

Afterword

By Jane Lugea

Dementia, in its many forms, challenges our very being. Stories explore our very being. Here, I want to reflect on what makes dementia worthy of exploring through stories, and what makes stories about dementia more than just that; I suggest that they offer a chance to interrogate what it means to be human, what we humans value, how we relate and care for one another. I'll be taking a look back at the stories included in this collection, as well as considering the several years of collaborative research that led to it. My perspective is informed by my love of language: as an academic linguist, I specialise in literary language, and how the rules of a language can be exploited, manipulated and bent by its users for creative means. But creative language is not just an aesthetic artform to be appreciated. It also disrupts our usual way of seeing things, providing an alternative lens for interrogating and understanding key challenges humans face. Dementia is one of those.

For all these reasons, I embarked on an eighteen-month research project in 2020, generously funded by the UK's Arts and Humanities Research Council. The aim of the project was to explore a particular kind of contemporary fiction – that which represents the *minds* of characters with dementia. I collected 400,000 words of such fiction and looked for patterns in the way dementia and its symptoms were represented in creative writing. Some of the findings are mentioned below. I also hypothesised that seeing the world through the eyes of characters with dementia might facilitate a better understanding and awareness of the condition in readers. This possibility was explored with my fantastic co-researchers at Queen's University Belfast, who brought their expertise in ageing societies, and in gathering public attitudes and readers' opinions: Dr Gemma Carney, Dr Paula Devine and Dr Carolina Fernández-Quintanilla. Jan Carson lent us her literary talents and community engagement experience. Together, we hosted reading groups using extracts from the fiction I had studied.

Each reading group had people with different experiences of dementia: there was a group of student social workers, a group of people who cared for loved ones with dementia, a group from the general public, as well as a group of people living with the condition. We learnt a lot from their different responses: about how fiction relates to peoples' realities, about how it can confirm, deny or challenge perceptions. The most significant thing I learnt is that creative writing offers ways of understanding dementia that medical factsheets, media representations or casual conversations cannot. Creative writing can represent the experience of living with dementia such that readers can simulate it, better understand it and maybe even better respond to it in our daily interactions.

Dementia and the person

As Jan outlined in her introduction to this anthology, dementia is an umbrella term for several hundred conditions, all of which involve a physical deterioration of some part of the brain. Despite the fact that it is clearly a physical illness, as a society we tend to focus on the mental and behavioural changes that occur in people living with dementia. Maybe we only believe what we can see. But this focus might also arise from the fact that those mental and behavioural changes are uncomfortable to witness for those without dementia. On a personal level, dementia can wreak havoc on a loved one's personality, changing the nature of our interactions with them, and on their memory, erasing or rewriting the relationship

history we share with them. On a societal level, dementia affects aspects of our being that fast-paced, neo-liberal, Western cultures hold dear: autonomy, cognitive abilities, multi-tasking (for more on this, see Ian Maleney's *Minor Monuments*). What these personal and societal reactions to dementia have in common is a perceived decay of the *person*, i.e. that dementia has reduced, diminished or erased the 'self'. To a certain extent, the self/person is defined by other people, or relationships with other people. For several decades now, advocates for 'personhood' in dementia care have been trying to emphasise the continued existence of a person behind the dementia. Despite these efforts, many representations of dementia in popular culture and conversation continue to focus on a perceived 'loss of self', or the 'dehumanising' effect of dementia.

Narrativising dementia: a paradox

I believe stories are one way of reinstating the person in our understanding of dementia, and our societal response to it. Stories invite us to depart from our own existence for a moment, to live vicariously in another person's shoes, and understand the world from their perspective. Important strides are being made by people living with dementia who are writing their own stories – testimonies to what it is really like to experience it. Surely, there is no better way to understand the person behind the dementia. But one limitation with the autobiographical story of dementia is the impossibility of capturing the later stages of the illness, when the person with dementia can lose the ability to tell their story.

Writers of fiction are increasingly tackling dementia in their stories. I believe that there are two main reasons for this. First, the rise in literary representations of dementia is in response to an increasing societal awareness of the disease. Ageing populations and more diagnoses are resulting in a greater prevalence of the condition, so more of us are affected. As I described above, the discomfort we have with the symptoms, and how they jar with what we know and hold dear, means that dementia demands exploration from Western writers. This theory is supported by the fact that existing fiction depicting dementia is predominantly from white, Western writers. We have tried to redress this by widening the canon in this particular anthology.

Second, narrativising dementia involves certain challenges that are interesting for writers. Dementia can entail memory loss and difficulties with language, both of which are necessary for telling stories. As such, a paradox arises when penning a narrator or character with dementia, because storytelling requires recall, putting events into order and into words. The creative prospects of narrativising dementia enable writers to experiment with form and narrative structure. Although Jan dealt with the ethical dimension of writing fiction about dementia in the introduction to this book, it is worth mentioning here: creative writers are not bound to tell the truth – that is the nature of fiction. They are free to use their creative licence, to play with the words available to them. That said, it is important that fictional representations of a lived experience (especially one that is so difficult for many) are well researched, honest and offer some kind of 'truth'. So while fictional representations of dementia have a complex relation to reality and peoples' lived experiences, they work best when they speak to, represent and interrogate different aspects of the condition, as the range of stories held here do. In the sections that follow, I provide examples of how the writers in this collection use language creatively to represent experiences of dementia.

Missing words

Although not all forms of dementia bring language difficulties, my research found that fiction often depicts this symptom, perhaps because it allows writers to experiment with language and memory in their stories. There are different ways of doing this. A character with dementia might repeat parts of the story, with us re-reading it verbatim, feeling like we've been here before, just like Niamh's father repeats, 'I had a Merc, once,' in Christopher Wright's 'Downbeat'. This gives us a sense of being caught in a loop, reliving the same memories on repeat.

Writers often depict the how characters with dementia can't find a specific word; if readers are experiencing the story from their perspective, we share in that loss and subsequent confusion. Of course, a story would not be readable if words were lost too often, or across whole sentences. Yet Anna Jean Hughes takes this technique to the limit in 'Sound Distraction', with opaque descriptions such as, 'She holds something out to me. It's orange round. Only small. I don't take it, so she starts to tear its skirt off.' Readers have to work hard to decipher that the character with dementia is describing a mandarin orange. First, the object is referred to using the unspecific term 'something', then by using the unusual word order in 'orange round' (noun + adjective), then by replacing the action of peeling its skin with a visually similar action 'tearing its skirt off'. This example illustrates how language can be used creatively to mirror the experience of dementia. The language lost to the character is also lost to the reader. The simple gesture of being offered a mandarin orange is made strange and alien, giving us insight into how dementia might affect daily experience. While there are many such examples across the stories in this collection, Anna Jean Hughes explores this to the utmost, offering a strange and profound simulation of the experience of dementia through word loss, word play and perceptual difficulties.

Although my research focused on fiction told from the perspective of characters with dementia, the contributions to this anthology are told from the perspectives of other characters too. Reading these contributions has made me realise that 'missing words' is not just an affliction attributed to characters with dementia. The narrator in Paul McVeigh's story, 'Coming and Going', describes his father as follows: 'Recently, someone's been there, just not the man who was my dad. A new man who bore no resemblance to the Dad I knew, physically or in personality. My not-dad.' Here, it is not the person *with* dementia, but the person *observing* it who uses under-specific terms, 'someone' and 'a new man'. This made me appreciate how dementia is also a new experience for the loved one, who can struggle to come to terms with the changing identity of a parent.

Interestingly, even the word 'dementia' is avoided entirely in some of the stories in this collection, where instead the symptoms or changes are called 'his *illness*', ('My Way Home', Caleb Azumah Nelson), or 'a *waywardness* in Mam' ('This Small Giddy Life', Nuala O'Connor), or 'her mother's *condition*' ('Heatwave', Oona Frawley). The avoidance of the term 'dementia' in these stories might reflect the characters' experience of the 'unknown', of the symptoms pre-diagnosis, or even a discomfort with the label itself. This technique captures how verbalising dementia, whether a character is living through it or watching a loved one, is difficult. As Henrietta McKervey's narrator observes in 'A New Day, Tomorrow', 'I'd use other words if I had them, but I don't. Language is like that. It lets you down when you need it most.' Yet these stories still capture what it feels like to grapple for words, when our experience is hard to understand and express.

The present, the body and the senses

My research found that fiction about dementia tends to focus on the body and bodily experience in the here and now. Most of the stories in this collection are told in the present tense; this is not the norm for fiction, but corresponds with what I've seen in fiction about dementia. I think the present tense allows writers to depict how dementia demands living in the moment, and emphasises the importance of sensory and emotive experience over memory. When using the present tense, writers are more free to explore present experience, which is governed by immediate sensory descriptions and fleeting emotions. I found these often go hand in hand, as in this example from Suad Aldarra's 'The Three Strangers': 'My heartbeats slow down like the end of a song. I am safe now.' The first sentence describes a physical sensation; the second, an emotion, and we are invited to make an association between the two. I believe that fiction is uniquely placed to capture sensory and emotive experience in this way (can you imagine a hospital pamphlet doing the same?!). I also believe that this technique reminds us of what might be important in dementia care and interactions; that is, focusing on the present, on stimulating and supporting the senses and emotional wellbeing.

The body, behaviours and emotions of characters with dementia are sometimes filtered through the perspectives of other characters. Considering how this is done can reveal something about how dementia is viewed and understood from the outside looking in. In Christopher Wright's 'Downbeat', Niamh describes her father:

Dad was fast asleep on the sofa. His bony hand sat cured on top of his chest, rising and falling with the sway of his shallow breath. Thick skin bunched and hung at the knuckles, his flesh spotted, pitted and lined in blue veins like a confluence on a map.

This description focuses on his body in a vulnerable state, marked with age. No doubt it reflects the complex experience of observing a parent change physically, the role reversal of caring for a person who once cared for you. Later in the same story Niamh attempts to fulfil her new role, offering her father a nutritional shake:

*I'm not fallin' fer that, he said, dropping his cigarette in the shake with a plop and a fizz and grinning at her through broken-grate teeth.
Fuck's sake, Dad.*

Despite his weak physical state and developing dementia, Niamh's father resists her care, dismissing it as trickery and literally putting out his cigarette in it. While this is immensely frustrating for his daughter, the interaction gives a sense of the tension between dementia, the ageing body, and an ongoing sense of agency in the person living through it. In this way, fiction can explore – without necessarily prescribing any answers – what it is like to live through these changes, and to observe them in a loved one. Characters with dementia can be shown to retain their 'personhood' through strong, defiant interactions such as this. Sometimes it is difficult to know if a person's behaviour is down to the dementia or is part of who they always were. For instance, Mary Morrissy's narrator in 'Fingerpost' is hurt by her friend's words and wonders, 'Was this the illness talking? Or was this what Delma had felt all along? In the past she'd often been sharpish with a hard glittery edge; now she was a

sword unsheathed.’ As this example shows, it can be hard to separate the person from the illness.

Alternatively, the effect of dementia on a person’s character might be an unexpectedly positive one, as in Sinéad Gleeson’s story, ‘Immurement’, where the affected mother develops a ‘new late-stage sentimentality’, not present pre-dementia, and manifesting in uncharacteristic tears. In Nuala O’Connor’s story, ‘This Small Giddy Life’, ‘There is awe and joy in her face, and it strikes me she is becalmed, no more the rushing hawk of her younger years. Stillness suits her, makes her cheerier, a thing none of us would ever have believed.’ In these examples, daughters observe the effects of dementia as physical and behavioural changes in their mothers, in their bodies and faces. Their mothers may be losing memories and words, but consequently, they are experiencing the world in a more immediate and sensual way, which might facilitate a different kind of emotional connection with loved ones.

Metaphors

For many people, literary language means metaphors. But metaphors are a lot more commonplace, and central to the way we think, than you might imagine. Metaphorical language includes metaphors and their sisters, similes; both describe one thing in terms of another. Often, a metaphor or simile describes something that is quite abstract, or difficult to ‘pin down’, in terms of something more real or concrete. Although literary language is known for using creative metaphors, it often uses metaphors that are quite conventional and close to everyday ways of expressing things. For example, Sinéad Gleeson’s narrator in ‘Immurement’ describes dementia as ‘a burst pipe in the brain’. Thinking about our brains as plumbing systems might be helpful for understanding the physical changes brought by dementia. The brain, the mind and consciousness, all of which dementia can affect, are extremely difficult for us to describe, so metaphorical language can help.

The narrator of Caleb Azumah Nelson’s story ‘My Way Home’, observes his father: ‘His illness stays pressed to his chest, announces itself before he can announce himself, his agency lost somewhere in the swirl of memories he keeps trying to grasp.’ The dementia (‘his illness’) is made physical, personified and given a voice that drowns out his father’s, while the memories are also made physical and out of reach. Here, the metaphorical language helps the reader imagine the unnamed illness as a more tangible thing, and understand the son’s perception of how it physically impacts upon his father. Our reading group research found that metaphors really strike readers and can shape or reinvent their perception of dementia.

Because it involves associations between concepts, metaphorical language reveals how we think. In everyday conversation, the brain is often talked about metaphorically as if it were an administrative or computer system. We can see this in fiction too, where the narrator of Henrietta McKervey’s ‘A New Day, Tomorrow’ (who does not have dementia) describes ‘the filing cabinets of my mind’, where the brain is a filing system for our thoughts and memories. This is a useful shorthand for dealing with the brain and its complexities, but if applied to dementia, might invite a conceptualisation of the condition as one that corrupts the internal filing system, wiping the data. If our minds and ‘processing power’ are so closely aligned with our personhood, with our identity, then this conventional metaphor could lead to the assumption that losing ‘data’ (memory) is a loss of our identity, i.e. that dementia makes us less of a person. Metaphors, then, can smuggle powerful ways of thinking in language and shape the way that we think about the world and people around us.

Metaphorical language also has the power to *challenge* traditional ways of thinking, especially when it brings together unconventional concepts. For example, in, 'The Three Strangers', Suad Aldarra uses a simile, 'I realised he was gone once again, like a beautiful sunset. I couldn't wait for him to rise again.' We don't often think of people as sunsets, that come and go with an infinite beauty. But doing so provides a comforting reassurance that this loved one will return and it will be a happy reunion. To be precise, it is not the narrator's *father* who is coming or going here, but his *consciousness*, so this example also offers a different way of understanding the human mind which, like a sunset, is universal and governed by nature. Like every individual consciousness, the sun will one day burn out, but the simile here conflates billions of years with a human lifetime – the duration doesn't matter; like the sun, we are all finite and life, while it lasts, is 'beautiful'.

Of course there are any number of ways that dementia, and our experience of it, can be represented in metaphorical language. But, hopefully, the examples discussed here illustrate how metaphorical language can help us handle difficult, invisible concepts such as dementia, help us understand them in more tangible ways, and even challenge or reshape our conventional ways of thinking about the phenomenon.

Voices, perspectives and realities

There's something else that fiction can do, unlike any other kind of language. It can weave together voices and perspectives so that an event or experience can be understood in many different ways simultaneously. An extreme example of this trick is found in Naomi Krüger's 'People Who Want History, Want *History*'. Her 'story' is not a traditional narrative, instead it brings together fragments of different texts – care home documents, a transcribed interview, and a student's literature essay. Using these fragments, the reader has to piece together an understanding of the character with dementia and a young student's naïve interactions with him in a reminiscence session. The care home documents prescribe how to do 'reminiscence therapy' and how carers and therapists should interact with residents with dementia. The young student attempts to implement this guidance in a reminiscence session with Eddy, judiciously steering him away from 'sensitive' topics, such as gay sex and violence, by stuttering to tell a story, a Polish folktale. The folktale, retold in an extract from the student's university essay, is about memory, its loss and its trickery. As all these snippets are pieced together, we are shown a contrast between 'reminiscence' as the care home prescribes it and the student tries to implement it, and the way that Eddy, the lively character with dementia, prefers to do it. Eddy is not encumbered by the institutional regulations that govern the care home and the university student, so his speech comes across as more fluent, his interactions more confident and spirited. This story, a creative patchwork of different voices, makes us appreciate the communicative skills of people with dementia; their conversational contributions may not be orderly or conform to everyday norms and expectations, but they can be rich, impassioned and are worth listening to.

Fiction gives readers access to characters' speech and thoughts. In fact, access to other people's thoughts is one of the unique advantages of reading, one of the only ways of getting inside the mind of another person, and surely a big part of why we enjoy reading fiction. Writers can present the voices and thoughts of characters in different ways, allowing us readers to appreciate multiple perspectives on the same situation. This can be beneficial for our understanding of something like dementia, which affects different people in different ways. The following interaction is from 'Sound Distraction', by Anna Jean Hughes:

'Mams, where did you go?'
It's my Pearl.
'I'm here, girl'

In this exchange, the narrator with dementia recognises and names her daughter 'Pearl' internally, even though she doesn't verbalise it. Instead, she calls her 'girl', leaving her daughter none the wiser that her mother, seemingly lost to her, recognises her by name. The reader has a privileged position, with insight into the mother's glimmer of recognition, but also a bittersweet awareness that the daughter doesn't know she was recognised. In this way, fiction can juxtapose different voices and perspectives, showing that the same situation is not experienced in the same ways by all those involved, and giving us a unique insight into the multiple experiences of dementia. The dramatic irony present here is something I found to be particularly pertinent in dementia fiction. If dementia entails a loss of memory, or an ability to express oneself, fiction provides a way of re-presenting those apparently 'lost' voices and thoughts. In this way, dementia fiction allows readers to understand the continued personhood of the character with dementia, even when it may not be visible to others.

We see a reversal of this in Elaine Feeney's story, 'What, You Egg', which is told from the perspective of a daughter who cares for her mother with advanced dementia. The daughter recounts her mother's early life spent by the Atlantic ocean in Donegal but, unusually, does so using the second person, 'you': 'You love water ... you've always wanted to jump in the sea.' This narrative technique creates an intimate dialogue between daughter and mother. But it also gives us a detailed account of the early life of the woman with dementia, at a time when she might not be able to verbalise it. In this way, narrative fiction can give voice to the voiceless. These fragments of her mother's past are interspersed with present-day interactions. In one, the daughter waits for her mother to come out of the shower, asking 'Are you swimming?', to which she responds, 'I am'. After the shower, her mother glows: 'I can't wait to tell her [Mrs Faye] I've been swimming in the mad ocean and that I was so happy.' This creates another kind of dramatic irony, where we readers know that the character with dementia is disorientated and understand that the daughter is facilitating her fantasy. Yet, through the mother's speech, we can see the joy the fantasy has brought her and understand the emotional benefits of the untruth. These examples show how fiction can narrate internal and external voices, leading readers to understand different perspectives and gain a multi-dimensional picture of how dementia can affect people.

As well as combining voices and perspectives in ways that other kinds of language cannot, fiction can also play with reality. The stories by Jan Carson and Caleb Klaces create alternative worlds to explore dementia, bending reality as we know it. While my research focused on fiction that represents dementia in a realistic way, these contributions offer something different. Klaces explores a world-within-a-world-within-a-world: a young man revisits his father's home, finds a story he wrote on an old computer, and tells that story, which is about using a Portal to enter the mind and body of an older man called Brian. 'The Portal' is an experiment in what constitutes memory, reality and personhood, all of which dementia challenge. In 'Our Dear Ladies Have Outnumbered Us', Jan Carson's absurd reality is narrated by an unnamed collective, 'we', who run a care home for a bevy of characterful ladies. After the arrival of the enigmatic Angelica, who seems to lead the ladies astray, the power balance is disrupted and strange things start to happen. The alternative reality gives

Jan a space to explore important issues in dementia care, such as power and agency, in an indirect and playful way.

It has been fascinating for me to observe how the contributions to this anthology correspond with my research on how dementia is represented in the minds of fictional characters. But the new stories collected here do a lot more than simply confirm my research findings. They add to the canon of dementia fiction by including a wider range of voices and perspectives than those previously published, giving a broader view of the experience. I hope to have shed some light on how creative language is uniquely placed to help readers understand dementia in ways that might facilitate awareness, understanding and care. Creative writing must be recognised as a form of cultural expression that allows key issues of our time, like dementia, to be interrogated and illuminated, with real-life consequence and value.