking to minutes before, smell the food being served, listen to the chatter and bustle of steps. The moment at which one first is present with the party *qua* party.

This is why seeing David in the garden was so touching to me. Why I could picture he was not simply letting the chirps pass through his ears but related to that little bird in light of all his life that had led up to that moment and his hopes for the world that would outlive him. Simultaneously, I pictured him fully present with the bird, letting the song make a difference to him, being touched. The entire hospice network and everyone he had forged strong connections with throughout his life was engaged in David's departure from life. It is hard to overstate the strength of the connections between Emma, David, Monica, the nurses, volunteers, David's room, his medical devices, and everything else in his surroundings during those last weeks of his life.

Then, he let go of his last breath. I was not there when it happened, but I heard it was a comfortable death. Monica and Emma were called up beforehand and arrived at the hospice just in time. He couldn't speak, but I read in the file folder that his presence was 'warm, calm, and grateful.' Next to the old file folder on the table in the volunteer room, there was one card from the family, thanking the hospice for the 'invaluable care and love' that we could provide for David. I took a moment to think about David before starting my shift.

David's room was empty. I could still remember how he filled the space, made it entirely his own. Simultaneously, I knew how fast a new guest would be able to make it

entirely *their* own. A pair of sweatpants with a post-it saying 'for Emma' was carefully placed next to the door. They must have forgotten to take those with them.

At the end of my shift, I found a letter from a volunteer who attended his funeral on the volunteer table: *"Monica and Emma each had a heart-warming and heart-breaking speech. It became clear what a caring man David was throughout his life. No other than he would have wanted, he was buried to the sound of 'Heroes' by Bowie. I will miss his presence in the hospice, but I'm so grateful to have experienced it when he was here."*

The hospice is a transitional space. For a while, the network of the guest gets brought into the hospice in its entirety. The guest's relations merge with the hospice network. Bodies, technologies, food, and narratives mobilize to enact the guest's relations and maintain their deep intertwinement with their surroundings. Then, the guest dies. Their family and friends stop visiting, go home to grieve and figure out how to live their lives without their loved one. The file folder and room get cleaned out and prepared for the next guest. The hospice workers end their last shifts with that guest present and go home to their own families. The hospice network and the guest's network untangle, and all actors go their own ways. Wherever they go, however, they carry with them the memories of a time at which they were intimately connected to one another. A time at which they came to an old building with stained-glass windows and were fully present with the things that life is truly about.

I put my jacket on, said goodbye to the other volunteers, and opened the big green door. Then, I turned around one last time. I heard some chatter coming from visitors in room two, the coffee machine gurgled in the kitchen, and I could smell the flowers in the hall. Then, I let the green door fall shut behind me, punctuated by a firm click of the lock. I hopped on my bicycle and glided back into the cacophony of the city's streets.

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