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Thinking with Dementia

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[Overview](#)

[Introduction](#)

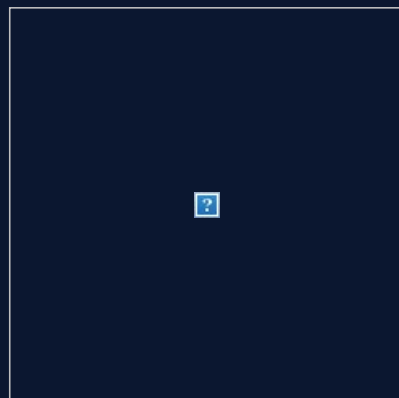
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Stories about time shifted, folded and shared, the extraordinary ordinary, and keeping separate and being a-part.

★ September 24, 2018

Burning down the house: When crisis becomes daily life in early-onset dementia

By Silke Hoppe

For my doctoral research, I interviewed family members living with a loved one with early-onset dementia, a diagnosis that one receives under the age of 65. Jans, not his real name, was the fourth person I interviewed in April 2015. Since he lived in a remote village in the east of the Netherlands, we met at a train station to conduct the interview. I had imagined going to a quiet café, but all we could find nearby was a snack bar where Ace of Base played in the background. On the way to the snack bar, I said that I was having difficulties understanding him because of his dialect, to which he replied: “I don’t have a dialect”.

Over the next four hours, Jans told me his story. Normally in the interviews, I first asked the person I was speaking with to describe the changes that he or she first noticed in the person with dementia, and then to proceed in a more or less chronological manner. With Jans it was different. He jumped back and forth, hardly said more than three sentences, and just casually dropped in some years or dates, which left me puzzling about the order of events that he was narrating. Based on how he told his story, I got the feeling that, in contrast to other interviewees, he had not told it to many people. Much later, I thought that the daily crisis that had been his life while taking care of his wife with dementia for more than a decade, seemed to be reflected in his incoherent way of telling his story. The story written down here is thus the result of me trying to put the pieces of the puzzle together.



Fifteen years ago, when Jans was 50 and his wife Klaartje was 44, Jans noticed worrisome changes in his wife. She started confusing the birthdays of their two sons, and congratulated her 10-year-old, even though it was the day to celebrate the birth of her 6-year-old. Even before that there had been times when he had been worried about her: following the birth of her first son she became pregnant again and had a stillborn child, and as a consequence had suffered from depression. But confusing the birthdays of her children had a new quality.

First Jans attributed her confusion to this earlier depression. But when Klaartje started having problems at work as well, Jans thought “This is not my wife anymore” and pushed Klaartje to see a doctor. The GP that they consulted, six years after the appearance of the first symptoms, like the confusion of birthdays, stated that Klaartje had a burnout. But Jans noticed that after some months of rest her condition got worse instead of better, and he became sceptical about the diagnosis. His background in nursing led him to conclude that his wife had dementia. Yet no one took his suspicion seriously. As a consequence, Klaartje was only officially diagnosed eleven years after Jans first noticed that something was seriously wrong and five years after the GP had diagnosed her with burnout.

When I asked Jans whether he was still working at the point when they had received the diagnosis, he replied that he had stayed at home with Klaartje and had wanted to go back to work once their children were older. But since his wife needed more and more care, he had never returned to work. Jans had also thought about getting a divorce and was encouraged by his son to leave Klaartje, but since he realised that his wife was no longer able to live independently, he had stayed with her.

Over the years, the situation at home had become unbearable. Klaartje had become very compulsive and everything had to be done her way. Jans recounted how Klaartje was convinced that she did everything right and that her children did everything wrong. Often she was aggressive and shouted angrily at her children, or even threw things, something she had never done before she became sick. Jans tried to channel Klaartje’s negative emotions in order to protect the kids, but in the end he was unable to shield his two sons from their mother’s outbursts. “If we were alone with Mom, she always fought with us”, both sons told Jans after her death. In an attempt to escape his mother, the oldest son bought a television and spent the majority of his time upstairs in his own room.

Jans experienced the situation at home as unliveable. Sometimes Klaartje, regardless of the time of day, just left the house without telling anyone where she wanted to go. Twice she was brought home by the police, who on one occasion had found her on the highway. The second time Jans’ youngest son stated that if it happened another time, he would move out, because he could no longer bear the situation at home. His youngest son struggled at school and was often involved in fights. According to Jans, this was his son’s way of dealing with the frustrations at home.

The longer the situation lasted, the more indifferent Jans seemed to have become.

Sometimes she ran away and we wondered where she was. So we came home and I said, “If they find her dead, I wouldn’t mind”. We often thought “Maybe she is already dead right now”, with all that

searching and going astray. If she dies or she goes astray and does not return, well then, that's how it is.

I remember being shocked about how matter-of-factly Jans talked about the situation. His voice did not reflect much care for his wife. His reasoning about the possibility that she might die in an accident seemed not to be about her and the fact that it would be good if she no longer needed to suffer, but about him being relieved of a burden. I got the feeling that he was so exhausted that he had no energy left to care.

Listening to Jans' story, I wondered how it had ended up like this. Why and how had the whole situation gotten out of hand and become so unbearable? There is no easy answer to this. The situation had resulted from a complex interplay of different aspects. Jans told me that if their old GP had not become sick, he probably would have seen much earlier that something was wrong and would have acted. Even before Klaartje had been diagnosed, Jans told the new GP that he could no longer stand the situation at home, but the GP had simply replied that he should keep going. In another attempt to call attention to his situation, Jans invited the GP to his home so that he could see with his own eyes how bad the situation was,^[1] but the GP only advised him to see a social worker.

In the beginning, friends still dropped by. But when Klaartje was no longer able to keep up a conversation, they stayed away because they did not know how to handle the situation. Jans' neighbour, who found the situation terrible and wanted to support him, had to conclude that she was unable to watch Klaartje for more than fifteen minutes. Thus in the end, Jans was left alone with the situation. He did not receive practical support, but also felt that no one realised how heavy the situation really was. Furthermore, the few friends who remained only ever inquired about Klaartje, and did not ask how he was managing. I got the impression that it was the lack of recognition, in combination with the chronicity of the situation, that made it so hard for Jans to keep going.

You are so terribly tired. It would not have taken longer and I would have collapsed. It is nice that the social network has to take things over,^[2] but you cannot uphold that situation. At a certain point there was so much anger. I think you will get whole family dramas. I once thought I will burn down the house, then we are done with it. Yes, that is what I thought.

Jans' anger, despair and frustration come together in the image of the burning house. It is an expression of extreme emotions and reflects the strong desire to leave the old behind.

Further along in the interview, Jans stated: "I did not receive any help". After the diagnosis, Klaartje received a case manager, which is a care professional whose task it is to coordinate the available care resources for a person with dementia. But Jans found him neglectful. Only when the GP finally managed to do a house visit did Klaartje receive an indication to go to a social care farm, a place where people with care needs can do meaningful work under supervision. However, as her illness had progressed so much by this point, she was not able to stay there for long. Jans had also tried to find a day care centre for her, but living in a rural area, he had found no place where young people with dementia could go.

When I asked him why he had not received more support from the case manager, Jans told me that the case manager had assumed that Jans wanted to care for his wife as long as possible, even though he never explicitly asked about this. Also, Jans assumed that the case manager was struggling with the situation because Klaartje was so young. In the end, Jans' cry for help was heard and Klaartje moved to a nursing home. This happened only a few months after her diagnosis, but since it had already taken eleven years to get the diagnosis, it was almost too late for Jans. Despite this, his family-in-law was not very understanding. Klaartje's mother vehemently scolded Jans and his children for sending her daughter to a nursing home, which she called a prison.

At the age of 57, Klaartje died, thirteen years after her husband had noticed the first changes in her. Her youngest son, who was 18 years old at the time, did not want to go to her cremation. When I asked Jans how he looked to the future, now that his wife had been dead for one and half years, he replied:

I don't see any future at all. I matter to my children, but other than that I see no future. At my age I won't be able to find work anymore. And doing voluntary work? I think I already did so much. I cared for her for ten years. What is your future? That is very difficult. I think, without the kids, I would have ended my life. It has been so heavy, all my life.

Since Klaartje's death, Jans' life has changed. The urgency of the crisis is gone, but the chronicity of the crisis over more than a decade has clearly left its mark on him.

I was moved by Jans' story and shed a fair few tears on the long train ride home. In the other interviews I did with families affected by early-onset dementia, I often encountered exhaustion, despair, loneliness and indifference. But in Jans' case, all of these emotions were accumulated in the extreme, as if his house was perpetually on fire.

[1] Although it does not happen that often, GPs in the Netherlands still sometimes visit their patients at home.

[2] Here he refers to recent developments in the Dutch health care system in which citizens are encouraged to take over care that was formerly organised by the welfare state.

Silke Hoppe is a PhD candidate at the [Long-term Care and Dementia Partnership](#) at the Anthropology Department of the University of Amsterdam. Her dissertation research focuses on the experiences of people with early-onset dementia and their families in the Netherlands. A central topic of her work is the relationality of people. Silke explores how through the course of an illness like early-onset dementia people's relations transform. Her latest publication "A Sorrow Shared is a Sorrow Halved: The Search for Empathetic Understanding of Family Members of a Person with Early-Onset Dementia" appeared in *Culture, Medicine and Psychiatry* 42 (1), in 2018.

This post is a contribution to 'Daily life' in the Somatosphere series 'Thinking with dementia.'

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Read the refraction of the theme [here](#).