



# Temporal Belonging: Loss of Time and Fragile Attempts to Belong with Alzheimer's Disease

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**Abstract** Building on 12 months of ethnographic fieldwork among people with Alzheimer's disease living in Denmark, I argue that the loss of a sense of time caused by Alzheimer's is not a subjective loss, but rather an intersubjective one. Alzheimer's disease entails living with desynchronized rhythms, time that can be made painfully explicit, and numbers becoming increasingly tricky to manage. Drawing on Thomas Fuchs' theory of how individuals live in "basic contemporality," I explore moments of temporal rupture, and how people with Alzheimer's challenge their social relations due to their different sense of time. The article contributes to ongoing discussions about belonging. Taking inspiration from Tine Gammeltoft's description of how belonging entails fragile attempts at being part of something larger, and is thus a joint social practice, I show how one dimension of belonging's fragility is the inability to be in synch with social time. By proposing the notion of temporal belonging, I suggest that sustaining a sense of belonging is also about being able to participate in the rhythms and tempo of social life.

**Keywords** Alzheimer's disease · Dementia · Belonging: Temporality

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## Introduction

“Well, I don’t know whether it is in the past, present or future... Sometimes it *is* something I have done—only it was 14 days ago.” An exasperated Ole sat in his living room next to his wife, Kirsten, as they described their most frequent type of fight: concerning whether or not Ole had completed a household task, such as emptying the dishwasher or washing the floor. Ole and Kirsten are both in their 60 s and live in a two-bedroom apartment in a Copenhagen suburb. Four years ago, Ole was diagnosed with atypical Alzheimer’s disease. Listening to Ole’s outburst over his temporal disorientation, Kirsten nodded eagerly, adding how frustrating she finds it when he routinely claims to have done things he has clearly *not* done: “It makes me SO angry!”. Further into our conversation, Ole explained how exhausting it is for him to make sense of time:

I think those of us who have Alzheimer’s spend a crazy amount of time thinking and trying to remember what has just happened. And really, it does not matter! (...) You won’t remember it anyway after half an hour. You just get so exhausted! When you leave later today, the conversation that we have had just now will bustle about in my head (...) If the brain could only remember it all, that would be wonderful, but you only remember fractions. It is like having a movie playing in your brain, but a movie that has been cut wrongly.

The distortion of time is a cardinal symptom of dementia that can be clinically observed early on (El Haj and Kapogiannis 2016:4). People with dementia have been described as “living in a timeless world,” or as “losing” their sense of time (Edwards 2002:184). Yet studies of time in relation to dementia remain sparse and constrained by laboratory settings (Liu et al., 2021:1512). In a systematic review of clinical studies on time distortion in Alzheimer’s disease, the authors find that compared to control groups, people with Alzheimer’s find it difficult to assess how much time they have spent performing specific tasks. Gauging time becomes more inaccurate when tasks are lengthy or complex (El Haj and Kapogiannis 2016:1). The authors find a close link between time processing and memory, both situated in the brain’s hippocampus, which is targeted by Alzheimer’s. This means that both time distortion and memory decline can make it difficult to place oneself in subjective time, which entails both the capacity to time one’s actions in everyday tasks and sustain a sense of self-continuity across past, present, and future contexts (ibid.). Or, as Ole explains, his experience of time distortion is like having a movie playing in his head where the scenes are cut out of sequence, making him confused about the present.

In this article, I explore how different experiences of time come to matter in the lives of people with Alzheimer’s disease through the following two questions: How does the changing sense of time affect the social relations of people with Alzheimer’s? And by looking at the ruptures and conflicts that arise from time differences in Alzheimer’s, what can we learn more generally about the notion of belonging as a sense of attachment? Instead of looking at the temporal experiences

of people with Alzheimer's solely as pathological signs of individualized suffering, I approach their sense of time from a social perspective, seeing it as a losing ability to be in a certain, "right" or normative way of being in time. This temporal change challenges their social relations, and amounts to suffering in some situations—both for people with Alzheimer's and their families. However, I show that it is also possible to participate in social situations where the inability to be in normative time does not result in suffering.

In looking at temporality as a social matter, I draw from Nancy Munn's often-cited review of anthropology and time (Munn 1992) in which she argues that time is "an inescapable dimension of all aspects of social experience and practice" (ibid.:93). Social actors are thus not only *in* time, social actors are also constructors *of* time, as they define both "right" and "wrong" ways of being in time (ibid.:94, 104). Further, Munn highlights that the multiple, co-existing dimensions of socio-cultural time in which people live are best understood when situated within everyday practices (ibid.:116). Building on 12 months of ethnographic fieldwork among people with Alzheimer's who live at home in Denmark, this article does just that, taking its starting point in everyday life. It describes how people with Alzheimer's challenge their surroundings with their different way of being in time, like when Ole disputes Kirsten's claim by insisting that he *has* emptied the dishwasher. Seemingly a mundane example, this kind of disagreement may be familiar to all kinds of households, and not just those that include a person living with Alzheimer's. Yet Ole and Kirsten's conflict is different, since it arises not merely from a disagreement about who has done what, but rather about whose perception of time *counts as real*.

I argue that by paying attention to the moments in which time differences challenge the social relations of a person with Alzheimer's, it becomes clear that the so-called "loss of a sense of time" is not a subjective loss but rather an intersubjective one. A different sense of time affects the ability of the person living with the disease to participate and belong in social life, while simultaneously drawing people closer, engaging partners and other actors in more or less frictional attempts to keep the person with Alzheimer's in the "right" time. Further, through the lenses of time differences in Alzheimer's, we can grasp variegated temporalities of belonging. To that end, this article contributes to ongoing discussions about the notion of belonging, a key concept within the social sciences that remains difficult to pin down (Mattes and Lang 2021; Gammeltoft 2018; Wright 2015). Following Tine Gammeltoft's argument (2018) that belonging entails fragile attempts at being part of something larger, which are created and sustained through joint social practice, I show that one-way belonging becomes fragile is through an inability to synchronize with social time. By proposing the notion of "temporal belonging," I suggest that sustaining a sense of belonging is also about being able to participate in the rhythms and tempo of social life.

## Theoretical Frame

### Belonging

Belonging is fundamentally important to social life and figures centrally in medical anthropology, as well as in the social sciences and humanities more broadly. Yet the concept remains vaguely defined (Wright 2015:391; Mattes and Lang 2021:5; Gammeltoft 2018:85), perhaps due to its multiple registers. Within this literature, belonging refers variously to a feeling, a practice, or ties to/displacement from a specific geographic area, such as “diasporic belonging” (Wright 2015). Reviewing the existing literature on belonging in the social sciences and humanities, Mattes and Lang conclude in a recent special issue of *Culture, Medicine, and Psychiatry* that there is a striking focus on migration in studies of belonging (Mattes and Lang 2021:7). The authors thus call for an exploration of belonging from perspectives other than those of migrants, yet equally underprivileged groups (ibid.). Rather than offer another definition of belonging, Mattes and Lang offer important insights into how belonging is embodied and inscribed in human bodies in various ways (ibid.:6).

With this article, I contribute to discussions of belonging as an analytical concept within a non-migration context. While I share Mattes and Lang’s view that it is impossible to reach a definitive delineation of the concept, I nevertheless seek to theorize belonging through the lens of temporality. To that end, I draw from the work of Gammeltoft (2018).

Gammeltoft explores belonging in contexts that outsiders might see as oppressive (2018:78, 92), based on extensive fieldwork in Vietnam on selective reproduction. Through a study of how intimate partner violence affects women’s health during and after pregnancy, Gammeltoft argues that belonging is not necessarily positive or productive, despite its felicitous connotations: “Belonging indexes fragile, uncertain, and often highly contingent human efforts to be part of something larger” (ibid.:77). She furthermore argues that belonging is not a pre-given but is rather created through joint social practice (ibid.:87). Belonging is thus a fruitful site through which to consider the debts, demands, and dependencies that are part of everyday life (ibid.:77). Gammeltoft suggests three key elements of belonging. The first element is *possession* (ibid.:77), with which she explores how humans come into being through social relations, rather than through the often-stressed ideas of agency and individuality. As she writes: “At issue in relations of possession, in short, is the capacity of human beings to transform one another’s identities from the inside—to inhabit each other in ways that are experienced as existentially forceful and binding” (ibid.:88–89). The second element that Gammeltoft suggests is *membership*, which she uses to describe how people enact belonging by weaving themselves into larger social collectives. Being a member of a larger social body can be painful and demanding, but it also allows individuals to rightfully expect protection and support from others (ibid.:89). To that end, the third element she describes is *moral obligation*, which illuminates how being possessed by someone or being a member of a larger social body allows individuals to place moral demands on one another. Individuals come into being by meeting, claiming, and

enacting moral demands on one another (ibid.). Drawing on Gammeltoft's work, I use belonging to refer to everyday attempts to enact moral demands on others in order to become a member of a larger social body, and hence come into being as a person. Further, by adding a layer of temporality, I contribute to Gammeltoft's theorizing of belonging, emphasizing how one-way belonging becomes fragile is through the inability to staying in synch with the rhythm and pace of one's social surroundings. To that end, I take inspiration from literature on temporality and illness.

### Temporality and Illness

Deviations of temporal experience have been a central subject within psychopathology (Fuchs 2005:195). Yet as Thomas Fuchs argues, such studies neglect the intersubjective aspects of temporality (ibid.; 2010). Though we often perceive time as independent of us, it is in fact only explicitly experienced when intersubjective time is desynchronized (Fuchs 2005:83). Fuchs distinguishes between two levels of human temporality: *implicit* and *explicit* time. Implicit time is exemplified by an image of a child playing, lost to the world, as if he has no sense of the time passing (Fuchs 2005:195). Temporality is pre-reflectively lived, remaining an undercurrent of experience (Fuchs 2013:77). When a disturbance occurs—such as a shock, a painful loss, or a break in interpersonal relations—continuity is broken, and time is rendered explicit and consciously experienced. The future becomes a “not yet” charged with longing, and the past becomes “no longer” fraught with grief. Consequently, explicit experiences of time are often melancholy, and is connected with displeasure or suffering (ibid.:79, 2005, 196).

At a young age, we learn to attune ourselves to others through the micro-dynamics of daily interaction, Fuchs argues, calling this “basic contemporality.” He describes how infants, in rhythmic–melodic interactions with their mothers, learn the unspoken feeling of being temporally connected to others; that is, of living in the same intersubjective time (ibid.:81–82). This attunement is a process of continuous synchronization, both biologically and socially. We are rarely conscious of being “in synch” (2010:81). However, as Fuchs writes: “...on the social level, uncompleted tasks, unresolved conflicts, and experiences of guilt, loss or separation lead to a temporary disturbance or lasting loss of lived synchrony with others.” (2005:196). Various forms of social coordination such as daily/weekly routines, time scheduling, appointments, and punctuality also render contemporality explicit (2010:82).

In the article, I take inspiration from Fuchs and later also from Henri Lefebvre's rhythm-analytical approach, whereby he describes that when rhythms of everyday life become discordant, there is suffering, a state of pathology (Lefebvre 2004:16). Where I part from these scholars, however, is that I challenge the pathologizing of time experiences that differ from prevailing, normative ways of being in time. Following Munn (1992), I instead approach the temporal experiences of people with Alzheimer's as one of many co-existing ways of being in time, forming the social time of everyday life.

## Temporality and Dementia

Medical-anthropological studies have explored states of desynchronization and temporality obtaining among different cognitive conditions such as ADHD (cf. Christensen 2021; Mikka Nielsen 2020; Rasmussen and Meinert 2019) and autism (cf. Jensen 2017). However, anthropological studies on temporal experiences in dementia remain sparse, especially with a focus on the here-and-now patient-perspectives. Jong-min Jeong's (2020) study of the repetitive movements by residents with dementia living in a Jewish care home in London is a notable exception. While staff viewed this behavior as signs of pathology, describing the movements of the residents as "wandering" and "obsessing," Jeong shows how these acts can be understood as the residents' way to engage with and attune to their ever-changing lifeworld by use of (among other things) tone, rhythm, and tempo (ibid.:3). Drawing inspiration from Lefebvre's rhythm-analytic approach, Jeong observes how the residents' movements change in accordance with their surroundings, as an attentive attunement to others (ibid.:13).

Some scholars have explored notions of time in dementia with a focus on the future, perhaps reflecting the general current surge of anthropological interest in the future (cf. Knight and Bryant 2019:9, see also; Appadurai 2013; Morten Nielsen 2011). Grøn and Mattingly (2018) have explored notions of hope for people reaching end of life, when living in a Danish dementia ward. Linking hope to temporality and the future, they show how hope in the face of death is relational and responsive, bound to the hope of staying a human being among others for just a little while longer. Gjødsbøl and Svendsen (2018) discuss how temporality comes to matter in a Danish memory clinic and a nursing home for residents with progressive dementia, whose institutional temporal frame, they argue, is defined by both prognosis and prophecy. The person with dementia is subjected to various medical and social interventions aimed at an improved prognosis, yet at the same time, the diagnosis entails a prophecy of inevitable decline (ibid.:4). The study further depicts different perceptions of rhythm at stake in the nursing home, but they focus on staff and relatives, rather than people with dementia. In Sandberg and Marshall's (2017) critique of the paradigm of "successful aging," the authors argue that dementia poses a threat to ideals of aging futures. Successful aging, a core concept defined in gerontology in the 1980s, posits that late-life should be defined by productivity, creativity, positivity, and independence (ibid.:3–4). People with dementia who fail to live up to these ideals signify an unwanted future, Sandberg and Marshall argue: "Thus the imaginary of dementia as monstrous springs not only from dehumanizing discourses which associate dementia, embodiment, and subjectivity with the living dead, but also with unknown/unwanted futures" (ibid.: 5–6, see also Driessen 2018; Herskovits 1995). Also dealing with "unwanted futures," Natashe Lemos Dekker (2020) describes how the predicted loss of control, dignity, and autonomy motivates people with dementia in the Netherlands to request euthanasia. Looking at how these requests are formulated, negotiated, and often deferred, Lemos Dekker shows how the temporal stance of anticipation creates and renegotiates the distance between present and future, making the future tangible while also keeping it remote, as a "not yet" situation.

In sum, while most studies on dementia and time have tended to focus on the role of the future,<sup>1</sup> I focus on the way temporality comes to matter in the present “here and now,” and pay close attention to the conflicts that may arise from different ways of being in time with Alzheimer’s.

## **Temporal Belonging**

In further developing the concept of temporal belonging, I take inspiration from the work of Georg Paul Meiu (2017), who adds the temporal dimension to the concept of belonging. Meiu argues that belonging is not just about being included or excluded in a social group, but also about subtle, everyday attempts to align with the rhythms of social action (ibid.:248). Describing how Northern-Kenyan young men, known as “Morans,” travel to the Kenyan coast hoping to establish transactional sexual relations with European women, Meiu examines how the pursuit of wealth affects their belonging to their ethnic group, the Samburu (ibid.:246). The commodification of Moran ethno-sexuality provides new means of making a livelihood (ibid.:242). However, earning money does not secure the Morans full membership in the Samburu. In fact, there seems to be a problem with the pace of those earnings: the faster the Morans turn a profit, the more weakened their claims to inclusion become. The Samburu gossip about the Morans to indicate that this “shortcut money” does not grant them full access to the ethno-region to which they wish to belong (ibid.:243). In other words, Meiu shows how the Morans’ desire to belong and gain recognition and respectability within their ethnic group is very much about temporal politics.

Thus combining the works of Gammeltoft, Meiu, and temporality literature on illness, I approach belonging as a series of fragile attempts to be part of something larger, highlighting its processual dimensions that must be continuously remade through joint social practice. Belonging risks being distorted when the rhythms of social action fall out of synch. In the empirical sections, I argue that the concept of “temporal belonging” can help us understand how people living with Alzheimer’s disease experience belonging when their sense of time changes. This concept is not however limited to cases of Alzheimer’s and dementia, but can be expanded to all social interactions, helping us grasp everyday attempts to align with the rhythms and pace of collective social life. I will return to this in the discussion.

## **Background and Methods**

### **The Danish Welfare State and Dementia**

This article is based on 12 months of ethnographic fieldwork conducted among people living with Alzheimer’s disease and their family members in Denmark. Approximately, 87,000 persons live with a dementia illness in Denmark, a country

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<sup>1</sup> Except Gjødsbøl and Svendsen (2018), who discuss rhythms in nursing homes but focus on staff and relatives.

with 5.8 million inhabitants. When speaking of belonging in terms of the Danish welfare state, it is important to remark how certain ideals about contribution and independence are at stake. The Danish welfare state is often presented as extremely generous. Its universalist model provides a wide range of free, social, and health-care services for all citizens, supporting them from the cradle to the grave. However, as Steffen Jöhncke (2011) shows, behind the welfare state's generosity lies implicit cultural assumptions shaping a strict cultural guideline for the normal life course of a Danish person (ibid.:48). The viability of the welfare state is conditioned by the fact that the vast majority provides for themselves through work, and only when in need makes use of welfare services. Thus, men and women are expected to take up employment outside the home, pay taxes, and leave it up to the municipalities and state institutions to take care of the children, sick, disabled, and elderly (ibid.:48–49). Denmark has one of the world's highest income tax rates, a high rate of labor-force participation (for both men and women), and a retirement age that increases 1:1 with the population's life expectancy (Jöhncke 2011:43; OECD 2022; 2021). Further, even after retirement, late-life is generally imagined through ideals of productivity, activity, and independence, which prevail in descriptions of what counts as successful aging. Following the baby boom after the Second World War, political and economic projections led to an increasing worry that the Danish welfare state could not finance the costs of the increased elderly population in need of more welfare services. In that perspective, active aging became key for policies on aging, with reference to how medical research evidenced that physical activities are essential for keeping one's functional abilities in shape and staying self-reliant and independent (Oxlund et al. 2019). I will return to these implicit, overarching ideals about contribution and independence when I discuss how people with Alzheimer's disease fall out of synch with both their intimate relations and society due to their changing sense of time.

Dementia is an umbrella term covering more than 100 different diagnoses, with Alzheimer's disease accounting for nearly two-thirds of all incidents above 65. A typical course of illness lasts between 8 and 10 years. The symptoms of Alzheimer's vary. In clinical descriptions of time distortion, the first symptoms include forgetting appointments, significant dates, or events that have just taken place. This can develop into a failing sense of the day or date. In the late stages, sleeping patterns may become disrupted or reversed. Eventually, the patient will need help with daily activities (Alzheimer's Society 2021).

### **Participant Observation and Interviews**

My fieldwork spanned a period of 29 months, which I divided into three blocks: 7 months from February to August 2019; then 4 months in fall/winter 2020; and finally, 1 month in the summer of 2021. In this way, my study is also defined by a specific temporal frame, enabling me to witness how research participants' disease developed from the early to middle—and for some also late—stages of Alzheimer's. In the empirical cases I present below, I have tried to make apparent the gradual changes in experiences of time I was able to detect by following research participants for 2.5 years.



Throughout the study, I closely followed five people living with Alzheimer's, visiting them regularly in their home. These five key research participants included three women and two men aged 57–84 years old. All had received their diagnoses one to two years prior to our first contact and lived at that point at home, managing life relatively independently. Two lived with a spouse and two lived alone. One man lived with two tenants. During the 2.5 years I followed them, two research participants moved to a nursing home, and two passed away. Typically, I spent half a day with them, talking, drinking coffee, and participating in activities they enjoyed: accompanying them for a walk or a bike ride, knitting, painting, shopping for groceries, etc.

Furthermore, I conducted seven semi-structured interviews with six family members of the key research participants: two spouses, three children (aged 30–65), and one 84-year-old mother. I have also done 11 semi-structured interviews with other people with Alzheimer's, sometimes accompanied by their partner if they had one. In a recent published article, Hanne Mogensen and I (2022) have described the methodological challenges and possibilities of qualitative research when studying the lifeworlds of people with Alzheimer's. We argue that despite a deteriorating language and the dissolving ability to situate stories in a coherent timeline, it remains important to pay close attention to the fragile stories of people with Alzheimer's disease.

To get a sense of life with Alzheimer's outside of the home, I participated in different activities offered by various organizations and institutions. For example, I attended a 5-day retreat for 20 persons with dementia, organized by the Danish Alzheimer Association. I also conducted participant observation for 6 months at a twice-weekly exercise club for people with different sorts of dementia illness offered by a sports organization and a municipality. In Denmark, nearly three fourths of all dementia cases are examined at a specialized dementia unit (Zakarias et al. 2019). To get a sense of the diagnostic procedures research participants went through, I did a short observational study at a memory clinic in Copenhagen.

## Ethical Considerations

Careful ethical considerations are necessary to conduct qualitative research among people with cognitive impairments, such as Alzheimer's (Sherratt et al., 2007). Research has taken place according to the ethical requirements for qualitative research at the Faculty of Social Sciences at the University of Copenhagen governed by Danish law, and has been approved by the Faculty's research committee (ID nr. 8053-00087B). Recruitment of research participants and storage of interview data took place in compliance with national data protection requirements and has been approved by the Faculty of Social Sciences at the University of Copenhagen (journal nr. 514-0056/19-2000). More specifically in terms of consent, I followed a method called "process consent," designed to enable people with dementia to make known their preferences concerning research participation. This method requires that the researcher at each data collection stage remind the research participant of the study's purpose as well as the right to withdraw at any time (Dewing 2008).

None of the participants withdrew. All names of people and places have been changed.

The second part of the fieldwork took place during the COVID-19 pandemic. When visiting a research participant, I followed the official guidelines of the Danish Health Authority. In late December 2020, I paused fieldwork one month earlier than planned due to a steep increase in COVID-19 cases. I resumed my meetings with key research participants in the summer of 2021.

## Data Analysis

I transcribed and coded my interviews and fieldnotes with Nvivo software. Through this coding process, I was able to identify recurrent themes and explore their nuances and variations. In the following pages, I present four recurring themes that deal with how a different and changing sense of time for research participants with Alzheimer's challenged their social relations.

## Breaking Out of Social Rhythms

Peter is 59 years old, has Alzheimer's disease, and lives with his wife Helle in a terraced house 20 km outside Copenhagen. Like most Danes, Peter had organized his life according to work, living up to the implicit cultural assumptions for an ideal life course centered around work, whereby one contributes to the welfare state for as long as possible (for an elaboration of this, see Jöhncke 2011). When I first met Peter, he worked full-time in a financial institution, where he had been employed since he was young. Peter loved his job, and according to himself, his wife, and their adult son, he had often tended to prioritize his career above all else. Upon receiving the diagnosis, Peter worried greatly about losing his job. For most of his life, it had been a major component of his sense of identity and self-understanding. Both Helle and Peter's boss supported his wish to continue working. For a period, they tried different ways to keep Peter working. Peter's colleagues also helped, making step-by-step guidelines to help him manage daily tasks. However, Peter found it increasingly difficult to follow these guides and became more and more drained from work. This made both Helle and Peter's boss worry that the job would become too big a burden for Peter, potentially accelerating the progression of his disease. Peter and Helle then commenced a strenuous battle in the social system to secure Peter early retirement. In effect, this task fell to Helle since Peter could not handle the multiple forms and inquiries required by the different parties involved. The battle placed a massive burden on Helle, causing stress and insomnia, but she relentlessly pushed through. Peter expressed great gratitude for Helle's persistence on several occasions. In the summer of 2019, Peter retired just two months before his 40th anniversary.

It turned out that the fear of losing his job ended up being a bigger worry for Peter than actually losing it. After his farewell reception, he cried for some days and admitted that he "felt empty." Over time, though, Peter felt more at ease, and the loss of his job was no longer a concern. Instead, he complained about becoming

restless, having too much time on his hands. While Helle was at work, he would spend most of his days watching TV or sleeping late. He expressed to me that he wished they lived around younger people like himself, people with whom he could spend time. He tried making time pass, taking short trips to the supermarket, biking to the train station to pick up a free newspaper for their elderly neighbors. He always used to bring them one when returning from work, so he continued this habit.

One warm summer evening, during dinner in their backyard, Helle told me how frustrated she gets by the fact that Peter does not do anything around the house unless she specifically asks. For instance, cleaning the gutter—a task he used to manage perfectly well on his own. Helle then turned to Peter, saying: “Sometimes when I come home from work, extremely exhausted, you ask me: ‘What can I do for you?’ But, why can’t you see for yourself what needs to be done? And why do you think you have to do something for me when you should do these things for us?” Peter just shrugged his shoulders. Helle added that though she knew that Peter’s disease hampered his ability to do these tasks, she struggled to comprehend this change.

Lefebvre’s theory of “rhythmanalysis” can help us understand Helle’s frustration. With Catherine Régulier, Lefebvre describes how in “Western” countries, work fundamentally structures our lives and subordinates all of its other aspects, such as the time we have to sleep, eat, see our children and friends, be entertained, and so on (Lefebvre and Régulier 2004:73, 83). According to Lefebvre, biological rhythms (of sleep, hunger, thirst) are conditioned by our working lives and social environment, and we train our bodies accordingly (Lefebvre 2004:xii). In Peter’s case, his work was also his main priority for most of his life and he greatly enjoyed it. Yet when Peter retired, Helle still worked full-time, and her daily life remained structured around work hours. In fact, since Peter’s diagnosis, she had become even busier, taking care of most things around the house plus Peter’s disease management (keeping track of his doctor’s appointments, his medication etc.). Helle longed for more leisure time; Peter had nothing but that. Their lives were no longer structured around the same thing (work), and so they no longer shared the same rhythms. In Lefebvre’s method for studying the rhythms of everyday life (2004), he argues that “Everywhere there is interaction between place, a time and an expenditure of energy, there is rhythm” (ibid.:15). Bodies consist of many co-existing rhythms, different but still in tune (ibid.:20). In everyday life, rhythms unite in the state of normalcy, but when they fall out of tune or are discordant, they become pathological, a sign of suffering (ibid.:16). With the arrival of Alzheimer’s disease in their marriage, Peter’s everyday rhythms change, which in turn affect Helle’s rhythms, causing the couple to fall out of synch.

Both Peter and Helle regretted this change of rhythm. Helle was frustrated by Peter’s diminished ability to help around the house, and Peter complained about feeling restless, longing to socialize. As Fuchs (2013) argues, a disturbance in life renders time explicit, which is often accompanied by an element of displeasure or suffering (ibid.:79). This disturbance, however, not only marks a rupture in their basic contemporality or shared rhythms; it also marks a change in their relationship. In their marriage, Peter and Helle possess one another, to use Gammeltoft’s description of belonging (2018:88). This mutual possession enables them to place

moral demands on each other. Yet the joint social practice essential for sustaining a sense of belonging has been altered by disease. When Peter cannot live up to Helle's expectations regarding the sharing of household tasks, she feels upset: it becomes clear that Peter may no longer be able to belong to their shared world in the same way as before. We should not see Helle's frustration with Peter as a mere conflict about being in a relationship where one part is functioning, busy, and working, while the other is not, due to illness. Instead, we see how being in an intimate relationship affected by Alzheimer's entails grieving the loss of shared rhythms while simultaneously trying to understand and accept new patterns imposed by the disease. Recall that the same issues are at stake in Ole and Kirsten's conflict described in the introduction. Rather than just a question about ill-functioning memory (whether or not Ole had emptied the dishwasher), Ole's changing sense of time challenged the rhythms so central for sustaining a temporal sense of belonging in their marriage, of sharing a "basic contemporality."

Having described these states of desynchronization in the intimate relations of people with Alzheimer's, I now turn to the role that mastering numbers play in one's ability to participate in the wider society's rhythms and tempo.

## Tricky Numbers

Børge was a key research participant in my study. When I met him in early 2019, he had been living for 20 years in the same rental apartment in Copenhagen. First with his third wife, and following their divorce, with two international students as tenants. He had three adult children. Børge was diagnosed with Alzheimer's disease in 2016. In the summer of 2020, after falling on the stairs and breaking his shoulder, he moved to a nursing home. He lived there for less than a year before succumbing to bone cancer in May 2021. In the following excerpt from my fieldnotes, I describe some of my struggles to make appointments with him. At this point, he was living in the nursing home:

Setting up a time and date for my next meeting with Børge was extremely difficult. When I called, he thought that I wanted to go for a walk just now. "Well, the weather is nice now," he said, indicating that he was up for a walk. I explained that no, I wanted to set up a meeting for next week. I suggested the 11<sup>th</sup> of November. He searched for a while for his calendar." What day is it today?" he asked when he found it. "The 4<sup>th</sup> of November," I said. I could hear him flipping through the pages. He mumbled: "I have a hard time with numbers." I tried to help: "Look for the number 4," I said. He found a page with a "4" on it. "Okay, I'll note down our appointment here, then?" he asked. "No, now you have to find the page where the number 11 is on," I said. Børge flipped through some additional pages before saying: "Here it is." As I was unsure whether he had located not only the page with the correct number of the day (the 11<sup>th</sup>) but also the correct month (November), I asked him: "And on that page, you have just there, what day is the 11<sup>th</sup> then?" "A Thursday," he replied. Relieved that this seemed to be the correct calendar

page, he noted our appointment, but as he was writing it, he complained that he could not read what he had written. I asked him if anyone helped him keep track of his appointments. “No, no one helps,” he replied. Before hanging up, he wanted to note down my phone number, and we had to go through the individual digits several times, before he felt sure he had noted them correctly.

Living with Alzheimer’s disease means that numbers become increasingly tricky to master, which affects one’s ability to be in the “right time.” Like Børge, all research participants in the study exhibited or expressed difficulties with grasping numbers such as times, dates, years, and phone numbers. For some, the sudden experience of numbers becoming difficult to keep track of was among the first noticeable symptoms. This was the case for Peter, whom we met earlier. He explained that one day when returning from work, the alarm went off at his house as he entered. As he tried to enter the code—his wife Helle’s birthday—to stop the alarm, he could not remember it. He had to call Helle for help. Bear in mind that at this point, Peter had been working professionally for nearly 40 years with the management of numbers. Just one week after the alarm incident, Peter found himself in a similar situation when a salesperson asked for Peter’s phone number to note on a receipt, and he could not remember it. These two successive incidents made Helle (who had been suspecting for a while that something was off) insist that Peter see a doctor, which resulted in his diagnosis.

Managing numbers is an essential tool in Denmark, as in many other places, for keeping in synch with social time. Numbers are used as reference points marking time, making it tangible in the form of seconds, minutes, hours, days, and years. In her review of anthropological studies of time, Munn (1992) insists that calendars and clocks are not neutral or natural objects; rather, they shape concepts of time and create normative ways of being in the “right” or “wrong” time (*ibid.*:104). For example, Munn describes how “being slow” is conventionally regarded as a negative value, because the actor’s speed fails to live up to a pre-defined standard. Since the nineteenth–twentieth centuries, Western societies have increasingly used the structure of clock time to delineate both labor time and other everyday activities (Munn 1992:104, Lefebvre and Régulier 2004:73). Using clocks as reference points for time-reckoning, people are thus not just “in time” but also constructors of time (Munn 1992:104). This point is central for my analysis. In a society in which social life is generally defined by work hours and clock time and where plans with family and friends are often made in advance, noted in calendars as appointments, numbers function as tools to designate normative ways of being in time. As Fuchs argues (2013:82), in order to live in synchronicity and basic contemporality, we depend on calendars, schedules, and a sense of punctuality to maintain social coordination. I argue that the trickiness of numbers experienced by people with Alzheimer’s offers insight into how synchronization comes to matter in a society defined by clock time. Like beats in a melody, numbers used to calibrate specific social events are tools to keep up with the pace of social life, constructing “right” and “wrong” ways of being in time. As I have argued throughout, belonging can be grasped as a process of weaving oneself into a larger social whole (Gammeltoft 2018:89). The ability to

belong as a member of Danish society—fundamentally structured by clock time—depends on the ability to manage numbers.

### **Differences Between Living Alone and with a Partner**

To gain access to the field I wanted to study, that is, people with Alzheimer's disease living at home, I made appointments with research participants each time I wanted to see them and vice versa—a method some has described as “appointment anthropology” (Hannerz 2006:34). If a research participant was living with a partner, I typically made appointments via the partner to agree on a time and date. This seemed to be a task delegated to the partner more generally, like Peter who always asked me to settle on a date via Helle, as “she was in charge of his calendar.” In this way, partners functioned as “timekeepers” for the person with Alzheimer's, ensuring they were in the “right time.” If a research participant lived alone, I made appointments directly with him/her. Making these appointments involved much confusion on both sides. It was particularly challenging to settle on a time and date over the phone, when I could not help research participants find the right calendar page or note my phone number. The above-described phone conversation with Børge was thus typical of my logistical exchanges with participants living alone. In these cases, it became clear that numbers were indeed tricky to manage.

This suggests that people with Alzheimer's who live alone may be at greater risk of social disconnection because they struggle to manage numbers according to the “right time” of others. On the other hand, and more broadly, several research participants who lived alone expressed that they were glad to be on their own. When I asked for elaboration, they replied that they would fear being constantly criticized if they lived with a partner. We can think here of married couple Ole and Kirsten's frequent fights about whose perception of time was real. A report from the Danish Center for Social Science and Research (2019) on people living alone with dementia in Denmark describes a similar finding, explaining how some interviewees were happy to live alone, as it enabled them to “create their own, individual rhythms” and “avoid conflicts with a partner” (ibid.: 51). Thus, a potential benefit of living alone was, according to some of the research participants, not being confronted—as often—with having an “incorrect” or “non-normative” sense of time.

When numbers become tricky, they challenge the ability of Børge and others with Alzheimer's to follow the rules of social synchronicity: adapt to timing and tempo that fit with their social relations; plan and keep appointments; and show up punctually at the “right” time and pace. Tricky numbers make it difficult to follow the beats of normative social time, hindering one's ability to participate in social activities, stay connected to family and friends, and maintain membership in the wider society. In the following section, I describe various strategies for synchronization between partners living together and among people with Alzheimer's living alone.

## Timework and Strategies for Keeping in Synch

“To me, Susanne’s loss of a sense of time was the most frustrating, challenging part of her illness. Every time I came up with a solution for it, it only lasted shortly.” Here, Erik reflects on a—so-far—5-year-long illness journey as Susanne’s husband.

Partners such as Erik tried to keep their loved-one with Alzheimer’s in synch with social time. In their various experiments with time, partners engaged with what sociologist Michael Flaherty calls “time work”: an effort “to promote or suppress a particular temporal experience” (Flaherty 2003:19). With the notion of time work, Flaherty seeks to combine a concept of agency with temporality, arguing that individuals actively engage with time in different ways to shape their experience; for instance, trying to make time last longer, go faster, or change the frequency of an event. Flaherty demonstrates that time work is both individual and interpersonal (ibid.: 17, Flaherty 2011:11), and moreover calls upon future research to investigate the types of time work done in different kinds of relationships (2003:32). The time work enacted by the partners I followed was not aimed at shaping their own temporal experience, but rather that of the person with Alzheimer’s. Looking at partner’s experiments with time, I highlight the loss of time as an intersubjective matter. Responses to this loss in the form of interpersonal time work can be grasped as attempts to enhance the person’s ability to continue participating in social life and thus belong. This does not mean that those living alone were left to themselves, however. Here, other actors stepped in, doing time work on behalf of the person with Alzheimer’s. This might include administering medicine that needed to be taken at certain times or creating a daily schedule, for example. Not being able to start one’s day before a care professional stopped by to apply a medical patch on one’s back also created a certain daily rhythm. Waiting for a municipal bus for transport to an activity center for elders is another example of how a person living alone with Alzheimer’s can experience the time work of others, or the imposition of certain rhythms.

### Experimental Time Work

In most couples’ homes, I visited a whiteboard of some sort was hanging in the kitchen that spelled out various dates and appointments. These scheduling boards were all made by the partners of the person with Alzheimer’s. For some, this was a method to prevent conflict. For example, a man told me that his wife had made such a schedule to prevent him from asking her several times a day what they were doing later. For others, keeping in synch with social time was an attempt to decrease anxiety for the person with Alzheimer’s about not knowing the plans of the day/week. This was the case for Susanne and Erik. At 54, Susanne was diagnosed with Alzheimer’s disease in 2016. When I met her and Erik for the first time in February 2019, they had a whiteboard in the kitchen exhibiting the week’s appointments. Every morning, Erik would wipe out the day passed and add a new one. Flaherty identifies five different types of time work (2003). One of them is *sequence*, which involves trying to customize the order of one’s activities (ibid.:21). In the case of

Susanne and Erik, though, Erik's experiment with time was not about trying to customize the sequences of the events in Susanne's week, but rather about helping her grasp it, putting the order of the week straight. For a while, this seemed to ease to Susanne's constant anxiety about what will happen when. The system, however, did not last long. Erik explained that he continuously had to shorten the period in view. He tried writing only five days ahead, then three. Today, Susanne lives in a nursing home, and in her room hangs a whiteboard. It says "Today," and something is only written on it if she has an appointment.

According to Flaherty, *timing* is another example of time work in which individuals seek to control when something happens (ibid.:21). In my study, timing was also part of the partner's attempts to keep the person with Alzheimer's in sync, like one of Helle's experiments with timing Peter's actions. After Peter retired, he started attending a local volunteer club that arranged daytime activities for retirees. Peter struggled to arrive on time, and he tended to oversleep unless Helle called. Therefore, Helle started setting an alarm clock next to Peter's calendar on the kitchen counter, exhibiting the correct date and appointment. In the beginning, she called him right after the alarm had gone off to remind him that this meant that he should prepare to leave. She also experimented to find the right interval that allowed Peter enough time to prepare to leave. She found that 30 min was just right. Further, Helle found that Friday was the easiest day of the week to "time right." On Fridays, Peter had to be at the DanAge club at 10am, which meant he only needed to get up, have coffee, and then leave to be there in time. Tuesdays were more complicated. The ping-pong team Peter was part of did not meet until 2:45 pm. This made Peter restless at home, not knowing what to do until the alarm clock rang. Helle had not found a suitable solution for that issue when we spoke.

Reflecting on Susanne's changing sense of time, Erik described another one of his experiments. While still living at home, Susanne started becoming more and more anxious about appointments she was either looking forward to (seeing one of her children) or worried about (going to the hospital for a check-up). These appointments had a way of imposing on her sense of presence above all else. Even if Erik reassured her that this was not to happen until later in the week, she would repeatedly return to it, asking him when to leave, anxious about not making it in time. Erik responded by emphasizing the temporal distance of these events, saying they were not to happen until "much, much, much late.r" Sometimes he even lied, stating that the event would not take place within the next month. Other times, he tried to make it more concrete, telling her that she had to sleep for four more nights until the right day came. This made Susanne, according to Erik, feel embarrassed, as if he were talking to a child. Flaherty describes *duration* as another type of time work, which involves trying to make an interval seem longer or shorter (ibid.:21). When a distant future event imposed on Susanne's sense of the present, making her worried, Erik responded by trying to create a greater distance to the event; that is, by seeking to change Susanne's sense of duration. He admitted not always being proud of how he did this, or how this made Susanne feel, but her constantly changing sense of time challenged him to the degree that he sometimes did not know what else to do.



## Society's Time Workers

In sum, by looking at partners' interpersonal time work, we see that responses to the changing sense of time are efforts to keep the person with Alzheimer's "in time." By trying to make sequences of the week graspable, timing actions to make appointments, and changing the duration of waiting time, the partners do timework on behalf of their loved-one with Alzheimer's, trying to change his or her experience of time. In exploring these responses, we see that the loss of sense of time is not solely something that concerns the person with Alzheimer's, rather it also affects their partners. Not all solutions were great, and they continuously had to be reworked as the illness progressed. Preventing the person with Alzheimer's from falling out of normative time was not only a means to repair the painful desynchronized rhythms in the intimate relationship. In a practical sense, the partners became "time workers" for the temporal regime of Danish society, requiring of its citizens the ability to manage numbers, clocks, and calendars. If ping-pong is at 2:45 pm, then the partners would try with all possible means to have to the person be there at 2:45 pm. Thus, staying in the right pace and rhythm is essential for keeping the person engaged in concrete activities. However, throughout my fieldwork, I discovered that people with Alzheimer's could also in certain social settings challenge and bend the normative temporal structures of society, with their different and alternative ways of being in time. I will describe this in the following.

## An Alternative Way of Being in Time

During my fieldwork, I participated in a twice-weekly exercise team for people with dementia for six months. Almost without exception, at each session, at least one participant would show up too late or leave too early. Consider the following vignette:

After doing warm-ups, we gathered to play around with cards. Sophia, the instructor, liked to mix physical exercise with cognitive games, though she had no specialized knowledge about dementia. The members of the exercise team were divided into groups of two. Anders and Hans formed a pair, and I followed their game. Anders kept mixing up the rules, making wrong moves. Sophia and Hans continuously corrected him in a friendly manner. Anders said laughingly to himself: "Just as I have started, I have to stop again", shaking his head. Then, Anders suddenly stopped, withdrew from the game, saying: "I have to leave now. I'm going to the DJØF (a Danish labor union for lawyers and economists). I asked Anders what time his appointment was. "Now", he said, without looking at his watch. He put on his jacket, greeted everyone, and left class one hour before it was done.

Sophia gathered the team to do a round of running exercises. One and a half hours into the class, as we were about to finish for the day, Jan showed up. Jan is 1.65 meters tall, a bit chubby, and has gray hair and a mustache. He is always in a good mood. Sophia told him that she had tried calling him and his

wife as the class started but in vain. Jan explained that he got off at the wrong bus stop and went looking for the sports hall, asking everyone he met on his way for directions. The others greeted him and invited him to take a cup of coffee, and the talk continued.

After participating for a while in the exercise team and seeing how the pattern of latecomers repeated itself, I became aware that the only people who seemed to notice were Sophia and me. We worried that a person not showing up meant that he/she had fallen suddenly ill or got lost on the way to class (which did occasionally happen, take the above example with Jan). Yet the rest of the team never raised an eyebrow when someone showed up late. In this particular setting, where participants with dementia made up the majority, and Sophia and I were in this sense a minority, a new temporal normativity reigned. In this particular social time, one could never be “too early” or “too late”; one was simply present, or not. This raises important questions about for whom clock time and punctuality are important? And who was out synch with social rhythms and tempo in this particular setting? As an alternative social milieu unmoored from clock time and punctuality, the exercise team demonstrates an alternative way of structuring social life that enables a more inclusive mode of temporal belonging. Rather than define belonging by an ability to align with the rhythms of social life, the mode of belonging created in the exercise team coalesces through regular participation, as we see when Jan insists on showing up even if the class is about to end, or Anders attending the first half hour before leaving. Further, the case indicates there are inclusive ways of being together in divergent experiences of time without pathologizing one experience of time over the other. Ultimately, the example shows that time differences and social belonging can synchronize under the right circumstances.

## Discussion

In describing how time difference comes to matter in the lives of people with Alzheimer's, I have explored two questions in this article. The first deals with how the so-called “loss of a sense of time” affects the social relations of people with Alzheimer's. The second explores what we learn about the notion of belonging by looking at the ruptures and conflicts that arise from a changing sense of time.

I have demonstrated that the loss of a normative sense of time in Alzheimer's disease is not solely a subjective loss, but also a social matter (Munn 1992). This loss is both experienced by people around the person with Alzheimer's and responded to in an intersubjective way. When Peter breaks out of the rhythms that he and Helle have established throughout their marriage, Helle is affected as well, longing for the past while at the same time experimenting with time, to keep Peter “in” time. When Susanne increasingly struggles to comprehend the week's plans, Erik is also affected, as both his ability to experiment with time and his patience are put on trial. Responses to the changing sense of time among people with Alzheimer's thus emphasize that the loss of time does not occur in a vacuum. On the contrary, partners become actively engaged with keeping the person in sync with

(normative) time, doing time work on their behalf in order to shape a particular way of being in time. Such responses to states of desynchronization are all aimed at enabling the person with Alzheimer's to continue participating in social time, aligning with the rhythms of social life in the Danish society's temporal regime, structured and heavily dependent on clock time and calendars.

Through the lenses of temporality and Alzheimer's disease, this article contributes to ongoing discussions about conceptions of belonging. Though I share Mattes and Lang's point that a definition of belonging cannot be absolute (Mattes and Lang 2021:6), I think that there is analytical potential in fine-grained, ethnographic studies of belonging. In fact, as Wright has argued, belonging's multiple meanings—as a feeling, a practice, as tied to a place or unmoored from one—may be why it has escaped theoretical scrutiny in the first place (Wright 2015:391). Following an understanding of belonging as fragile attempts at being part of something larger, created through joint social practice (Gammeltoft 2018), we gain nuanced insights into what belonging entails, how it is practiced, sustained, and in turn becomes fragile.

By illustrating how the notion of belonging is contingent on temporal aspects of social life, I suggest that a concept of *temporal belonging* can help us understand why and how belonging can become fragile. To that end, I take Meiu's point that belonging is embedded in temporal politics, entailing subtle, everyday attempts to align with social rhythms (Meiu 2017:248). From the perspective of people with Alzheimer's disease, I have illustrated that one-way belonging can become fragile is when one falls behind in the rhythms and tempo of normative social time. Yet people with Alzheimer's are not doomed to fall out of sync with social time, nor does their sense of belonging simply dissolve when they struggle to align with social rhythms. Instead, they are subjected to various, more or less successful and frictional attempts to be in social time. This point underlines Gammeltoft's concept of belonging as a joint social practice (Gammeltoft 2018). Aligning to the social rhythms of everyday life is thus very much a *mutual* process of establishing a sense of temporal belonging. Therefore, this article also offers a critical view on the pathologizing vocabulary prevailing in much of the existing literature on temporality and illness. Such literature primarily describes the experiences of time that differ from the normative ways of being in time, as states of individual suffering, displeasure, and pathology. However, by exploring people with Alzheimer's different and changing ways of being in time—and their social relation's responses to this—we catch sight of both how multiple dimensions of time can co-exist in ways that are not solely defined by suffering. Both from the ruptures in synchronization, the time work done by partners and the exercise team's experimental and alternative way of being in time show that temporality is always socially embedded and deeply relational.

From looking at people with Alzheimer's different ways of being in time, we catch sight of the intimate rhythms between families and friends and the greater temporal structures of society. People with Alzheimer's are unable to live up to ideals in Danish society prescribing how proper citizens contribute to society and remain independent for as long as possible. In that respect, losing one's job and becoming more dependent on others means breaking away from the general, ideal

life course that has significant impact on the daily lives of Danish families (see Jöhncke 2011). With inspiration from Lefebvre (2004) and Munn (1992), we further see that the Western use of clock time and calendars are normative tools, constructing “right” and “wrong” ways of being in time, designating specific times for specific activities. A byproduct of a society heavily structured by clock time is the risk that those unable to manage numbers and align with certain rhythms and pace are not only excluded from participating in certain social activities, but essentially from belonging to society in a much broader sense.

The ongoing work of temporal belonging demands an ability to adapt to and align with the rhythm and pace of one’s social surroundings. If we are to include people with Alzheimer’s disease (and other forms of dementia illness) in the rhythms of everyday life in Denmark, it is critical to make space for their different ways of being in time and offer ways of being together that are less dependent on clock time and the management of numbers.

## Conclusion

The concept of temporal belonging helps us understand how intersubjective senses of belonging can become fragile. Alzheimer’s disease entails living with rhythms that are increasingly desynchronized, time made painfully explicit, and increasingly tricky numbers. Exploring how people with Alzheimer’s struggle to align with the social rhythms of everyday life, we see how belonging requires the ability to be in social time.

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## Declarations

**Conflict of interest** The author declares no conflict of interest.

**Ethical Approval** Recruitment of interviewees and storage of interview data took place in compliance with national data protection requirements, and was approved by the Faculty of Social Sciences at the University of Copenhagen (journal nr. 514-0056/19-2000). Research has taken place according to the ethical requirements for qualitative research at the Faculty of Social Sciences at the University of Copenhagen governed by Danish law, and has been approved by the Faculty’s research committee (ID nr. 8053-00087B).

**Informed Consent** All participants provided their oral and written informed consent to participating in interviews following clear information about the purpose of the research.

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