

ARTICLE

Enacting citizenship through writing: an analysis of a diary written by a man with Alzheimer's disease

Ann Therese Lotherington¹  and Aud Uhlen Obstfelder²

¹Centre for Women's and Gender Research, UiT The Arctic University of Norway, Tromsø, Norway and

²Department of Health Sciences in Gjøvik, Faculty of Medicine and Health Sciences, NTNU, Gjøvik, Norway

Corresponding author: Ann Therese Lotherington; Email: ann.t.lotherington@uit.no

(Accepted 6 March 2023)

Abstract

Citizenship and dementia studies have, during the last 15 years, grown into a substantial body of research recognising the experiences and agentic powers of people living with dementia. This article aims to contribute to and extend this research field. We undertake the aim through a feminist posthumanist non-representational analysis of a diary written by a man with Alzheimer's disease to explore the diary's potential to enact citizenship. The first section of the article examines current approaches to democracy, citizenship and dementia, and advances the concept *intra-active citizenship*, an approach that extends the individual and understands citizenship as enacted in and through entanglements of human–more-than-human agents. The second section is a theory-informed analysis of the diary, in which events, relations, doings and affective resonances constitute the analytical categories. The third section discusses whether the diary and the writing of it might enact citizenship, and if so, what kind of citizenship. The article concludes with a reflection on how our posthumanist, non-representational approach might pave a new path for theorising and, hence, contribute to new understandings of dementia and citizenship.

Keywords: agency; Alzheimer's disease; feminist posthumanist non-representational theory; human–more-than-human entanglements; intra-active citizenship; writing

Introduction

The other day I really outdid myself: Vegard has the contract. The ace and queen of clubs were on the table. I'm the opener, with the king of clubs in my hand. If later in the hand Vegard plays clubs, my king will inevitably be lost when I play it. My only option is to make Vegard believe that the king is with my partner, not with me. Against all other rules, I therefore open with a small club against the table's case. And quite rightly so: Vegard felt sure that I would *not* have played away from the king, so he played his ace. Voilà! This way he makes my king

© The Author(s), 2023. Published by Cambridge University Press. This is an Open Access article, distributed under the terms of the Creative Commons Attribution licence (<http://creativecommons.org/licenses/by/4.0/>), which permits unrestricted re-use, distribution and reproduction, provided the original article is properly cited.

good. When I finally play it, he exclaims in amazement: so, *you* had the king! To brag a little: it's the best and cheekiest bluff I've ever done at a bridge table! (pp. 39–40; 12 January 2011)¹

This quote is from a diary written by the Norwegian Professor of Political Science, Thomas Christian Wyller (1922–2012). He began his diary project after he was diagnosed, at age 85, with Alzheimer's disease, and the book *En dements dagbok* was published post-mortem in 2013 (The diary is published in Norwegian only). When it came out, the book was described as 'The unthinkable book' (Jordheim, 2013) because it was written by a person with a dementia diagnosis, or 'a demented' as both Jordheim (2013) and Wyller (2013) write, but we do not to avoid identifying a person with dementia as *the illness*. Over the years, the understanding of life with dementia as decay (Latimer, 2012) has been challenged by a body of research on democracy and citizenship, including Human Rights, related to dementia (e.g. Nedlund and Nordh, 2018; Shakespeare *et al.*, 2019; Bartlett, 2021; Cahill, 2022; Asaba *et al.*, *in press*). This academic debate has made it clear that persons with dementia have the potential to live full lives as citizens provided that their surroundings support them in the course of their illness. The implications are that policy documents and dementia care systems and practices, such as dementia-friendly societies, more and more take these new understandings of dementia and life with dementia into account (Nedlund *et al.*, 2019). Within this broad theoretical approach Wyller's book becomes thinkable. This is promising, as the responses we get when talking about Wyller's book in public, also in 2022, are about some form of 'unthinkability'.

Unfortunately, in current society dementia is still associated with cognitive decline and frailty (Shakespeare *et al.*, 2019; Cahill, 2022; Peoples *et al.*, *in press*). When dementia is understood as a brain damage causing cognitive decline, the mental health of individuals with dementia can only get worse, their societal contribution only more marginal and the burden on societies only increase (Latimer, 2012). Gilleard and Higgs (2010) depict this understanding of dementia as a stepping-stone to the 'fourth age' – metaphorically characterised as a black hole of ageing, in which an Alzheimer's disease or other dementias (ADD) mark a boundary or 'event horizon' (Gilleard and Higgs, 2010: 125) creating a point of no return. Zeilig (2014) has demonstrated how the black hole metaphor captures the horror of the fourth age generated through third-party narratives represented in hegemonic Western images of dementia, and how these representations affect the way dementia is understood in society and consequently also is acted upon. Even today, horror films about dementia are made, e.g. the Australian psychological horror film *Relic* from 2020.

Because this image still thrives in the public dementia discourse, the ongoing critical dementia research we have referred to is crucial for producing change. Academics should, therefore, contribute to continual theoretical advancements to understand life with dementia, and how society can develop into a place in which we can live in difference together, be it class, gender, sexuality and age differences, differences in cognitive status, and the intersections between them. Our contribution to this theoretical advancement is to include insights from feminist posthumanist non-representational theory as potential new paths for theorising

citizenship and dementia. Until now, such non-representational analyses have been rare. However, we find scholars such as Fritsch (2015), Jenkins (2017), Latimer (2012) and Quinn and Blandon (2020) inspiring as they challenge understandings of dementia and disability with posthumanist, non-representational theories. We also see, which is promising, that early career scholars, such as Lukic (2019) and Mittner (2021), are entering the field of critical dementia research with this feminist posthumanist approach.

The purpose of our article is to perform a feminist posthumanist non-representational analysis of Wyller's book to propose *intra-active citizenship* as a potential new path for theorising dementia and citizenship. Doing this allows us to de-centre the human and analyse the becoming of individuals (Jenkins, 2017) and understand citizenship as distributed achievements (Ursin and Lotherington, 2018). We pursue the purpose in four steps. First, a theory section examining current approaches to democracy, citizenship and dementia, and, drawing on feminist non-representational theory, advancing an alternative approach to citizenship that extends the individual and understands citizenship as enacted in and through entanglements of human–more-than-human agents. Second, a theory-informed analysis of Wyller's diary in which we focus on events, relations, doings and affective resonances. Third, a discussion of the findings to inquire into whether the diary and the writing of it might be considered citizenship, and if so, what kind of citizenship. Fourth, a conclusion about what a posthumanist, non-representational approach might do the understanding of dementia and citizenship.

Theoretical approach

Democracy and citizenship

The right to participate in, and the obligations to contribute to society, are considered the bedrocks of democracy and citizenship (Bonvin *et al.*, 2018). At the most basic level citizenship means membership of a community, of which members are eligible to control their own life and influence one's society. Those belonging to the community are recognised as members, and entitled to agency. As such, citizenship is both an inclusive and exclusive concept: some are members holding certain rights, some are not and someone defines the borders. Historically, dependent people, such as slaves, women and mentally ill people, have been excluded, due to an idea of them as non-agentic and unable to fulfil the defined requirements of citizenship. Gradually, through class, feminist and, more recently, disability struggles, working-class people, women and disabled people have gained access to citizenship rights, even though not necessarily always and fully on equal terms.

Feminist scholars have theorised the problem of women's lack of access to citizenship in different ways, but what they have in common is that they theorise power and agency (Siim, 2000). These scholars have had substantial impact on citizenship studies. Examples are Lister (2003) in her distinction between citizenship as status, or being a citizen, and citizenship as a process, or acting as a citizen; Nussbaum (2011) with her capabilities approach; Fraser (2000) with recognition, redistribution and representation; and Young (2000) with belonging and inclusion, attending to social difference and civic organising. Yet, few of the scholars concerned with equal participation under conditions of difference question the premise that the

theories *presuppose cognitively coherent individuals* (Ursin and Lotherington, 2018) or presuppositions regarding what it means to be a human (Jenkins, 2017). Herein lies a dilemma: if democratic societies demand that their citizens take part in societal development, and such participation requires cognitively coherent subjects, then the fast-growing population of people living with ADD (Wimo *et al.*, 2015) are excluded from societal participation and influence, and consequently not considered as citizens. However, we see that an international Alzheimer's movement (*e.g.* Alzheimer Europe and the Alzheimer's Society²) is engaging in a similar struggle as, for example, the women's movement, to define people living with dementia as citizens with rights and duties (Weetch *et al.*, 2021). Alongside, and as part of this political struggle, academics steadily theorise citizenship, reformulate who is eligible, and who has the right to participate and seek societal influence. From Bartlett and O'Connor (2007) onwards, a research field on dementia and citizenship has emerged. The concern has been to see beyond people living with dementia as care recipients and beyond their cognitive impairment, to treat them in research and everyday life as a diverse group of women and men, and, drawing on Lister (2003), include their ability to *be* as well as *act* as citizens.

Citizenship and dementia literature

The research field on citizenship and dementia has paved the way for recognising the experiences of people living with dementia as not only a personal matter but also a matter of power, both in society and politics (Nedlund and Nordh, 2018). Social and relational citizenship have been introduced as helpful concepts, and instead of speaking *for* people living with dementia, their voices are heard and included on equal terms in research (Bartlett, 2014; Brannelly, 2016; Peoples *et al.*, *in press*). To this Kontos and Grigorovich (2018) add embodied selfhood as a relational and intracorporeal approach, allowing for an understanding of the body as having intentional and creative capacities. Others underscore how everyday life situations are crucial for enacting influence and, hence, for sustaining democracy (Lee and Bartlett, 2020; Asaba *et al.*, *in press*). These moves open for agentic power despite cognitive impairment and represent critical steps towards an understanding of inclusive democratic societies in which a person with dementia or other neurodegenerative conditions is entitled to the same human rights as the general population. This approach capacitates people who, within the dominating Western neoliberal governmental regime, otherwise would be incapacitated and put out of order (Vaittinen, 2022). Furthermore, this thinking is increasingly becoming a foundation for dementia policy throughout Europe (O'Connor *et al.*, 2022).

In their recent scoping review of the dementia and citizenship literature, O'Connor *et al.* (2022) underscore the rich achievements of this field of research over the last 15 years but point to the need for further development along three tracks: first, to actively apply an intersectional lens to more fully understand the diversity of lives with dementia; second, to expand the understanding of citizenship with the inclusion of responsibilities, not only rights as so far has been dominating; and third, to engage in a discussion about the appropriateness of the citizenship approach itself to 'resolve the tensions between vulnerability, rights and responsibilities' (O'Connor *et al.*, 2022: 36). Without disagreeing with these suggestions,

and even partly relating to them, we wish to expand the field even further through a posthumanist approach to citizenship and dementia. Hence, our suggestion is not to deny the importance of the current approaches and present an alternative, but to increase the diversity of possible paths forward.

Posthumanist citizenship

A posthumanist approach allows us to fully challenge the foundational but limiting individualised subjects of neoliberalism, and, to paraphrase Fritsch (2015), challenge the undesirability of dementia. This is not about desiring current dominating understandings of dementia, but possibly ‘radically alter how we desire dementia [disability in the original text], in addition to altering what dementia [disability] is, how it is practiced and what it can be’ (Fritsch, 2015: 43). For this we have developed an understanding of citizenship as intra-active, drawing on posthumanist non-representational theory (Alaimo and Hekman, 2008; Thrift, 2008; Vannini, 2015). These theoretical propositions grapple with the magnitude of the human-more-than-human in time-space as forces of becoming, rather than with coherent, unambiguous human subjects, meaning that we do not study ‘inter-action’ between independent, self-contained actors, but how individuals and other actors emerge through their situated entanglements, or ‘intra-actions’ (Haraway, 1997; Barad, 2003). ‘Intra-action’ allows for understanding individuals as entangled and becoming: ‘Individuals do not preexist their interactions; rather, individuals emerge through and as part of their entangled intra-relating’ (Barad, 2007: IX).

With this move, the centre of attention shifts from individuals’ actions and relations between coherent human subjects, to understanding the entanglements and their effects. The core interest for research shifts from practitioners to *practices*, from the doing subjects to the *doings*. Consequently, events replace individuals as objects of inquiry, as they encompass both relations and doings. The researcher’s position turns away from a supposed abstract one outside the phenomenon of study to become an active part inside it, loosening up the distinction between the knower and the known (Haraway, 1997; Barad, 2003), and simultaneously between ‘us’ and ‘them’. The categories used for exploration, understanding and describing the world are not taken for granted as fixed and clean in simplistic binary, individualised terms, such as women/men, sick/healthy, public/private but inquired as they unfold. They are enacted, not defined *a priori* (Mol, 2002), and more important than reporting on what happened in the past, what happens now and what might become next concerns the analysis.

The consequences of this approach for our study are that we do not predefine citizenship but explore Wyller’s book as ongoing intra-related practices in which everyone/everything is entangled, and in which citizenship might be enacted. This means that we cannot decide before we start the investigation whether citizenship is enacted, and if so, what kind of citizenship. Whether social, political or other forms of citizenship are enacted is a *result* of our investigation, not a *premise* for it.

Furthermore, citizenship becomes possible, or not, through entanglements, and not as result of what individuals can and cannot do. With this approach the illness becomes just another intra-acting agent, not the one causing specific and predictable effects as described in biomedical definitions of dementia. A non-

representational approach transcends the human as a coherent unit and focuses on the entanglements of human-more-than-human agents, attending to *affect as a force* unanchored in human subjectivity. To affect means to make a difference, to have an influence on someone or something, often connected to feelings, sensations and emotions, *i.e.* the bodies' capacity to be moved and affected, and the bodies' capacity to move and affect others (Vannini, 2015). Following this line of thought, a non-representational citizenship analysis treats *affect as capacity*, and affective resonances as the capacity of enacted feelings, sensations and emotions to move individuals and societies.

When citizenship is considered an effect of human-more-than-human entanglements, not what an individual has or does not have, can or cannot do, the entanglements, not the individuals, must be investigated to understand what citizenship might be or become, and likewise, how we learn what participation, agency, power and societal influence might be. Consequently, the significance of a dementia diagnosis for everyday life, and the significance of cognitive abilities for agency and citizenship, depend on the events in which dementia and cognitive abilities are enacted. Given certain entanglements, the body's capacity to be affected and to affect others might be a stronger force for agency, power and citizenship than cognition. Through an analysis of affective resonances of Wyller's diary as a final product – the published book – and the affective resonances of what he writes about and how, we explore, in what follows, the potential our posthumanist citizenship approach might have for advancing critical dementia thinking.

Analysis of the diary

Publishing books, journal articles, feature articles, letters to the editor, social media posts and other written public articulations are important channels for voicing opinion, potentially gaining political and societal influence and, hence, act as a citizen. To be heard and taken seriously, the utterances need to be logical, argumentative and informative, even if the mission is merely protesting a given case. In addition, the utterances need to follow the genre within which one is writing. Except for social media, Wyller frequently, during a lifetime, used all these channels to utter professional and personal opinions about various political and societal issues. Also, after he got the Alzheimer's diagnosis, he published a book about the role of his family during the Second World War (Wyller, 2011), and he submitted a feature article about the referendum connected to the debt crisis in Greece to one of the main newspapers in Norway, *Aftenposten*, that was rejected. He understood that the issue was relevant, as the editor wrote about the Greece case a few days later, 'partly with my arguments' (Wyller, 2013: 166), but that his treatment of it was not according to the newspaper's requirements. He was disappointed but realises in retrospect that most important was not to see the post in print but to know that he managed to write sensibly about difficult issues. He returns to writing the diary, also with the attitude that the most important part is not to be published but to write.

Diaries and memoirs of people living with dementia is an emerging genre (Bitenc, 2020). The majority are penned by a named or unnamed ghost-writer, often a journalist or a family member. In this respect Wyller's diary is an exception.

There is no ghost-writer. In the preface his son, Torgeir Bruun Wyller, describes thoroughly his role in getting the book published after Wyller died, whilst at the same time underscoring his father's major role as writer of the text. Therefore, when analysing this diary, our point of departure is that the author was Thomas Christian Wyller. However, according to the reactions when the book came out, writing the book should not be possible for a person with a dementia diagnosis, nor should it be possible to understand the text as a political statement and an expression of societal participation, agency and influence.

Wyller's diary and other similar diaries or memoirs, e.g. Wendy Mitchell's *Somebody I Used to Know: A Memoir* (Mitchell 2018),³ are less about the illness as a misfortune and failure, more about how it became a new aspect in life, a new agent to relate to. The entries in Wyller's diary demonstrated a rather pragmatic attitude regarding a life with dementia, with ambitions to contribute to and participate in societal and political debates on equal terms with people deemed healthy. The book challenged biomedical and commonsensical understandings of dementia, particularly the strong connections these understandings draw between cognition, rationality and agency, and hence the idea that cognitive coherence is a prerequisite for citizenship. These challenges have inspired our attention to theorising citizenship, and we use Wyller's diary as the empirical scope of the analysis.

Wyller's diary is not one thing. To paraphrase Mol (2002), it is *The Diary Multiple*. First, and mundanely, the book is a diary the Norwegian Professor of Political Science and a renowned writer and columnist Thomas Christian Wyller (1922–2012) wrote after he was diagnosed with Alzheimer's disease. He describes how he felt a need to demystify the disease and write a diary about his various experiences, including how the disease afflicted him (Wyller, 2013). He told his general practitioner (GP), whom he calls 'the dementia expert', about his plans but the GP advised against it. He said that the process would be too demanding but also extremely frustrating for him if he did not manage to follow through. But Wyller comments:

It is thinkable that my impaired abilities fitted his diagnosis at that point. But I had no intention whatsoever to let the project go. (p. 42; 23 January 2011)

His greatest hope for life was to 'die standing' (p. 112; 23 September 2011), that is, to write and having a life worth living till the very end. It is fair to say that his wish came true. He wrote the first entry in September 2010, and the last one in January 2012, ending with these sentences:

To write a diary about past and present has inclined me to experience a future: I believe a future still might provide me with a lot. The full stop in this book is, therefore, not the full stop of a life. Only a book. (p. 221; epilogue, 15 January 2012)

Three months later he dies, nearly 90 years old.

In parallel to the mundane understanding of the diary, it might be at least four different things analytically. First, a *biomedical analysis* might classify Wyller as a dementia patient in family care at home, and search the entries for signs of increasing frailty, loss and progression of the illness over time. Second, a *literary analysis*

might examine what was told, the idea, the plot, the characters and the writing style employed to narrate a desired story: what he included and what he omitted, although the latter would need more than the diary to decide, and hence, be some sort of representational idea. Third, a *representational analysis* might put the authenticity of the events, the authorship or both under scrutiny to judge its reliability as a true representation of what happened in the past, and/or consider the diary's ability to capture a coherent, individualised narrative of Wyller's experiences with a life with dementia. Fourth, a *non-representational analysis* would put the subject on a back burner and seek to understand what the diary does here and now, and what it might do to open possibilities for imagining a prosperous future with dementia, or, according to Vannini (2015), alternative futures, and hence, desire dementia differently (Fritsch, 2015).

By pursuing a non-representational approach, we engaged with the text emotionally, here, and now, as part of *our* everyday scholarly lives. We were not present and observed the events described in the diary as they unfolded, but the diary, the theoretical propositions and the authors' emotions intra-related and generated conceptions of what citizenship might be and become. Methodologically speaking, this is diffractive reading (Haraway, 1997; Barad, 2007; Lukic and Mittner, *forthcoming*). We, the authors, are not in focus as individual subjects but as instruments for the research process. Despite, but respecting, the differences between the diary, the theoretical propositions and our emotions, we treated them non-hierarchically and read dialogically through one another to enable creative thinking and generate new knowledge. The iteration process began as the diary randomly came into the first author's possession and affectively resonated with her preconceptions of life with dementia. Accompanied with the second author and the theoretical propositions, an emotional chaos about what the book did to us, gradually transformed into systematic iterations that, with support from Vannini (2015), culminated in a pertinent thematic coding scheme consisting of events, relations, doings and affective resonances (Figure 1).

Events

Non-representational theory recommends events or practices in all their details – what, where, when, who – as objects of inquiry for research. The events may range from occasional happenings to regular occurrences and come with conflict and drama that might be analysed for relationships, doings and affective resonances pointing towards potential alternative futures. The events we scrutinise in this article are Wyller's *diary entries*, not the events he writes about or the authenticity of the life and experiences of the writer. He knew, and we know, that what he writes might not be correct representations of what happened in the past. Wyller says:

And as I write, the memory of things I thought was forgotten is mobilised. From the depths of my mind – where they have survived and so to speak have been kept in custody – they come to the surface and produce memories. That's why I don't really write about the events *per se*, but about what I remember here and now. Not about what happened daily, but about what I remember happened. And, to make it extra intricate: about what I've been told and therefore 'remember' indirectly. (p. 170; 12 November 2011)

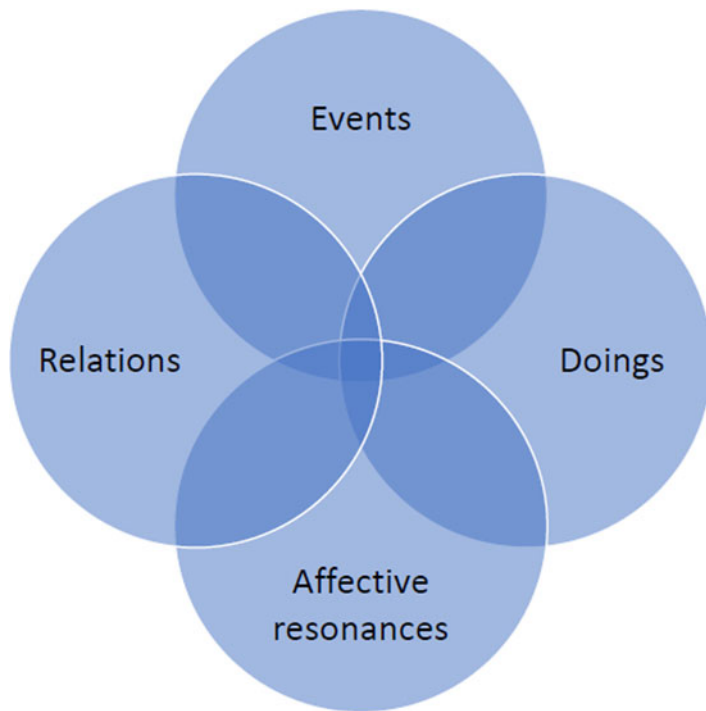


Figure 1. Entanglements of events, relations, doings and affective resonances.

As our analytical aim is to explore what the diary does here and now related to understandings of dementia and citizenship, the accuracy of what he writes about the past and present is of subsidiary relevance. What is important, however, is the effects the writings have on the writer, the reader and the environment; and the entries did their job by intra-acting with these readers' emotions and thoughts, creating the ground for the emergence of new understandings of dementia and citizenship.

The published 220-page diary contains 88 entries, including a prologue and an epilogue, dated from 18 September 2010 to 15 January 2012. The entries are between one-quarter of a page to eight pages. The most common length of an entry is between half a page and two pages. Only eight of the entries are four pages or more. The writing activity varies. Some months have more than one entry every second day (September and November 2011 with 17 each), whilst others have none (December 2010 and July 2011). In addition to Wyller's entries, the diary contains a preface by Torgeir Bruun Wyller, the diary author's son, who happens to be a geriatrician. He writes about how his father involved him in editing the book (p. 7), his role in getting the book published after his father died, and some background information about the situation and the family.

Relations

The non-representational claim that individuals do not pre-exist but become or emerge in and through entanglements of human–more-than-human agents

(Barad, 2003) implies that the study of relations, not self-contained units, are privileged. According to Vannini (2015: 8), 'life arises from the entanglement of actors...'. The researcher should, therefore, study such entanglements to understand the becoming of individuals and things. Transferred to our case, a writer and a published book are not mere self-contained units but effects of entangled human–more-than-human agents, and we should study the becoming of the writer and the published book through the entangled relations.

Wyller's diary is not a raw text from Wyller's hand, it is edited like all other books published by serious publishers. While the editing of other books often takes place between the author and an editor at the publisher's, this book went through a thorough editing process before it was submitted. Because a major difficulty for Wyller was keeping an overview of the book, the family helped with deleting sections already described, and 'to get the best possible outline and coherence of the text' (p. 7). Wyller read and accepted the changes before he died, and also trusted the son's judgements regarding the final editing phase before publishing. To some extent this practice might be understood as editing away the most obvious expressions of a non-coherent mind to avoid him standing out as a cognitively impaired person. We cannot know, but what reading the entries reveals is that Wyller did not deny how the illness afflicted his life. He writes a lot about how the illness sometimes ruined, sometimes benefited his days, and sometimes was not noticeable at all, but also about inter-dependency. From a non-representational approach inter-dependency, or rather intra-dependency, is considered the norm, as we all are dependent on and intra-related with other humans, non-human animals, organic matter and objects to emerge as individuals and live our lives. However, with what, who and how we intra-depend on and intra-relate to vary over time and with space and place. When dementia becomes part of the intra-relations, new forms of intra-dependency emerge and new agents become involved; some more prominent but all important for the enactment of a writer.

In addition to helping with the editing of the diary, the family stands out as extremely important for the configuration of a vital everyday life. His wife, sons and daughters-in-law took turn to see to that he was never left alone, that he was taken out for walks to get some exercise and breaths of fresh air. They also provided him with good food and drinks, dinner parties with family and friends, weekend trips to the mountain cabin and summer holiday at the coast. He appreciates it all:

...a quality dominates my life: the care and love I meet from my loved ones ... They always care about my wellbeing, day and night. I feel a warmth flowing towards me daily. I am not only a lucky, but a happy man with such people around me and about me. (p. 48; 17 February 2011)

I'm carried ahead. Have long been spoiled. (p. 156; 2 November 2011)

However, dementia is also part of the configuration of the family's everyday life, either it acts daunting, knocking Wyller out into depression, apathy and passivity, or uplifting, playing a trick, leaving the memory intact for reciting a long poem in the car home from a trip to the cabin ('the Buck ride' from Ibsen's *Peer Gynt*) or singing out loud together at a dinner party, accompanied on the piano by a family

friend described as being severely afflicted with dementia. Hence, the various expressions of the illness intra-acts with other human-more-than-human agents, enacting a spectrum of emotional situations affecting everyday life in the family. Wyller describes how he comes to realise that he has to take an active part in shaping an engaging life, and struggle to keep the illness-agent at a distance through mobilising his own will and strength:

Suddenly, one day, I realised how having a man in the house sleeping almost all day must have affected her [Kari, his wife]. Even though she did not reproach me: what a burden [for her]! In that same moment I decided to change both attitude and behaviour, become active, engaged, come up with something nice for both of us. I suddenly noticed a surplus and a determination that could trigger such a life change – and make it last, at least until further. Then I informed Kari. Guess how happy she was! (p. 26; 30 September 2010)

He saw his own will but also resistance from the environment as necessary for continued growth, and how short-sighted being served everything would be: ‘Only by being challenged and by mobilising own strength to defeat the challenge, one can grow’ (p. 145; 27 October 2011). Being intellectually challenged through the writing of the diary was part of this engagement.

In addition to various family members, Carmencita, a Newfoundland family dog, steadily appears in the entries. She evokes new emotions and takes part in shaping the atmosphere of everyday life. ‘She is adorable, yes delightful, [I] feel that she feels good for us all’ (p. 58; 7 March 2011). It is not that the family has not had dogs before, they have, but Carmencita is the first dog Wyller has ever cared for. He simply loves her! This amazes him, not the least because he reads in a dementia information brochure from the GP’s office that one dementia characteristic is affection for pets. Apart from this reference and a few other exceptions, health care and biomedicine are agents that rarely appear in the entries. One exception is the GP whom Wyller, probably ironically, calls the dementia expert. The GP’s advice and recommendations are apparently not highly regarded. Medicine against pain in his left thigh is another facing the same fate. The medicines do help but also take away the zest for life: ‘The pain is exchanged with sleepiness, moodiness, cries, sadness, lost appetite for life, no singing, feeling down’ (p. 124; 27 September 2011). On his wife’s recommendation he stops taking them, because ‘it is less damaging to have pain in a leg than to have pain in the soul’ (p. 124). After a while without the medicines, he struggles with his thigh but sings a merry melody in the morning and serves Kari coffee in bed. Two other exceptions with opposite sign: the home care service personnel coming every day to help with compression stockings; the illness itself making him forget an unpleasant hospital experience. He writes warmly about both. They are important agents making a difference in everyday life, making him able to write and hence to become something more than a dementia patient.

Wyller describes an affectionate relationship to his computer and the desk in the room he has at his disposal, without which he would not be a writer. The relationship between the writer and the computer often involves others, but not always:

...but one thing I must note immediately: Today I have for the first time managed to start my computer after it has been turned off at night. And not only that: *I* have found the script I'm working on! Hurray! It not only simplifies my work but testifies that I may not be incurably demented in all areas! (p. 36; 10 January 2011)

However, nine months later he confesses that he has become a technological illiterate: he does not master the phone, does not understand Facebook, is not allowed to use the stove or to iron alone, and 'I can neither open nor close the computer' (p. 130; 30 September 2011). But he has a strategy:

...to brag about my weaknesses, mark that I have other values, cultivating a different lifestyle than the vast majority. It leads to a lot of practical problems daily but also a certain satisfaction when I ask others what Facebook is, what Twitter means.

We see how the writer emerges from the human-more-than-human entanglements, making doings possible.

Doings

A non-representational focus on doings means to attend to practices and performances as a form of action to get things done. Here we analyse the process of writing as a doing or a set of doings. Writing was one of Wyller's passions, national and international politics another. Throughout his entire adult life, he contributed to the public debate through publishing books and feature articles about current political issues. Professionally he brought his passions together in teaching and research as a Professor of Political Science at the University of Oslo. He acted as a citizen. When he was diagnosed with Alzheimer's, writing about his new life with the disease seemed not only natural to him, but also possible to do as the disease had not affected his language skills. He had just recently written a book about his family during the Second World War that came out in May 2011 (Wyller, 2011), as the diary project was well on its way. He describes how happy he was when the book came from the publisher: 'We celebrated ... with oysters and champagne' (p. 74; 5 May 2011), and how this recognition stimulated him to moving forward with the diary. Still, he could identify as a writing person, one who writes about what he is passionate about. However, the passion shifted from major political issues, via family history, to life with dementia and writing.

Several of the entries are about writing: the writing process, the urge to write and the creative aspects of writing. Despite his wish to communicate a nuanced imaginary of a life with dementia, the act of writing stands out as the most pressing purpose of the diary project. Writing becomes vivifying and necessary for continuous growth and development, for having a life. After a period of no energy or drive for any kind of intellectual work, he describes how the urge to write suddenly came back:

Now I cannot find enough time to sit at my desk. I feel that I am in the most creative phase of life – it is immensely satisfactory, even though the 'creation' does not hold qualitative standard ... I will seek to exploit this phase to a maximum – nobody knows for how long it will last. (p. 87; 1 September 2011)

It lasted, and on 20 November 2011 he writes:

Writing? One might believe I was aiming for a Nobel Prize, I'm that eager. I consider this eagerness positive – whether it is quality is less important. Fame? Hardly, I am not yet completely out of the world! (p. 176; 20 November 2011)

The entries present the writing process as decisive for the quality of Wyller's later life, relating quality of life to being creative and having a purpose, as if it were an individualised task, something Wyller decides to do and then does. However, the doings become possible only in and through the entanglements. The writing process is intra-active, enacting potential affective resonances.

Affective resonances

From having written a lot about national and international politics over years, his attention in the diary turns towards his own condition and everyday life, and how the two recursively create each other. His former daily obsession with keeping up with societal and political news turns into a mere obligation. He does not *feel* anything for the political events taking place and does not remember the affection he had for past events – even shocking events like 9/11 does not recall emotions. He can remember the event but not the affect. Politics simply does not give much meaning anymore:

My interest in the world around me is diminishing, not fast, but steadily and surely: what happens, happens, nothing more to say about that. (p. 184; 26 November 2011)

Now and then I take part in discussions and conversations. But mainly without a personal engagement. I live the days and years I may have left, in the present. The future is no longer my business. I am an observer where I before was a participant. (p. 219; epilogue, 15 January 2012)

So, Wyller writes about everyday life in which dementia might stand out as an important actor, moments in which dementia becomes a friend and times when it plays no role. For example, in one of the last entries he writes:

An Oslo school invited me to a church concert before Christmas. I did not feel well and was not in a festive mood. Still, I went. And what an experience! Here the school management had arranged a feast, touching for both believers and unbelievers. The students in a huge choir with high-class soloists, chamber and soloist music on every conceivable instrument and with a repertoire from Mozart and Brahms. And I, both irreligious and sensitive to loud noise, I sat like a light, touched deep into my soul. The dementia was chased down into the basement, and along with it both emotional guilt and depression. It was magnificent! (p. 205; 17 December 2011)

The sound, the space, the togetherness affected him and made the moment memorable, worth writing about and, hence, also affecting the reader.

He writes about life's highs and lows, *e.g.* the cheeky bluff in the game of bridge and the reciting of 'the Buck ride' on the high side and, on the low side, nightmares, attacks of weeping and apathy. He describes how these highs and lows affect the writing process but writes about himself from an outsider's perspective. When he writes about emotions, he rarely describes them in such a way that the reader may feel the same as he did when he had them but reflects soberly on having had them. He writes about the painful situations when they are over, maintaining a writing style of a distanced researcher. However, he writes with humour and irony, unpretentiously about himself. For example: 'My forgetfulness is still dominating and partly annoying, at least for the family' (p. 41; 18 January 2011).

Memory and forgetfulness are important themes in the diary, but he knows that he cannot write about what he has forgotten, precisely because he has forgotten. Hence, he reflects more on memory as a central theme than the actual events he remembers or has forgotten. That was also the case for a hospitalisation during the summer holiday. He has heard that it was bad and that he was very ill but does not remember a single moment, thanks to dementia! Dementia acted to his advantage, and he is thankful for it. That is what stands out as important from that lost memory. Hence, dementia is not *only* bad and not *always* bad. He says:

To what I will name 'my' dementia – which I do with a feeling of right because I perceive all the disease attacks as individual – I will add something else and more. I will not only moan and complain, invoke difficulties and special considerations, things I do not get done and cannot do. The years behind me have given me a lot, and now every day is full of content, the years (?) to come are probably uncertain, but also promising, dementia or not along the way ... How do I experience dementia? ... It is enough to summarise, I feel demented within different areas of life and with varying strength, here weak, there strong. (p. 177; 20 November 2011)

In the epilogue, he concludes:

My own diagnosis is still clear: I have not become more demented than I was. On the contrary, I attribute this development to two general reasons as well as a more special one: the care I meet with and have received from my loved ones and the life motivation this has created in my mind. In addition, if I am allowed, the joy of writing this diary. The quality? Without significance. The important is only to be able to meet an intellectual challenge. (pp. 219–220; epilogue, 15 January 2012)

Discussion: citizenship as enacted effect

From the feminist non-representational analysis of Wyller's book, we turn to a discussion of our findings to propose intra-active citizenship as a potential new path. Doing this, we relate back to the introductory presentation of feminist citizenship theory and citizenship and dementia studies. Having citizenship status, or being a citizen, means to be entitled to certain legal rights in a country, such as residency and voting rights, in turn for duties, such as taxation and general allegiance towards the state. People living with dementia have citizenship if they are not legally incapacitated, but they do not necessarily use it and act as citizens. Citizenship might remain a passive status. Citizenship as process, on the other hand, means having

the capacity to use the citizenship status and influence one's own life and society, *i.e.* having the necessary capabilities for acting as a citizen (Lister, 2003; Nussbaum, 2011). Because of the diversity among people with dementia, regarding class, gender, sexuality, age, cognitive status and their environment, the actualisation of the necessary capabilities to act as citizens vary. This variation worries the citizenship and dementia scholars because it produces inequality. These scholars' contribution to citizenship thinking – that agency beyond cognitive decline is both possible and desirable – are therefore crucial for enabling people living with dementia to have active citizenship (Nedlund and Nordh, 2018; Bartlett, 2021; Peoples *et al.*, *in press*). We bring this fundamental understanding into the discussion.

An important insight from feminist citizenship theory is the concepts belonging, recognition and agency (Young, 2000; Fraser, 2000; Lister, 2003). With these concepts, the legal aspect of citizenship, and the nation-state, are no longer central. The concern is who belongs to, and are included in, a certain community, who are recognised as equal participants and whose agency is influential. Citizenship as process, or to act as a citizen (Lister, 2003), require all: belonging, recognition and agency are all necessary conditions for citizenship, but they are not sufficient in and of themselves, individually. They must operate together. We pair these concepts with the non-representational concepts we used in the analysis of the diary: relations, doings and affective resonances. The combination of these concepts are the building blocks for the development of our understanding of intra-active citizenship. With this novel conceptual framework, we discuss whether the diary and the writing of it might be considered citizenship and, if so, what kind of citizenship, and in the end, whether the framework is helpful for radically altering how we desire dementia.

Relations–network–belonging

The analysis of the diary revealed that the production of the book was a collective effort. It was not that Wyller told his story to a ghost-writer who then wrote it, but that the human–more-than-human network he was an active part of together formed relations that made writing the book possible. Loved ones, including the dog, a room, a desk and a computer, fresh air, walks, good food, solid economy, dinner parties, singing, reciting poems, home care staff, a challenging 'dementia expert', dementia brochures, dementia diagnosis, holiday cabins, bridge games, memory, forgetfulness, and more, intra-acted and created a 'possibility room' (Mittner, 2021) in which the writer was enacted. However, it was not only the writer that was enacted, also all the other agents. This is a core premise within non-representational theory, which Barad (2007) phrases as 'human-more-than-human in time-space', and an advancement of how we earlier have described citizenship as distributed achievements (Ursin and Lotherington, 2018). According to what a distant reader may see, Wyller thrived in these entanglements, he belonged to this community. Some scholars might describe what is enacted in this entanglement as wellbeing (Kaufmann and Engel, 2016), whilst others might see social citizenship (Bartlett, 2021). So far, we do not see belonging–relations–network as enough for citizenship, but one condition for it is met.

Doings-writing-recognition

As a professor and active public debater, Wyller had, through his professional and popular writings, a long history of recognition. He was recognised as a knowledgeable, influential and respected citizen in the Norwegian society. After he got the Alzheimer's diagnosis he continued along these lines, and successfully published a book about his family's role in the Second World War, which he describes as intensely fulfilling. However, his attempt to publish a feature article in a national newspaper fails. He realises with regret that he is not there anymore and that he will not get recognition as a writer from the external environment anymore. The verdict from the 'dementia expert' confirms it. Nevertheless, he writes on and finds it extremely meaningful and satisfying. Being published or not is no longer significant. It is the process, it is the doing, that matters. The act of writing, of being creative, evokes meaning to life. The writing process becomes life-giving. External recognition might have diminished but even so, through intra-action he becomes an active contributing agent in the community in which he belongs. Following the line of thoughts of Asaba *et al.* (in press), we see here how creativity, emotional and social resources together allowed for engagement and influence in everyday life, which they assert is a crucial dimension of democracy in later life. Within our conceptual framework we might conclude that recognition was enacted, and that yet another condition for citizenship was met.

Affectionate resonances-content-agency

Wyller writes about what affects him, which might or might not affect others, meaning that what the book does is not one thing. Its influence and agency will vary with the different entanglements in which it is enacted.

Individually: Writing the book obviously had a tremendous effect on Wyller's life. It made a difference. But the diary as a final product also touched and affected our lives as readers, otherwise we would not have spent time on reading, rereading, analysing and writing about it.

Locally: Family and friends are affected. Not only do we see this through what Wyller writes, but also through reading the son's preface.

Societally: As published the book becomes a voice in the public debate. It is read and debated, reviewed, and analysed in a Norwegian context, and now, with this article, it reaches an international audience. Eventually, it might be useful as a change-making tool for the Alzheimer's movement.

The book affects and resonates and enacts agency as a third condition for citizenship.

Belonging, recognition and agency play together and enact citizenship beyond the individual, distributed and not individualised. Yet, we do see the individual, not as a coherent unit with presupposed human capacities, but as enacted and, hence, becoming. By de-centring the individual we avoid normative assumptions about what it means to be human and open up for 'more human-non-human relationships to emerge' (Jenkins, 2017: 1484). It is the human-more-than-human

relations that enact the writer, it is the writing process, the doing, that produces affectionate resonances, and the affectionate resonances that have the transformative powers. Through the entanglements citizenship is enacted, sometimes as social, sometimes as political, and sometimes as several things at the same time. What it becomes is situational, it depends on the human–more-than-human intra-actions in time-space.

Conclusion

With a non-representational approach to the analysis of the diary, we have challenged individualised understandings of dementia, and opened a new path for theorising citizenship as intra-active enactments. Our conceptual framework consists of a merger of feminist non-representational theory and feminist citizenship theory operationalised through the analytical categories ‘relations, doings and affective resonances’ intertwined with ‘belonging, recognition and agency’. Through this theoretical lens we have seen how the writing and publishing of the diary enacted dementia desirably in certain time-spaces and how citizenship became a potential political force. The empirical analysis opened for seeing differently and, hence, for seeing different things. Both dementia and citizenship multiples. Therefore, the effects of de-centring the human has been to liberate the thoughts about the role of cognition for citizenship and hence to recognise power as an enacted effect of certain entanglements, not limited to an individual’s capacity to act.

With our theorising we have contributed a foundation for a feminist posthumanist, non-representational understanding of citizenship and dementia that we invite the research community to develop further with us. The approach is feminist, but we have not privileged gender here as might have been expected. Our purpose was to analyse citizenship, not gender, but in the enactment of citizenship gender was one among more intra-acting agents. We have described Wyller as a multiply privileged man with a loving wife and a caring family, and we understand from the diary that these privileges, including his male gender, had been an advantage to him throughout his lifetime, and important for his achievements both before and after he was diagnosed with Alzheimer’s disease. To explore the gendered part fully, another reading of the diary might use our feminist posthumanist approach to interrogate gendered power structures or the emergence and change of masculinity and femininity in a life with dementia, but we leave this option to another time.

Acknowledgements. We appreciate as a necessary condition for our scrutiny Wyller and his family’s efforts in making the writing of the diary possible and making the result available to the public. We recognise them as co-producers of one important entity in our diffractive reading process, the diary, and are thankful for that. We conducted the analysis in deep respect for them. Many thanks to the members of the research group FemArc at UiT the Arctic University of Norway, for thorough and thoughtful comments on an early draft of this article, and especially to Anka Ryall and Marit Anne Hauan for support and advice. Finally, we would like to thank the editor and two anonymous reviewers for constructive comments.

Competing interests. The authors declare no competing interests.

Ethical standards. Ethical approval was not required.

Notes

- 1 Throughout the article, quotes from the diary are referred to in the form (page; date of entry). All quotes from the diary are our translations from Norwegian. However, the translation of this quote is refined by two English-speaking bridge experts. Thanks to Keith and Nico!
- 2 See <https://www.alzheimer-europe.org> and <https://www.alzheimers.org.uk>.
- 3 Mitchell's book was written together with a ghost-writer, Anna Wharton. The distribution of responsibilities between the two in the writing process is not spelled out.

References

- Alaimo S and Hekman S** (eds) (2008) *Material Feminisms*. Bloomington, IN: Indiana University Press.
- Asaba E, Mondaca M, Josephsson S and Johansson K** (in press) Everyday influence – democracy when health and social care are part of everyday life. *Ageing & Society*. Available online doi:10.1017/S0144686X21001653.
- Barad K** (2003) Posthumanist performativity: toward an understanding of how matter comes to matter. *Signs: Journal of Women in Culture and Society* 3, 801–831.
- Barad K** (2007) *Meeting the Universe Halfway. Quantum Physics and the Entanglement of Matter and Meaning*. Durham, NC: Duke University Press.
- Bartlett R** (2014) Citizenship in action: the lived experiences of citizens with dementia who campaign for social change. *Disability & Society* 8, 1291–1304.
- Bartlett R** (2021) Inclusive (social) citizenship and persons with dementia. *Disability & Society* 7, 1129–1145.
- Bartlett R and O'Connor D** (2007) From personhood to citizenship: broadening the lens for dementia practice and research. *Journal of Aging Studies* 2, 107–118.
- Bitenc RA** (2020) *Reconsidering Dementia Narratives, Empathy, Identity and Care*. London: Routledge.
- Bonvin J-M, Laruffa F and Rosenstein E** (2018) Towards a critical sociology of democracy: the potential of the capabilities approach. *Critical Sociology* 6, 953–968.
- Brannelly T** (2016) Citizenship and people living with dementia: a case for the ethics of care. *Dementia* 3, 304–314.
- Cahill S** (2022) New analytical tools and frameworks to understand dementia: what can a human rights lens offer. *Ageing & Society* 42, 1489–1498.
- Fraser N** (2000) Rethinking recognition: overcoming displacement and reification in cultural politics. *New Left Review* 3, 107.
- Fritsch K** (2015) Desiring disability differently: neoliberalism, heterotopic imagination and intra-corporeal reconfigurations. *Foucault Studies* 19, 43–66.
- Gilleard C and Higgs P** (2010) Aging without agency: theorizing the fourth age. *Aging & Mental Health* 2, 121–128.
- Haraway D** (1997) *Modest_Witness@Second_Millennium. FemaleMan@Meets_OncoMouse*. London: Routledge.
- Jenkins N** (2017) No substitute for human touch? Towards a critically posthumanist approach to dementia care. *Ageing & Society* 37, 1484–1498.
- Jordheim A** (2013) Den utenkelige boka [The unthinkable book] (Book review). *Forskerforum*, December 6.
- Kaufmann EG and Engel S** (2016) Dementia and well-being: a conceptual framework based on Tom Kitwood's model of needs. *Dementia* 4, 774–788.
- Kontos P and Grigorovich A** (2018) Integrating citizenship, embodiment, and relationality: towards a reconceptualization of dance and dementia in long-term care. *Journal of Law, Medicine & Ethics* 46, 717–723.
- Latimer J** (2012) Home care and frail older people. Relational extension and the art of dwelling. In Ceci C, Björnsdóttir K and Purkis ME (eds), *Perspectives on Care at Home for Older People*. New York, NY: Routledge, pp. 35–61.
- Lee K and Bartlett R** (2020) Material citizenship: an ethnographic study exploring object–person relations in the context of people with dementia in care homes. *Sociology of Health & Illness* 43, 1471–1485.
- Lister R** (2003) *Citizenship. Feminist Perspectives*. Basingstoke, UK: Palgrave Macmillan.
- Lukic D** (2019) Multiple ontologies of Alzheimer's disease in Still Alice and A Song for Martin: A feminist visual studies of technoscience perspective. *European Journal of Women's Studies* 26, 375–389.

- Lukic D and Mittner L** (forthcoming) Diffracting dementia: co-creative experiments with agential realism and multisensoriality in a residential care home in northern Norway. In Just E, Udén M, Weetzel V and Åsberg C (eds), *Voices from Gender Studies: Negotiating the Terms of Academic Production, Epistemology, and the Logics and Contents of Identity*. Routledge.
- Mitchell W** (2018) *Somebody I Used to Know: A Memoir*. London: Bloomsbury Publishing.
- Mittner L** (2021) Resonating moments. Exploring socio-material connectivity through artistic encounters with people living with dementia. *Dementia* **1**, 304–315.
- Mol A** (2002) *The Body Multiple: Ontology in Medical Practice*. Durham, NC: Duke University Press.
- Nedlund A-C and Nordh J** (2018) Constructing citizens: a matter of labeling, imaging and underlying rationales in the case of people with dementia. *Critical Policy Studies* **12**, 253–272.
- Nedlund A-C, Bartlett R and Clarke L** (2019) *Everyday Citizenship and People with Dementia*. Edinburgh: Dunedin Academic Press.
- Nussbaum M** (2011) *Creating Capabilities*. Cambridge, MA: Harvard University Press.
- O'Connor D, Sakamoto M, Seetharaman K, Chaudhury H and Phinney A** (2022) Conceptualizing citizenship in dementia: a scoping review of the literature. *Dementia* **21**, 2310–2350.
- Peoples H, Varming J and Kristensen HK** (in press) Social citizenship when living with dementia: a qualitative meta-study. *Journal of Occupational Science*. Available online doi:10.1080/14427591.2022.2061040, Accepted March 2022.
- Quinn J and Blandon C** (2020) *Lifelong Learning and Dementia: A Posthumanist Perspective*. London: palgrave macmillan.
- Shakespeare T, Zeilig H and Mittler P** (2019) Rights in mind: thinking differently about dementia and disability. *Dementia* **3**, 1075–1088.
- Siim B** (2000) *Gender and Citizenship. Politics and Agency in France, Britain and Denmark*. Cambridge: Cambridge University Press.
- Thrift N** (2008) *Non-representational Theory: Space, Politics, Affect*. New York, NY: Routledge.
- Ursin G and Lotherington AT** (2018) Citizenship as distributed achievement: shaping new conditions for an everyday life with dementia. *Scandinavian Journal of Disability Research* **1**, 62–71.
- Vaittinen T** (2022) An ethics of needs: deconstructing neoliberal biopolitics and care ethics with Derrida and Spivak. *Philosophies* **4**, 73.
- Vannini P** (2015) Non-representational methodologies: an introduction. In Vannini P (ed.), *Non-representational Methodologies. Re-envisioning Research*. London: Routledge, pp. 1–18.
- Weetch J, O'Dwyer S and Clare L** (2021) The involvement of people with dementia in advocacy: a systematic narrative review. *Aging & Mental Health* **9**, 1595–1604.
- Wimo Anders, Ali Gemma-Claire, Guerchet Maëlienn, Prince Martin, Prina Matthew, Wu Yu-Tzu and Alzheimer's Disease International** (2015) *World Alzheimer Report: The Global Impact of Dementia. Analysis of Prevalence, Incidence, Cost and Trends*. London: Alzheimer's Disease International.
- Wyller TC** (2011) *Verdenskrig og hverdagsliv: en Stavangerfamilie under krigen* [World War and Everyday Life. A Stavanger Family During the War]. Sandnes, Norway: Commentum forlag.
- Wyller TC** (2013) *En dements dagbok* [Wyller's diary from his life with dementia]. Oslo: Vidarforlaget.
- Young IM** (2000) *Inclusion and Democracy*. Oxford: Oxford University Press.
- Zeilig H** (2014) Dementia as a cultural metaphor. *The Gerontologist* **2**, 258–267.

Cite this article: Lotherington AT, Obstfelder AU (2024). Enacting citizenship through writing: an analysis of a diary written by a man with Alzheimer's disease. *Ageing & Society* **44**, 2684–2702. <https://doi.org/10.1017/S0144686X23000223>