



## Questions of (non)Disclosure among People Living with Alzheimer's Disease in Denmark

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### Abstract

This article explores questions of (non)disclosure among people diagnosed with Alzheimer's disease, arguing that whether to reveal one's diagnosis to family and friends is not a straightforward choice. I use the term (non)disclosure to emphasize the fluidity of that choice, as participants often toggle between revelation and concealment. Common to various strategies is an aim to avoid the strong associations with dementia as social death. By following the aftermaths of disclosure, the article shows that people with Alzheimer's disease living in Denmark do *not* experience social death. Rather, they experience marginalization and estrangement but also continuing care. The article reveals that while social death is commonly ascribed to Alzheimer's, this ascription does not account for the manifold social implications of the diagnosis. The continuing care that people with Alzheimer's disease receive is often overlooked. To challenge commonplace mischaracterizations of dementia as social death, we must take seriously the experiences of people living with the disease and contribute to redefining common understandings of dementia in ways that include the continuity of social recognition and the possibility of living a good life.

**Keywords:** *Disclosure; Social death; Diagnosis; Alzheimer's disease; Ethnography*

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# Anthropology & Aging

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## Questions of (non)Disclosure among People Living with Alzheimer's Disease in Denmark

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### Introduction

My biggest fear is that when I become more ill, no one wants to visit me because they are afraid of sitting in front of me when I am a bit strange, unable to answer questions. If you are locked up in a nursing home, only seeing staff members, you will fade away. You will die more quickly. I am certain of that. We are social beings, right? And you don't get less social having dementia. You may have some symptoms that make people think they should keep away from you, but that is not the point. No humans want to be all by themselves.

These words were shared with me by Dea (48 years) a married mother of three small children. As she sat in her bright kitchen, Dea described falling into "a black hole" of depression in the five months following her diagnosis of early-onset Alzheimer's disease. During that period, she could only foresee loss. To pull herself out of the black hole, Dea sought psychological counseling, read every book, and saw every available movie—both academic and public-facing—on dementia. In these sources, she found portrayals of people with dementia disappearing into the disease. But she also found descriptions of how it is possible to live a good life. Even in the late stages, there can be care and laughter. Though Dea still dreaded her future, these other, more joyful images of life with dementia helped her come to terms with her disease. She channeled her urgent desire to re-write the narrative of dementia into numerous interviews with journals and women's magazines, as well as appearances on national TV. Dea explained, "I had this idea that I wanted to break down the taboo [of dementia], because the person with dementia is not to be blamed." If only people had a better understanding of how to interact with people with dementia, she insisted, then life would still be worth living, even in the final stages.

Drawing on 12 months of ethnographic fieldwork over 2.5 years among people with Alzheimer's disease living in Denmark, this article describes the *social* implications of an Alzheimer's diagnosis.

Patient organizations across the globe urge newly diagnosed people with dementia to share information about their diagnosis with family and friends, framing disclosure as "an important first step towards integrating dementia in one's life" (Alzheimer's Association US, n.d.); "a means to prevent social isolation and loneliness, making it easier for friends and family to reach out" (Danish Alzheimer Association 2021); and "a push-back on the stigma

associated with dementia” (Alzheimer’s Society of Canada, n.d.). Dea was exemplary in following this advice, disclosing her diagnosis broadly and engaging in advocacy work. Yet, for other participants in the study, questions of (non)disclosure proved to be much more complicated.

Like Dea, all participants expressed, to a greater or lesser extent, a fear that their diagnosis would result in them becoming isolated from their social relations, and gradually becoming unable to discern where and with whom they belong. This fear arises from pervasive medical and colloquial characterizations of dementia as social death, and as I will show, it led participants in the study to deploy different strategies for (non)disclosing their diagnosis to their social relations. Exploring these strategies, I argue that whether to reveal or conceal one’s diagnosis is rarely a straightforward choice. I use the term (non)disclosure to mark it as non-mutually exclusive; one can toggle between revelation and concealment. Yet, common to the various strategies employed by people with Alzheimer’s is an aim to remain socially relevant and avoid social death. Secondly, by following the aftermaths of disclosure, I show that people with Alzheimer’s in fact do *not* experience social death. Rather, they experience marginalization and estrangement but also continuing care and social recognition from close relations. My material therefore shows that social death is not a fitting term for what happens to people living with Alzheimer’s disease in Denmark. I argue that to challenge commonplace mischaracterizations of dementia as social death, we must take seriously the experiences of people living with the disease in ways that include continuity of social recognition and the possibility of living a good life.

### **Disclosure and Social Death**

In 2021, Denmark introduced a national dementia symbol through a government-supported campaign that aims to help people make their “invisible disease visible” by wearing the symbol in public as a pin. Concurrently, the campaign aimed to raise the general public’s awareness about dementia. Paradoxically, this pin, aimed at making dementia explicit, does not explicitly state anything related to dementia; it simply displays two hands reaching for each other. The website about the dementia symbol explains: “When you see the symbol of the helping hand, you are facing a person with dementia that might need a bit of extra help” (National Movement for a Dementia-friendly Denmark, n.d.). Thus, the pin user is dependent on other people understanding the pin’s symbolism. In other words, disclosure in this sense anticipates people who are knowledgeable about dementia. This points to the overall argument of this article: disclosure is rarely a question of either-or, but, rather, revealing and concealing coexist. While patient organizations call for openness to fight the stigma of dementia, a great deal of secrecy persists alongside attempts to carefully reveal to people who care.

A vast body of literature has explored the circumstances of disclosing a dementia diagnosis in clinical settings, describing how medical professionals choose to communicate the diagnosis to patients and their families (see Derksen et al. 2006; Downs et al. 2002; Merl et al. 2022; Milby and Winthrop 2017; Nielsen et al. 2020). However, little research considers how people diagnosed with dementia choose to disclose their status to their social relations. The present study does just that, attending also to another overlooked element in (non)disclosure – the simultaneous practices of concealing and revealing a diagnosis.

In studies ranging from Uganda to Denmark to Burkina Faso, scholars have described how patients living with HIV/AIDS continuously balance discretion and revelation when considering what to disclose to whom, at what time, and for which purpose. Showing that disclosure is a social process, such studies add nuance to the simplified understanding of disclosure in public health discourses (see Mogensen 2010, 2011, 2020; Samuelsen and Østergaard, 2012). In studies of cancer, scholars have described how concealing a diagnosis can be a sign of care in Botswana (Livingston 2012), and how concealment allows hopeful attempts by family members and patients to integrate a life-threatening diagnosis in an already vulnerable social situation in India (Banerjee 2019). Looking specifically at practices of non-disclosure in dementia, Jieun Lee (2019) studies family members in South Korea who withhold the

diagnosis from the afflicted relation. Lee argues that while ethically fraught, non-disclosure can be seen as granting “the person with dementia a subject position that is different from what she or he might fear” (Lee 2019, 503). The above-mentioned studies illustrate that practices of (non)disclosure are charged with relational tensions and social aspirations extending beyond the individual living with the disease. I will draw on this point when exploring different strategies for (non)disclosing one’s diagnosis in the face of fearing social death.

Further, I am inspired by George Simmel’s (1950) understanding of mutual (non)knowledge as the basis for all social interaction. Simmel argues that through the gathering of knowledge about each other, we know how to interact with one another (1950, 307). However, the image we shape of another person will never be entirely representative of what is really occurring within this person in a given situation. As individuals, we may deceive ourselves and others in order to maintain our life and potentials, and we only present curated selections of our inner psychic state to others (310–312). Simultaneously, as individuals, we exercise discretion towards the other by respecting her/his secret and reasons for secrecy, but also by steering away from all knowledge that is not explicitly revealed (321). This link between revealing and concealing forms an essential premise for social interaction and is actually socially productive, Simmel argues (315). He writes, “Relations among men are thus distinguished according to the question of mutual knowledge—of either ‘what is not concealed may be known,’ or ‘what is not revealed must not be known’” (321).

Rather than automatically assuming that full disclosure is *the* means to live the best life with dementia, Simmel’s theory of mutual (non)knowledge as the basis of social relations can inform a deeper understanding of research participants’ different strategies for (non)disclosure. By exploring these strategies, I show that concealing and revealing work to sustain social recognition, avoiding social death.

Common understandings of dementia remain heavily influenced by discourses of social death. Within the social sciences, social death was first described in the 1960s in studies that described situations in which patients were treated as dead long before biological death (Králová 2015, 231; Sweeting and Gilhooly 1997, 94). Social death has since been explored from various angles, including slavery (Patterson 1982), mental illness (Biehl 2013; Goffman 1961), young soldiers in West Africa (Vigh 2006), and genocide (Card 2010). Writing about solitary confinement in US prisons, Lisa Guenther (2013) defines social death as

the effect of a (social) practice in which a person or group of people is excluded, dominated or humiliated to the point of becoming dead to the rest of society. Although such people are physically alive, their lives no longer bear a social meaning; they no longer count as lives that *matter*. (xx; emphasis in original)

Guenther further shows that the socially dead are expelled from social networks, particularly kin relations, that would otherwise support, protect and give meaning to this person’s precarious life (2013, xxi).

In popular, mass-mediated medical discourse, dementia is frequently associated with social death. The condition itself is depicted as a “funeral without an ending,” (Kontos 2006, 195) while the person living with dementia is described as “drowning in a sea of forgetfulness” (Hashmi 2009, 209), that while still alive, is not perceived as “fully there” (Moser 2008, 104) but rather a “living dead” (Walrath 2011, 94). In a review of both medical journals and popular literature on Alzheimer’s, Susan Behuniak (2011) identifies several ways in which zombie metaphors are applied to people living with dementia. Behuniak warns that these metaphors casually taint the general discourse of life with Alzheimer’s and questions whether this should continue to be the norm (2011, 78). In her review of the literature on social death, Jana Králová (2015) finds that the concept is deployed too frequently and argues that it should only refer to the most extreme circumstances. Inspired by Králová’s arguments and Behuniak’s warning, I will later discuss whether dementia does in fact constitute social death.

Joining “the personhood movement” as laid out by Tom Kitwood’s (1997) notion of person-centered care, several studies criticize how cognitive abilities have come to define what it means to be human. Such studies argue that personhood is also indexed by social interaction (Leibing 2006), can be embodied (Kontos 2006) and that even people with severe dementia can display with their bodies which activities they (dis)like (Driessen 2018). In a pioneering essay about her mother’s dementia, Janelle Taylor (2008) draws on Paul Ricoeur’s theory of recognition as fundamentally a social and political matter. From here, Taylor asks, “When everyone keeps asking me ‘Does she recognize you?’ I believe the question really is— or should be— ‘Do you, do we, recognize *her*? Do we *grant her recognition*?’” (Taylor 2008, 315; emphasis in original). In line with this literature, I will show how people with Alzheimer’s fight to sustain a sense of social recognition. After a brief discussion of the study’s methods, I will describe different practices of (non)disclosure and mutual (non)knowledge as the basis of social recognition.

## Methods

The material for this article is based on 12 months of ethnographic fieldwork over a span of 2.5 years among people diagnosed with Alzheimer’s disease living in Denmark. Approximately 87,000 persons live with dementia illness in Denmark, a country with 5.8 million inhabitants (Danish Dementia Research Centre 2021). I used multi-stranded recruitment to secure the needed participants for the study, reaching out to different actors, including municipalities, the Memory Clinic at the Copenhagen University Hospital, and the Danish Alzheimer Association. Most participants were recruited by five health care professionals working with dementia patients in five municipalities close to Copenhagen. Through their daily work of following and supporting people with dementia, the health care professionals could help me identify and establish contact with potential research participants. Research design entailed participant observation conducted in the private homes of people with Alzheimer’s and at different social activities for people with dementia. Further, it included 16 interviews with 13 persons with Alzheimer’s disease and seven interviews with six family members.

Fieldwork comprised of three phases: seven months from February to August 2019; then four months in fall/winter 2020;<sup>1</sup> and finally, one month in the summer of 2021. Dividing the fieldwork into phases enabled me to follow research participants for 2.5 years, and witness how their disease developed from the early to middle—and for some also late—stages of Alzheimer’s. Being able to witness the progression of the disease gave me insights into the temporal aspects of living with Alzheimer’s disease, and the opportunity to observe the impact of cognitive and physical losses on each participant’s social life.

Some of the participants I only met during one or two phases of fieldwork, however I closely followed five research participants for all three phases, visiting them regularly in their homes. These five key participants included three women and two men aged 57-84 years. All had received their diagnoses one to three years before our first contact and, at the time of research, still lived at home, managing life with none or minimal support. I initiated contact by conducting a semi-structured interview with key research participants (and potentially their partners, if they had one). In these interviews, I asked questions about their life histories, as well as about the time leading up to and following the diagnosis, focusing on their reactions and thoughts on how and to whom they had (non)disclosed. In addition to interviews with the five key participants, I conducted another 11 semi-structured interviews with other people with Alzheimer’s.

Following the initial interviews with key research participants, I shifted to participant observation. I would typically spend half a day with them, talking, drinking coffee, and participating in activities they enjoyed, like accompanying them for a walk or bike ride, knitting, painting, shopping for groceries, etc. This enabled me to gain a deeper understanding of their everyday lives, which generated loosely structured conversations about their interests and pressing thoughts and concerns. During the 2.5 years I followed these five key research participants,

three of them moved to a nursing home and two of them passed away. I also conducted seven semi-structured interviews with six family members of the key research participants: two spouses, three children (30-65 years), and one mother (84 years). Interviewing family members separately allowed for conversations about life as a caregiver without the worry of how hearing this might affect the person with Alzheimer's.

I conducted participant observation in various activities offered by different volunteer organizations and public institutions, such as participating for six months at a twice-weekly exercise club for people with dementia, and a five-day retreat for 20 people with dementia. In total, throughout the study I have been in contact with 48 people living with dementia, accounting both for the key research participants, people I met once or several times.

When conducting research among people with cognitive impairments it is necessary to make careful ethical considerations (Sherratt, Soteriou, and Evans 2007). All procedures in the research project were performed in compliance with relevant laws and institutional guidelines, and the project has been approved by the appropriate institutional committees. I have both obtained written consent from all participants and concurrently followed a "process consent" method. This method is explicitly designed to enable people with dementia to assert their preferences concerning research participation. At each stage of the data collection, process consent requires that the researcher remind the participant of the study's purpose and the right to withdraw (Dewing 2008). None of the participants in this study withdrew. All names of people and places have been changed to preserve anonymity.

## Results

### *Revealing and Concealing Alzheimer's Disease*

Different practices of (non)disclosure offer insight into the fears attending the news of an Alzheimer diagnosis – the fear of becoming marginalized, isolated, and unable to know to whom one belongs. All participants in the study were centrally concerned with being perceived as socially relevant, as well as with sustaining or regaining social recognition through different practices of (non)disclosure and mutual (non)knowledge. In the following section, I present different strategies and motives for revealing and concealing the diagnosis.

In the summer of 2018, Egon (56 years) made the following announcement in a Facebook post:

Hello friends ♥  
 The last couple of months have been very difficult to process and get through for me & my beloved family. ♥ I have been diagnosed with early Alzheimer's dementia 🙄 ♥  
 I have troubles with my memory, so should I pass you without saying hello, it is not due to bad intentions, please just grab me and say hello 😊  
 I hope to have many years left 😊  
 I hope and pray that you will support my wife - children - children-in-law & my highly beloved grandchildren because they are facing difficult times ♥  
 I will do all I can, not to lie down and give up, I will fight to the very last ♥  
 To those of you who are wondering why I no longer drive, it is not because I have been caught drunk-driving, it is my doctor who has banned me from driving ♥  
 ♥ ♥ Love, Egon ♥ ♥

Egon lived with his wife Ghita (53 years) in a town with roughly 20,000 inhabitants in Jutland, Denmark. None of his four children, who were between the ages of 25-31, lived at home. Due to a work-related injury in his back, Egon received an early retirement pension and had already stopped working as a bus and taxi driver when he received his diagnosis. Disclosing the diagnosis not only to his closest family but also to friends and a broader network was essential for Egon. He worried what others would think of him if they did not know the cause of his actions. Ghita

and Egon discussed how to share the news of his diagnosis and decided that a light-hearted, explanatory post on Facebook would be an effective and humorous way to go about it. The couple was overwhelmed by the positive response. Ghita proudly explained how a colleague said it was the most touching post she had ever read.

The weeks following the diagnosis had not been easy, however. Egon was devastated. From his knowledge of Ghita's work as a care assistant at the local dementia-specialized nursing home, he foresaw what his disease entailed. Immediately, he envisioned himself sitting in a nursing home, not caring about anything. During an interview one year after the diagnosis, Egon described how he felt immediately afterwards: "I have to admit; at that point, I did not want to live any longer." Egon explained that he thought his family would send him to a nursing home straight away, and as a solution, he considered "finding a bench out in the nature, where [he] could take some pills and disappear." Egon told Ghita about these thoughts, and they went to the doctor, who prescribed anti-depressants. He explained,

It took about a week where I more or less cried from the moment I got out of the bed until I went back to sleep in the evening. Then I turned, thinking like, 'Well, I am still here. Ghita is still here. My children are still here, the grandchildren. My beloved grandchildren.

After this realization, Egon's first thought was to make a poster with pictures and names of his children and grandchildren. The poster hung in the living room, and Egon told me that he looked at it often, training his brain to remember their names.

What is striking in Egon's story is his concern for staying socially connected. What followed his diagnosis was a horrific fear of becoming an apathetic, atomized individual, detached from social life. However, his present state of being is the direct opposite: his family is what makes his life worth living and the reason he chooses to live. Furthermore, Egon is preoccupied with a wish to hold on to his social relations, as evidenced in the Facebook post to disabuse friends and acquaintances of any misperceptions and the poster that would help him hold on to the names and faces of his loved ones. He is thus motivated by a wish both to make his disease known and to continue knowing his immediate family.

Egon was not alone in his concern about losing the ability to know with whom he belonged. Several research participants explained how they considered committing suicide once they reached a point in their disease where they could no longer recognize their loved ones. At the same time, they were painfully aware that once they reached that point, they would probably not be able to follow through with a plan (see Lemos Dekker, 2020 for a discussion about the requests for euthanasia by people with dementia living in the Netherlands). My research participants' suicidal ideation indicates how closely tied a sense of belonging is to the very essence of existence. Anticipating no longer being capable of knowing with whom we belong creates the perceived experience of ceasing to exist.

When I initially met my research participants, one to two years after their diagnoses, the majority had disclosed their status broadly. Like Egon, several of them had been open about their diagnosis from the beginning, calling or mailing family and friends immediately after learning the news. For this group, sharing the diagnosis was a way to cope and ensure that everyone was in the loop and prepared to offer support, such as Egon's call for future support for his family. For those who still led an active work-life, disclosing the diagnosis to their employer and colleagues was necessary to either make supportive arrangements to continue their job or terminate it.

Not all, however, were satisfied with the outcome of disclosure: some expressed regret. This regret became apparent in a discussion I observed among three people with Alzheimer's about the (dis)advantages of disclosing their diagnosis beyond their immediate family. The three women – Karen, Tanja, and Mette – met in a moderated online

group session for people with dementia. The sessions were organized by the Danish Alzheimer's Association during the second COVID-19 lock-down in Denmark in the autumn of 2020. The moderator initiated the conversation, asking Mette how she felt about disclosing her diagnosis. Mette answered that being open about her disease had helped her cope with it. While she anticipated that people would not always know how to react to her diagnosis, she would never hide it. The two others felt differently. Tanja said, "In some ways, I regret telling about my diagnosis...My friends and family pity me instead of seeing me as I am. My friends don't have the same interest in me as before. I am no longer interesting." Karen began to speak, explaining that she had told her five closest friends but had since regretted this. She felt that her friends had started treating her differently, and in turn she had started acting differently around them.

When I am with my friends, I make an effort to speak about my previous work. I was the director of an arts center. I never spoke much about my work beforehand, but now I have this big urge to talk about it. And I ask myself, why is this so important now? I think it is due to anxieties of being seen as inferior; they might think I am unintelligent. It matters how others perceive me or how I think they perceive me. Probably both. I am terrified that my friends will treat me differently. I think they do.

Both Karen and Tanja's stories point to how the fear of dementia as social death impacts other people's perceptions of the person with Alzheimer's. Or at least how the person with Alzheimer's *feels* that others perceive her/him differently. And, as Karen suggested, this in turn changed how she interacted with her friends. Thus, the effects of revelation go both ways, mutually affecting both parties in the social interaction. Though the disclosure could not be undone, Karen tried counterbalancing it by emphasizing her former job and accomplishments. Through this effort, she sought to regain her friend's social recognition not as someone with Alzheimer's, but as someone still intelligent and interesting. In short, Karen was fighting the fear of social death.

For older research participants, changes in behavior were not unambiguously ascribed to Alzheimer's, as they sometimes wondered if the changes they experienced were caused by disease or simply by the aging process. Sometimes, age-related changes were used to conceal the diagnosis. This was the case for some of my participants, including Lone (79 years) who had not disclosed beyond her immediate family and a few friends. Lone participated in an exercise group for people with dementia, which I followed during fieldwork. Here, conversations about life with dementia would often come up during the coffee sessions. During an interview in her apartment, Lone said that she was puzzled by the others' openness. She explained how they would share their diagnosis with everyone in the supermarket queue to avoid annoying the other customers. Lone said, "I would never do that. I told my children about my diagnosis in a letter, but I don't need to signpost it. Having dementia isn't something to brag about...It's not something I am ashamed about, but it is not like winning a gold medal either."

Sitting next to her on the white couch was Bernt, Lone's partner of 30 years. As Bernt listened to Lone, he commented that if it were him who was ill, he would want to be as open as possible. Lone interrupted him, "To me, it is important to be perceived as normal for as long as possible." Bernt nodded saying that obviously he respected that. Lone explained that she would not mind if one of her friends specifically asked Bernt if she had Alzheimer's. Then Bernt could share it. "I don't mind that they know," said Lone, "but I think it is okay if people in all innocence just think that I am getting old. And I am! I'm approaching 80. You don't have to call it a brain disease." While Lone went downstairs for a brief moment, Bernt leaned towards me and whispered that he had been pushing Lone for a long time to let her children know. He now hoped to get her to disclose to some of their friends. "I need her to be open. I need all the support and help I can get."



Lone's efforts to keep her diagnosis concealed show her resistance to the close link between dementia and social death. She wished to be perceived "as normal" for as long as possible. Remaining vague about whether changes in her behavior were age-related or pathological allowed Lone to define the boundaries of what should be revealed and concealed about her condition. Even if her friends suspected something was wrong, most would probably by virtue of discretion, as described by Simmel (1950), stay away from asking her outright. This can be understood as respecting Lone's secrecy, following her lead by not asking questions about what Lone had not revealed. Yet Lone was open to a scenario in which a friend might break this rule of discretion by asking Bernt directly; she would allow that friend to be enlightened in this case. Such cases show that the question of being open or closed about one's disease is not necessarily a question of either-or, rather it involves toggling between sharing and not sharing knowledge and acting with discretion as a means to sustain social recognition. Further, through Bernt's whisper, we see that the practice of (non)disclosure is not always agreed upon, even within intimate relationships.

In the following section, I present different ethnographic cases that consider research participants' negative experiences following disclosure of their disease and discuss if this should be called social death.

### *Sensing Social Death?*

Tora (60 years) recalled last Christmas Eve with great sadness. As she sat around a nicely set dinner table with her husband, an aunt, their children, and a grandchild, Tora realized that no one at the table would talk to her. It was as if they looked right through her, addressing everyone but her. "It was the cruelest thing I have ever experienced...I went into my bedroom and cried twice that night. I think it was just horrible...It was like I was just plain air." That December she had received confirmation of what she had feared for more than a year: she had early-onset Alzheimer's. She did not know why her family avoided speaking to her that Christmas night. Perhaps because they did not want to pressure her, she thought, but it made her feel awful. Ever since she was diagnosed, Tora noted a series of changes. She explained that it felt like she was "crumbling away." She tried to keep herself together by doing things that made her happy: exercising, sewing clothes for charity. Still, Tora found her disease difficult, especially when she was in the company of others. She cited Christmas Eve as an example but also described how all of her neighbors seemed to know about her diagnosis, despite having only shared it with one of them. Tora felt that her neighbors tried to avoid her but she wished that they would approach her, since she was the one who was ill.

Experiences of exclusion and marginalization were reoccurring themes for my research participants. Like Tora, they explain that their social networks tend to "mute" them by avoiding conversation or interaction. Many experienced that some friends withdrew from their company and eventually lost contact. Another common theme across participants' stories was how family and friends tended to speak on their behalf. I observed this repeatedly during my visits, where typically the spouse would start answering questions I had directed to the person with Alzheimer's. This happened so consistently that I often had to arrange for a separate meeting in order to hear their opinions without interruptions. Bente, who at 72 lived alone, explained that she had asked her two daughters not to participate in the interview I had arranged with her because they habitually do all the talking. Egon, whom we met earlier, had experienced the same with his family. They had a habit of interrupting him and finishing his stories. He told me,

I'm demented, and I know that there are some things that I can't remember, but it is still unbelievable that I am not allowed to speak for myself. You feel a little bit dehumanized! Then I end up only saying 'yes, no, oh,' because at least they will not interfere with that. But it hurts like crazy inside, and I think that is the worst part of it all right now.

When family and friends exclude them from conversations or speak on their behalf, Tora, Bente, and Egon feel that they cannot participate in social interactions, as if they are socially irrelevant. In this way—perhaps unintentionally—family members and friends sometimes contribute to the exclusion and marginalization of persons with Alzheimer’s, diminishing their voice and presence in intimate settings. In the literature, such examples might be characterized as social death, and Egon himself uses the word “dehumanizing” to describe how he feels when his stories are continually interrupted. I however argue that it is problematic to consider such scenarios as social death because they depart from Guenther’s (2013) definition. None of the research participants were treated by family and friends as socially irrelevant to the extent that their lives no longer mattered. And while several participants did experience friends and even family members withdrawing from their company, they were not excommunicated from their entire network of social relations, as Guenther characterizes social death. Rather, they were still able to form and sustain meaningful relations with others. This is not to diminish experiences of estrangement, marginalization, and isolation; these can all be extremely difficult and painful to live through. But by referring to them as social death, we risk reinforcing dangerously pervasive discourses about dementia as social death. As I will show, painful experiences of marginalization and exclusion can coexist with continuing life and care.

### *Lives Go On*

I still think I have a good life. Physically I am doing well. I have lots of friends, a good family, and two kids. I think I cried for two days, but then I thought, ‘No, it is not worth the trouble.’ I tell people that I have Alzheimer’s but can still do many things.

Maren shared these thoughts with me during a five-day retreat for people with dementia organized by the Danish Alzheimer Association. We were in the middle of an introductory round in which different participants had been asked to present themselves. While tears were shed and some sidestepped stating their disease, there was also an atmosphere of optimism. Of course, this might be due to this specific social setting, a retreat focused on all the things people with dementia can still do. But I encountered statements like this frequently throughout my fieldwork, also in more intimate one-on-one social situations. Therefore, I suggest that we look closer at positive experiences of life with dementia.

To that end, I consider all the things my research participants were still able to do and enjoy doing. These include creative activities such as knitting, sewing, and painting, or visiting museums, enjoying art, or attending concerts. For others, it was to go for daily walks, meeting and engaging in casual conversations with whomever they met, or to go for a bike ride. For Dea (48 years) being able to spend much more time with her children than she did while still working was a ray of comfort. These activities were generally things that research participants had always enjoyed doing and which now, following a diagnosis, gave them a feeling of continuity of self.

“Living life in the moment” was a mantra many research participants expressed and tried to live by in various ways. Rather than focusing on the difficult days, many were preoccupied with an effort to collect the “good days.” Reminding themselves that, hopefully, they would have many years ahead, that perhaps their course of the disease would be one of the “slower” ones, was another way to stay positive. But at the same time, the diagnosis also became a catalyst for doing things while one still could, like traveling to places one had long wanted to visit but had never found the time. For one research participant, it was to go to Prague to see a concert featuring the Dutch musician André Lieu. For another, it was to join her husband on a motorbike trip through Europe.

Many participants in the study attended activities explicitly offered to people with dementia, such as the exercise team previously mentioned, the retreat offered by the Danish Alzheimer Association, or activity centers organized by their municipalities. While some found joy and relief in being able to joke or cry about the disease with others

who were going through the same experience, others highlighted that they appreciated being in the company of others who had the same condition without explicitly having to talk about it. Both talking and not-talking about one's disease with others who had dementia were thus sources of comfort and joy.

Experiencing continuing and, for some, even increasing amounts of care from others made the most profound impression on research participants and helped them recognize ways in which their lives did go on, despite all the hardship. Care could turn up in unexpected ways from near strangers. Egon felt safe walking around in his local neighborhood, knowing that his neighbors knew he might lose his way. Following his Facebook post, even the residential area's janitors had promised to keep an eye on Egon. Probably most important to emphasize is the continuing care and concern displayed by immediate kin. As I followed research participants and their families for 2.5 years, I was repeatedly struck by the continuous efforts of wives, husbands, children, and siblings to sustain the social recognition of the person with Alzheimer's. For example, this was evident in careful attempts to preserve a sense of time by keeping the person with Alzheimer's in synch with the social time of their surroundings, while carefully adjusting these efforts as the disease progressed (Glavind 2022). It was also evident in the ways in which partners became experts in reading the body language of their spouse with Alzheimer's, understanding without the use of words in which activities they wished to participate and which would be too overwhelming (Glavind and Mogensen 2022). Further, intimate care was apparent in quarrels concerning the sharing of household tasks and in partner's efforts to balance how to engage the person with Alzheimer's in household chores as much as possible, while also acknowledging the limitations caused by the disease. Finally, care suffused the efforts of adult children and siblings of the person with Alzheimer's to regularly call them; to stop by with groceries and medicines; accompany them to doctor's appointments; and help them, in any way they could, to feel safe and at home when moving to a nursing home.

Continuing care and concern did not go unnoticed by the research participants themselves. Many expressed immense gratitude toward their families for all the care work they had taken up. Consider Peter (59 years) who one day directed my attention to huge piles of paperwork laid out by his wife Helle on the living room floor. "Look at all this," Peter said and waved his arm over the papers. "Helle has to deal with all of this." He shook his head in resignation. Attached to the piles were Post-it sticky notes printed with "Agency of Family Law," "Pension provider," and "Unemployment Benefit Office," indexing the process of Peter—and especially Helle—to file for his early-retirement. With few words and gestures, Peter indicated to me that he was aware of all the effort Helle had put into helping him and how grateful he was.

By highlighting positive aspects of life with Alzheimer's disease as experienced by those living with the condition, my intention is not to understate the difficult changes the condition entails. And while speaking of a good life with dementia might be provocative or even unthinkable to some, I argue that it is crucial to shed light on the ways in which life with dementia also continues in positive ways in order to challenge pervasive characterizations of dementia as social death. One way to do so is by including positive aspects of life with dementia, such as sustaining social recognition and continuing care, within the envisioned futures of life with dementia. By doing so, caregivers' strenuous, continuous efforts are also brought to the forefront, potentially giving them some of the acknowledgment they deserve.

### **Concluding Reflections: Conceptualizing a Social Prognosis of Dementia**

The relationship between dementia and disclosure is not as straightforward or easy as presented by patient organizations, as illustrated through the Danish dementia symbol's implicit public disclosure. Further, the complexity of this relationship is evident in the different modes by which people with Alzheimer's (non)disclose their diagnosis. While most of the participants in this study—like Egon—had eventually chosen to reveal their diagnosis to their family, friends and broader social networks, not all felt they benefitted from it. Disclosure can be

followed with regret, as shown in the cases of Karen and Tanja. Disclosing or non-disclosing is not a question of either-or, as seen through Lone's appeal to old age to remain vague about her condition of: one can move back and forth between transparency and discretion by masking the disease with old age, or counterbalance the revelation by emphasizing previous prestigious jobs. As Simmel demonstrates, this shaping of knowledge and non-knowledge happens in relation to 'the other' and shapes the interaction with 'the other,' which is also shown by Mogensen (2020, 185-186) inspired by Simmel, through the concept of mutual (non)knowledge which can be the basis of social recognition.

Understanding the social aspect of (non)disclosure practices of people with Alzheimer's is crucial. While practices of (non)disclosure in this study varied greatly, all participants expressed individual concern that the diagnosis would cause heavy isolation, as well as diminish their ability to know with whom they belong. Practices of (non)disclosure should be understood as responses to the close associations between dementia and social death. As I have argued, a biomedical diagnosis entails not only cognitive and physical changes, but also shapes how others perceive and interact with diagnosed people, and in turn how these people view themselves and interact with others. Research participants' fear of diminished social recognition echoes pervasive mischaracterizations of dementia as social death, culminating in a person who does not matter in the eyes of others (Guenther 2013) and who, zombie-like, is unable to recognize others (Behuniak 2011). This suggests fulfilment of what Behuniak (2011) has warned against: that medical and colloquial discourses on dementia as social death have come to shape popular understanding of life with dementia.

In the prerogative of disclosure, the locus of responsibility is placed on the person with Alzheimer's. When disclosing is framed as a matter of breaking down stigma, making it easier for friends and families to reach out, the person with Alzheimer's becomes the frontrunner for societal change in attitudes towards dementia. This requires that the person with Alzheimer's bear the responsibility of owning the social nature of the disease. Further, the imperative to disclose does not take into consideration what Simmel has emphasized – that social relations are just as much about mutual concealment as they are about shared knowledge. Social relations benefit from keeping certain things concealed, and the research participants' practices of nondisclosure and regrets about disclosing are a testimony to that. Furthermore, literature on friendship and dementia points to the issue that disclosing one's diagnosis does not necessarily result in social literacy. Friends need more than just knowledge of the diagnosis; they need guidance on how to interact with the person with dementia (see Taylor 2017, 2019, 2020). Therefore, rather than assume that the people with Alzheimer's should be the leaders of a paradigm-shift, we should explore how to sustain social recognition in dementia.

To create nuance in how we understand dementia as an experience, it is crucial to challenge automatic associations between dementia and nursing homes. We see this association in Egon and Dea's concerns about the implications of the diagnosis. They immediately envision themselves living in nursing homes once their disease progresses, apathetic and isolated. While it is true that people with dementia make up the majority of residents living in Danish nursing homes,<sup>2</sup> this association to the end-stages of dementia leaves little space for seeing people with dementia as capable to continue, in some sense, their pre-diagnosis lives for several years after diagnosis. Furthermore, having followed research participants as their disease developed from early to mid and late stages of dementia, I was also able to observe how the care and love they received from closest social relations continued, even as they moved to nursing homes.

In the medical world, patients receive prognoses that indicate a "doctor's judgment of the likely or expected development of a disease or of the chances of getting better."<sup>3</sup> While the course of Alzheimer's varies, its biomedical prognosis is rather bleak: a progressive series of irreversible cognitive and physical impairments culminates in a shortened life span (World Health Organization 2021). However, prognoses are not solely restricted to medical

settings, and not only doctors make prognoses. Broadly speaking, a prognosis is “a statement of what is judged likely to happen in the future, especially in connection with a particular situation.”<sup>4</sup> Exploring the manyfold social implications of a biomedical dementia diagnosis, it is perhaps fitting to start thinking about the *social prognosis* of dementia, rather than just the biomedical diagnosis.<sup>5</sup> Unlike the biomedical prognosis, the social one is not explicitly stated; rather it arises from pervasive medical and colloquial characterizations of dementia as social death. I argue that, for people with Alzheimer’s, the social prognosis is in some ways even scarier than the biomedical one, influencing their choices of (non)disclosing the diagnosis. And, if we are to change the social prognosis of dementia, it is essential to keep in mind how mutual (non)knowledge can form the basis for social recognition, and not solely insist that full disclosure is the only means to sustain one’s social recognition.

Furthermore, it is clear from looking at the aftermaths of disclosure that research participants did experience what some might call facets of social death: becoming marginalized, isolated, and muted—even with their most intimate family and friends. But a continuation of care also defines life with Alzheimer’s. In that sense, though at times people with Alzheimer’s did feel that they didn’t matter in others’ eyes, they did not undergo the bereavement of contact with kin that Guenther (2013) cites as a defining aspect of social death. In fact, some relations—not all, and not only kin but also friends, depending on the individual’s social situation—drew closer to the person with Alzheimer’s, helping them in everyday life. Thus, contrary to a *prophecy*—which can be understood as a prediction of a future situation.<sup>6</sup>—a prognosis refers to a likely outcome.<sup>7</sup> Yet, my material shows that social death is not necessarily the outcome of an Alzheimer’s diagnosis. In order to challenge commonplace mischaracterizations of dementia as social death, I argue, we must take seriously the experiences of people living with the disease and contribute to redefining the social prognosis in ways that include continuity of social recognition and the possibility of living a good life. We must listen to their stories of how life, after all, does go on.

## Notes

1. Due to a steep increase in COVID-19 cases in Denmark, I paused the fieldwork one month early.
2. Approximately 40% of residents in nursing homes have a dementia diagnosis. However, the numbers are presumably much higher, as there are many underreported figures and many elderly persons in general who have not been diagnosed with dementia (Danish Ministry of Health 2016).
3. *Cambridge Dictionary*, s.v. “prognosis (n.),” accessed March 30, 2022, <https://dictionary.cambridge.org/dictionary/english/prognosis>
4. *Cambridge Dictionary*, s.v. “prognosis (n.),” accessed March 30, 2022, <https://dictionary.cambridge.org/dictionary/english/prognosis>
5. I thank Ayo Wahlberg for thinking with me on the concept of social prognosis.
6. *Merriam-Webster*, s.v. “prophecy (n.),” accessed March 29, 2022, <https://www.merriamwebster.com/dictionary/prophecy>
7. In analysis of dementia care in Denmark, Iben M. Gjødsbøl and Mette N. Svendsen (2018) have similarly made use of the concepts of prognosis and prophecy, but not social prognosis or the social implications of the diagnosis. Focusing on the perspectives of care professionals, they show that in Danish memory clinics and nursing homes, dementia is simultaneously approached as a prophecy of “inevitable future discontinuity of personhood and life” and “as a prognosis that renders the future indeterminate and open to intervention” (Gjødsbøl and Svendsen 2018, 2).

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