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“I do want euthanasia, but not now.” Timing a request for euthanasia with dementia in the Netherlands

Lemos Dekker, N.

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Thinking with Dementia

Edited by Krause, Kristine;
Pols, Jeannette;
Driessen, Annelieke
and Yates-Doerr, Emily

Contributors

[Susanne van den Buuse](#)
[Francesco Colona](#)
[Annelieke Driessen](#)
[Alessandro Duranti](#)
[Silke Hoppe](#)
[Kristine Krause](#)

1 Comment [Natashe Lemos Dekker](#)
[Ingunn Moser](#)

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★ September 17, 2018

"I do want euthanasia, but not now." Timing a request for euthanasia with dementia in the Netherlands

By Natashe Lemos Dekker

Sitting on orange seats in the corridor, Ms Verbeek, her niece Hannie and I are waiting for the general practitioner. Ms Verbeek seems a little restless and is quiet. She is 79 years old and lives by herself in a small town in the south of the Netherlands. We have met several times before, sometimes one on one, and sometimes together with Hannie. Those previous meetings had taken place at her home, but this time we are in the nursing home where the doctor has his practice. He arrives, and after greeting each of us we walk to a small meeting room. The doctor, Maarten Terbrugge, is a young and jovial man. He is wearing a striped shirt and jeans, and gives an approachable impression that usually enables him to create open conversations with his patients. The meeting room is painted white and furnished with a light wooden table and six chairs. Terbrugge gestures that we should all take a seat. Ms Verbeek and Hannie sit next to each other and I take a chair opposite Ms Verbeek. Terbrugge has taken a chair at the head of the table with his back to the clock on the wall. I check to see if he is wearing a watch, but he is not. Terbrugge is not preoccupied with clock-time. On the table is an entirely different temporality: the timeframe of a request for euthanasia.

Ms Verbeek has established three written statements: one declaring that she does not want to be resuscitated, and two specifically for euthanasia, in which she solicits the general practitioner to end her life if and when her suffering



becomes "unbearable".

Opening the conversation, Terbrugge asks Ms Verbeek how she feels she has been doing since their last meeting.

"Oh, I think I've been doing reasonably", she answers. "I am often forgetful, but usually it does come back, you know? It's not that I cannot function."

"Did you manage to keep track of your diary?"

"Yes, I think so. They are not full pages, of course."

"Well, let's see it then", says Terbrugge.

Hannie bends down to pull the diary from her bag and passes it to Terbrugge. The diary is a simple black pocket-sized agenda, with each day printed on a separate page. Terbrugge slowly browses through the pages and reads the lines Ms Verbeek has written. Most of the pages contain only one or two sentences, written in classic script. On one day she wrote that she had been working in the garden with Hannie. On another, her godchild had come to visit, who wrote that they had had a cup of coffee and that it had been very *gezellig*.^[1]

"I do very normal things", Ms Verbeek comments. "So what I write down is very ordinary. Sometimes I have to search for something I have lost, that drives me crazy. But usually I find it again. But everyone has that, every now and then."

"I notice that you record quite well what you have been doing", says Terbrugge, who is still browsing through the pages. "And I see that you often mention nice things as well. I think that is very good. It indicates that you are enjoying life. But I also see that there is very little about the things that are becoming more difficult."

"Yes, well, but that does not happen so often. Things of which I would say, 'Oh I can't do that anymore', or 'I find that difficult', or, I don't know, that I forget something."

I notice that Hannie frowns and looks disapproving each time Ms Verbeek says she is doing well or that she is not very forgetful.

"Well", Hannie intervenes, "yesterday wasn't all fun, was it?" Hannie, a stern and tall woman in her late thirties, has not said much up to this point. She talks in an assertive tone.

"Yesterday", she continues, looking at Terbrugge, "I came by and I told her that we would go to the doctor today, and she became angry with me".

Terbrugge looks at Ms Verbeek, who hesitantly answers, "Yes, I did not like that". When Terbrugge asks her if she can explain, she elaborates.

"It always makes me a little scared. Not of you, but of what you might say. I am so afraid to be evicted, to be taken out of my house and moved to a nursing home. I would find that terrible. Now I still have so much freedom and I can still do so much. And then I think, what to do?"

Terbrugge nods, and asks: "Are you afraid I would bring up that topic?"

"Yes. Or that you find things are not going well. That I indeed forget too much. I don't think I do now, but if that were to happen, I wouldn't know what to do against that, I cannot stop it."

"Well, these things don't happen overnight", Terbrugge comforts her.

"She keeps asking me why we have to go to the doctor all the time", Hannie says. "And when I then talk with her about those things that are not going well, it makes her unhappy. I find it difficult to confront her with that, but I find that I have to. Otherwise she thinks everything is fine, and it is not."

"I am just afraid I will not be able to live at home anymore", Ms Verbeek repeats. I notice her tone of voice has slightly changed. She had been speaking softly, as if she had been afraid to talk, and afraid of what might be said. Now that the topic of her fear is openly on the table, she seems to become more steadfast. "It is not that I am sad about it for days, but I think about it often."

"Actually", she continues, "I wish to stay at home as long as possible, until I do not know it anymore and I need to move to a nursing home. Then I want euthanasia, because I do not want to go to a nursing home".

"Why is having to leave your home a limit for you?" Terbrugge asks Ms Verbeek.

"Well, that I walk onto the street and don't find my way back home. You hear that sometimes, of people who start wandering. I would not want that."

"So for you, admission to a nursing home means you will have degenerated to a point where you think you will be doing things you don't want to do?"

"Yes. Then life has no point anymore, has it? I also don't think it's easy for you, a question like that."

"So what makes that the limit?" Terbrugge repeats his question. "What are you afraid of? Is it the fact that you would have to leave your home, or further degeneration?"

"Well, those two come together", says Ms Verbeek. And, after a short pause, "Both my father and brother lived in a nursing home, so for me that is a limit. Then it is enough. To be closed in in a ward, what kind of life is that? I won't say I still do everything right, but I feel I can still stay at home a while longer. This situation will only get worse. I am sometimes a bit forgetful, and then I will not be able to discuss it anymore. So I felt I had to start this on time."

Terbrugge takes a deep breath and says, "The point is that when the moment arrives when you would no longer be able to live at home, is often also when you will have regressed cognitively to a point where it will be hard to oversee. That you do not see the degeneration yourself. This can become a problem when we enter a euthanasia trajectory, and you cannot oversee the trajectory yourself".

To which Ms Verbeek answers, "Well, I do want euthanasia, but not now".

What can we learn from the need to start 'on time', the repetition of statements and questions, the fear that it will be 'too late', and a sense of inevitability leading towards an apocalyptic scenario? Thinking through dementia and euthanasia about temporalities and future-making, I explore a request for

euthanasia as an act of responding to, and preparing for, an imagined but unwanted future, and which constitutes an anticipatory practice. In anticipating the end of life through euthanasia, the person with dementia searches for an ideal moment which should consist of overlapping timeframes wherein she can still explicate her wish for euthanasia while achieving a point where life is deemed not worth living anymore. Often, these timeframes exclude one another. How then to think about the future, when the only possible dignified future is to have no future at all?

[1] Gezellig has no equivalent in English, but refers to a certain cosy or nice atmosphere.

Natashe Lemos Dekker is a PhD candidate in medical anthropology at the University of Amsterdam and a research fellow at the Leiden University Medical Centre. Through ethnographic fieldwork in nursing homes in the Netherlands, her PhD research addresses the social processes and the moral values in death and dying with dementia. She assesses the politics of death and dying by questioning normative conditions for the production of lives worth living. As a research fellow she studies the implementation of palliative care in nursing homes through a critical evaluation of palliative care tools for observing and marking the end of life. The questions raised in the story for the series *Thinking with Dementia* form the background of a longer article that she is currently working on. Her latest publication "Moral frames for lives worth living: Managing the end of life with dementia" appeared in *Death Studies* 42 (5), in 2018.

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