

Writing Our Futures Possible

Inspirations from the Dementia Letter Project

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Abstract

Life with dementia urgently needs to be reimagined. The dominant social imaginary of dementia perpetuates a story in which people with dementia cannot have a life that is 'good'. In this Position Piece we draw from eight letters written for the Dementia Letter project, in which the letters' authors address their potential future self with dementia. We found that using the creative method of letter writing opened up possibilities for writers to fill uncertain futures with dementia with new experiences and relations, as well as opportunities for exploring multiple temporalities and versions of themselves. We highlight five inspirations from the letters: living with what is, the future as a space of possibility, populating the everyday, folding time, and cultivating multiple selves. Through these, we argue, alternative futures, and a present, with dementia can be reimagined, and made differently.

Keywords

Dementia, Disability, Care, Future, Creative methods.

Introduction

The dominant social imaginary of dementia is one in which life is over before death and the individual is lost to self and others (Gilleard and Higgs 2010). This fearful imaginary hinges on the assumption, widely shared in Western societies, that what makes living a good life possible rests on ideals such as autonomy, cognition, and physical independence. This imaginary is not innocent: in perpetuating a negative story of life with disability, it suggests that a future with it cannot be but bleak (Kafer 2013). By foreclosing the telling of alternative stories, it shapes the very realities it seeks to describe.

The Dementia Letter project starts from the premise that life with dementia urgently needs reimagining. For this project, we build on Annelieke's doctoral research, an ethnography situated in Dutch nursing homes, in which she foregrounds such alternatives to the negative imaginary of dementia. By telling stories about care practices in which people with dementia can be desiring, appreciating subjects, Annelieke challenges the idea that a life with dementia is a fate characterised by loss and decline (Driessen 2017, 2018, in press). We furthermore build on Hannah's Utopia Now! project, in which young people living in South London engaged with their hopes and fears about the future through arts-based workshops. The project invited young people to become active in imagining—and therefore building—a better world for themselves (Cowan, Kühlbrandt, and Riazuddin 2022). Taken together, our two projects demonstrate how positions that people (can) take in relation to their own and collective futures can be shifted and enriched through collective, creative approaches.

For the Dementia Letter project, Annelieke extended an invitation¹ to people (initially friends, colleagues, and acquaintances, but later also healthcare professionals and others who were interested) to write a letter to themselves in a possible future with dementia. This invitation explicitly left open the way in which letters 'should be written'. It encouraged letter writers to conjure up imaginaries which could afford a wider range of positions for people with dementia than projected by the dominant imaginary of dementia. Hannah initially wrote a letter and then became involved in writing about the larger set of letters.

The thought of your own possible future with dementia is likely to be unappealing. Our possible future with dementia is 'an unwanted future' (Lemos Dekker 2021) and one we tend to reject until we can no longer do so. A collection of letters to our future selves with dementia is urgent precisely for that reason: rather than wishing dementia away, the letters open up ways of reckoning with the fact that a life with

1 To access the invitation letter to the Dementia Letter project see: <https://www.anneliekedriessen.com/dementia-letters>.

dementia is a possibility for us all, and allow us to address the question of what would make such a life 'good'.

Researchers interested in imaginations of the future have found that asking people about the future can lead to rather stereotypical or abstract descriptions (Phoenix, Smith, and Sparkes 2007). Arts-based methods have been found to provide at least a partial solution, through their ability to make research more accessible and help researchers to capture thoughts and experiences in novel ways (Carabelli and Lyon 2016; Sools 2020; French, Lovatt, and Wright 2023). Moreover, McKittrick (2021) sees multiplying the ways in which we work with knowledge through creative practice as a method of generating an ever-expansive and productive diaspora of knowledge that refuses a single, fixed position. In resonance with this, we found that letter writing freed our participants of academic or literary conventions of writing, both in terms of structure and content, and allowed for a breadth of generative depictions of life with dementia.

This Position Piece captures the creative, collective, and speculative effort of taking seriously the possibility of our dementia futures. Paradoxically, our interest is not solely in such futures, but how, in imagining that future in a preferred personal way, we might open up alternative possibilities for living with dementia in the present.

Five inspirations

In the first eight letters we received, we identified five inspirations that unsettle the dominant imaginary of dementia: living with what is, the future as a space of possibilities, populating the everyday, folding time, and cultivating multiple selves.

1. Living with what is

In the face of how dementia is currently perceived, it seems an understandable response to desire a future without it, and to invest in the hope of a cure. Imagining possibilities for our future selves with dementia, however, cannot be done without some degree of acceptance. One letter-writer, Ralf Jox², framed dementia as a phase of decrescendo: 'Maybe dementia is just the most radical way of symmetry in life: the long crescendo in childhood, adolescence and early adulthood is mirrored by a dwindling decrescendo towards death'.

When first reading this excerpt, we wondered if the use of this image may inadvertently reinforce some of the negative images of dementia we are trying to disturb in the project. But Ralf clarified that, for him, a decrescendo was not at all negative. He explained that in music, one needs both a crescendo and a

2 See <https://www.anneliekedriessen.com/dementia-letters-ralf-jox>.

decreasing to make it interesting, rich, and lively. And so, the winding down of life is an essential, creative part of life.

Other letters illustrate how life with dementia can encompass crescendos as well as decrescendos across days, weeks, and a complete lifetime, which allows for the appreciation of the beauty of life as a whole. The act of living with what is can in itself be a powerful force, even if that means living with the absence of what once was. For letter-writer Becky Field³, even if memory fades, the present remains:

You will get frustrated and worried. Things will go wrong and you will forget things and get in a muddle. But forgive yourself. And then carry on. You have been very lucky to be loved and to love. If these memories start to fade then, well, you will have to try to accept being in the present.

We learn that only with acceptance of the difficulty that dementia inevitably entails, can some of it be reframed. In her letter, Meri Westlake⁴, for example, suggested that: 'There is healing and insight in being a forgetful being', and hoped that it might bring comfort:

You have always worried about your memory, even from as early as your mid-20s. It almost seems poetic in nature to succumb to what has worried you the most. Without your sharp cognition the world perhaps almost feels bearable to live in. Perhaps, I hope, you no longer see the juxtapositions and ambivalences present in society that used to bring so much pain.

Through the explicit acceptance of the losses that dementia brings, a space opens up in which a more positive way of living with dementia can take shape.

2. The future as a space of possibilities

In dominant discussions of dementia, there is often talk about who somebody was before the diagnosis and about memories of the past. Besides highlighting memories of and reflections on the past, Maddy Pearson's letter⁵ also stages an open future—a part of life still to be lived and enjoyed:

Let us think of the possibilities, let me write (y)our future possible. The reins of guilt tie you to a past you don't remember, a past that treats you like a stranger, staring in through steamed up glass. Let us cut them loose. I give you permission to not remember. You can live here now, in the future. If you don't

3 See <https://www.anneliekedriessen.com/dementia-letters-becky-field>.

4 See <https://www.anneliekedriessen.com/dementia-letters-meri-westlake>.

5 See <https://www.anneliekedriessen.com/dementia-letters-maddy-pearson>.

remember me, make us someone for today. I'm going to stop telling you who we are. [...] I want you to have a future, a future of your, our own.

When the dominant cultural imaginary of dementia frames people in terms of their past, and of a life ending—thereby excluding people with dementia from their futures—it is a powerful practice to think of this phase of life in the exact opposite terms: in terms of possibility. Maddy makes an important intervention in the focus on the past in relation to dementia that denies people with dementia a 'future of their own'. For her, opening up the future as a space of possibilities requires an acceptance of forgetfulness, which then frees her future self of the past that cannot be remembered. And so, the last phase of life can be more than an ending of a life; it can be a valuable part of life itself.

Rather than prescribing what their future will be like, authors sought to explore the possibilities their futures could entail. In her letter, Melanie Lovatt⁶, for example, opened up the future through asking her future self questions:

I want to know who and what matters to you in your life. Who do you care about? Who cares about you? Who do you spend your time with? What do you spend your time doing? What do you look forward to? What makes you annoyed?

Floris Tomasini⁷ suggests in his letter that the potential of this future seems to be unlocked by the very act of accepting it as a possibility:

Remember, Floris, in [the film] *Still Alice*, when Alice [...] was imposing her will to end her life upon her future self. Alice could not let go of the person she so valued, in order to leave any space to be the person she would become in the later stages of the disease. Floris, can you accept your future self with dementia? [...] so the phoenix of your new self can rise from the ashes.

And thus, for Floris, the ending of one 'life' can also be the beginning of another.

3. Populating the everyday

There is an assumption that futures with dementia are stripped of meaningful people and things, gradually emptied to an increasingly lonelier existence. But in the futures imagined in these letters these lives are not empty or small. They are populated with generative human and non-human relationships that fill and broaden lives. Melanie writes:

6 See <https://www.anneliekedriessen.com/dementia-letters-melanie-lovatt>.

7 See <https://www.anneliekedriessen.com/dementia-letters-floris-tomasini>.

I suppose it's the everydayness of your life that I'm interested in. And while that's hard for me to imagine, I know that if you can see the trees from your window, and hear the birds singing, and maybe even have a cat resting at your feet, you'll be doing just fine.

Populating this 'everydayness' allows writers to think not only about their future lives, but their future selves. It is the relations with the world that generate life: they matter for who we are now, and who we can become. For many, the exercise of letter-writing seemed to bring about a shift in what they considered might be of value to them in the future. In particular, there was a renewed appreciation of nature—a hope, perhaps, that a life with dementia is a retirement from a life filled with worries and responsibility. For Jeannette Pols⁸, who addressed her letter from a future to the present, relations with nature could also become entangled with technology:

The good thing is that I can be outside every day, and feel the wind in what is left of my old hairs. I enjoy this so much, the rustling that tunes in with the soft rustle of the hearing aids that do not bother me anymore. Because spring is coming in, I am extra happy. I like the crispy cold weather that is laced with flecks of sun.

That technology can at times be a hindrance to relating to the outside world, and at other times facilitate it, demonstrates how what is 'good' can be very different for different people, and different at different times.

For Meri, writing the letter helped her to navigate what is of value to her now, and what may be of value to her in the future. With self-compassion, she offers recommendations for her future self: 'I hope that [...] you are still able to sway and dance to a familiar record. Should you be struggling for a tune I recommend 'We've Lost Dancing' by Fred Again and The Blessed Madonna'.

So whilst the letter-writing exercise led many to speculate and wonder what may populate our future everyday lives, they also expressed hope. This hope helps articulate practical material suggestions for care and support of what may add value to our later lives.

4. Folding time

Whereas people with dementia are frequently depicted as disoriented in time, this is not how they themselves seem to experience time. Instead, they can suddenly live in a time when their parents are still alive, when they are still taking care of their young children, and when they need to go to work. Whilst this 'time travel'

8 See <https://www.anneliekedriessen.com/dementia-letters-jeannette-pols>.

(Pols 2018) is often experienced as problematic by family members, our letter writers also found positive ways to let the present and the past overlap.

For Ralf, the letter allowed him to let the present in which he is writing overlap with the past he is writing about, as well as his past and his future through a wish for similar care to be part of both:

With great gratitude I think back to my mother, my father, my family and all the others who led me into life when I was a small child. I do not have a lot of explicit memories, but I still have the unmistakable feeling that I was secure and taken care of. [...] This wonderful caring cocoon I had in my early life is the one thing that I wish you most at the end of life.

Dementia has been part of Floris's life for some time in the form of his father's vascular dementia, which also lets his and his father's youths overlap in time:

Dread arises if I imagine my future self as othered; [but] I realised I don't need to imagine this because I have lived with my father who has had vascular dementia. [...] I vividly remember sitting in a restaurant near his home in Deventer (in the Netherlands) laughing, laughing, about something that only he and I found funny. [...] In that moment we were both so young.

Taking such overlaps of past, present, and future seriously as an alternative for a linear understanding of time, we approximate to what Michel Serres and Bruno Latour called 'folding time' (1995, 60). Like two points on a handkerchief that can be a distance apart, but will touch if the handkerchief is crumpled, past and present can overlap, sometimes so much that the end can simultaneously be a beginning. By the same token, dementia may be folded into lives through genetic dispositions that make writing a letter not just a theoretical exercise but an engagement with a very real and very likely possibility that one day, one may develop dementia.

5. Cultivating multiple selves

Exploring different temporalities, and folding time, also allowed some writers to explore different versions of themselves; the multiplicities they hold. This counters more dominant narratives of dementia, which focus on the loss of self as a constant threat and cause of concern. Multiplicities arose, in part, because writers playfully engaged with the idea that they do not know 'who' they are writing to.

Instead of seeking stability of identity through enforcing a coherent self defined by the past, these letters cultivate an openness to the idea that we may have, and be, multiple selves over the course of our lifetime, perhaps even simultaneously. As

Hannah Cowan⁹ suggests in her own letter, our future selves with dementia may be in a better position to embrace these possibilities than our present ones:

Our bodies can also split off into a multitude of different directions. [...] If we embrace it, it could also give us something – allow us to explore and accept the multiple versions of ourselves. Whilst I'm meant to stay stuck together in the present, day-to-day rigmarolling, you can let yourself go off with some of these pieces.

But these letters do not only look to past selves, they also look to the future. Just as Floris used the letter-writing to describe a 'phoenix of [their] new self', Maddy used this new found freedom in imagining the future to create new identities and new selves, that she co-creates with her future self:

I was never particularly fond of our name. I don't know if you know it, so I won't put it here. You can call us what you like. What do you, we, feel like today? The sun is shining, illuminating a walled garden, maybe today we are a Marigold? Tomorrow it might be overcast, you, we, are tired, a little pensive and reserved, perhaps a Willow? You see, a little space to dream ourselves each day.

What these letters allowed, then, was not only a reflection on life, or an attempt to speak from a stable positionality, but an exploration of multiple selves across temporalities in collaboration with their future self.

Dementia reimaged

The letter writers that responded to our invitation have tried to imagine their future with dementia. They did so by not feeling hampered by political, cultural, and social imaginaries and instead through speculating freely. But they also explicitly took bodily, practical, and relational limits into account. The five themes we have examined unsettle the dominant cultural imaginary of dementia, in which losses of memories of the past, a dwindling self, and fading relationships take centre stage. Our letter-writers, by contrast, open up a door to a life with dementia in which new relationships and more-than-one self is possible. In doing so, they contribute to the urgent task to reimagine life with dementia, now and in the future.

And so, we may take these letters and the alternatives they present as a catalyst for the diversification of the ways we think dementia possible. If there is an investment in the search for a good life with dementia, dementia will continue to

9 See <https://www.anneliekedriessen.com/dementia-letters-hannah-cowan>.

mean drastic change in the lives of the individuals, families, and communities affected by it, but it will no longer be a sealed fate.

*** Would you like to write a letter to yourself in a possible future with dementia? Visit the website to read the invitation letter. For any questions on the project or to send your letter please contact Annelieke at annelieke.driessen@phc.ox.ac.uk.

Authorship statement

The Dementia Letter project was conceptualised and driven by Annelieke, who also led on inviting project contributors. After writing her own letter, Hannah joined Annelieke's initial work in analysing the letters. The current text is based on a joint analysis and was written by Annelieke and Hannah. Both authors also helped letter writers refine their texts for publication.

Ethics statement

As this project is not classified research, no ethics approvals were required. All letter writers have consented for the display of their letters on the project website, <https://www.anneliekedriessen.com/dementia-letters>. All names but those of the consenting authors have been removed to ensure anonymity. No funds, grants, or other support was received to conduct this project or the preparation of this manuscript.

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About the authors

Annelieke Driessen is an ethnographer and post-doctoral researcher at the Nuffield Department of Primary Care of the University of Oxford. She obtained her PhD in medical anthropology from the University of Amsterdam in 2019, with an ethnography exploring the good life with dementia. Annelieke currently researches initiatives to improve access to primary care services in England as part of the [GP-SUS](#) team.

Hannah Cowan is a medical anthropologist working at the Department of Population Health Sciences, King's College London, interested in activism, social inequalities and health. She currently leads on the [Utopia Now!](#) project, which works to bring non-academic communities and researchers together to find everyday ways of resisting the reproduction of inequalities in health.

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