

Kruger, Naomi, "‘We are all unreliable narrators’: Solidarity, Memory and Identity in Contemporary Dementia Narratives" in *Solidarity, Memory and Identity*, eds., Wojciech Owczarski and Maria Cremasco (Newcastle: Cambridge Scholars, 2015) pp. 322-332.

“WE ARE ALL UNRELIABLE NARRATORS”: SOLIDARITY, MEMORY AND IDENTITY IN CONTEMPORARY DEMENTIA NARRATIVES

NAOMI KRUGER

If we are, as has been claimed “the sum of our memories”, it is no wonder that the idea of dementia inspires such fear.¹ As Raymond Tallis asserts, the prospect of dementia is the loss of certainty and of agency. It is the pruning of memories and the warping of identity as “the rich connectedness of the ‘I’ is pulled apart.” It is a diminishing future as well as a shrinking past, being confined to “an eternal present” where we try “to make sense of a world that has become... a permanent and often terrifying question mark.”² If we are afraid of dementia, the loss of memory, perception and selfhood, it is not surprising that this fear is readily transferred to the people who already live with the disease, who constantly remind us of its threat. As Susan Sontag argues, “...pity, far from being the natural twin of fear... seems diluted—distracted-by fear, while fear (dread, terror) usually manages to swamp pity.”³ This fear is further intensified by a largely reductive media focus that concentrates on all the “most debilitating, demeaning and despairing features.”⁴ These biomedical representations, casting people with dementia as zombies or “the living dead”, contribute to levels of disgust and terror that can have a direct impact on the kind of care a person receives:

Attempts to communicate with the patient stop, life-prolonging treatment is withheld, and force is used to control undesirable behaviours.⁵

Seen in this light, fictional representations of dementia are ethically complex. As a writer working on a novel partly narrated by a character with Alzheimer’s, I am interested in the problems and possibilities of such narratives. By looking at three recent novels that attempt to represent the experience of dementia, as well as considering my own writing process, I intend to question whether fiction can strengthen this fear or destabilize it. Do contemporary texts inevitably position readers as fearful voyeurs and amateur neurosurgeons, or can they challenge the reductive focus on what is lost through dementia and alert us to what may remain? Do these narratives simply reinforce othering and distance or can they create space for empathy, connection and solidarity?

In writing *Still Alice*, a novel about early-onset Alzheimer’s, Lisa Genova claims that she wants to “sit the reader right up against Alzheimer’s”, so that they can “feel [Alice’s] confusions and frustrations and terror right with her.”⁶ What does it mean to sit right up against Alzheimer’s? Tellingly, the disease seems to be cast as the dominant character here. Although the author’s aim is a kind of solidarity and understanding, providing a space for readers to feel what Alice feels, it is the disease that consumes, rather than the consciousness being consumed, that emerges as the most compelling force in the novel. In one scene, Alice is struggling to remember a story as part of a medical assessment:

She swallowed her panic, and it lodged, heavy and hulking, right above her diaphragm, making it uncomfortable to breathe. Either her pathways to the details of the story were impassable or she lacked the electrochemical strength to knock loudly enough on the neurons housing them to be heard.⁷

The title character of the novel is a Harvard professor of psychology, so it is arguable that the biomedical discourse in this passage is not wholly out of place, but it still seems that readers are invited to peer inside Alice’s brain, to consider her diagnosis rather than to sit next to her in the waiting room. The novel is narrated mostly in focalised

¹ Shenk: 16.

² Tallis: 21.

³ Sontag: 67.

⁴ Jolley: 117.

⁵ Behuniak:74.

⁶ Genova: 298.

⁷ Genova: 129.

third person and while it is highly affective at documenting the progression of the disease, there is also, I would suggest, a strong sense of distance between reader and character. Throughout the story readers seem to be positioned as medical professionals observing Alice as an illustrative specimen:

Her ability to use language, that thing that most separates humans from animals, was leaving her, and she was feeling less and less human as it departed.⁸

The reason this troubles me is that it is already too easy to see people living with dementia as kind of other, a collection of symptoms or simply bodies to be managed. Susan Sontag claims that “the other, even when not an enemy, is regarded only as someone to be seen, not someone (like us) who also sees.”⁹ With a focus on biomedical accuracy at the forefront, whatever the author’s intentions, it is difficult for the character with altered perception, memory and consciousness to become anything more than a medicalised figure – one that as readers we can define ourselves against; a comforting confirmation of difference.

Unlike *Still Alice* – where the linear unfolding and explanatory prose means readers can never be in any doubt of what is happening, Samantha Harvey’s 2009 novel *The Wilderness* is structurally inventive and shot through with lacunae. The novel is centred on Jacob, an architect with Alzheimer’s. Indeed a critic has claimed that although it is narrated in third person, the scope of the book is kept firmly “within the ever-narrowing parameters of Jacob’s mind”.¹⁰ Important questions are left unanswered, gaps and silences proliferate. More ordered chapters alternate with Jacob’s increasingly confused present experience, his struggle with language and perception and the intrusion of and longing for memory. In this extract, the protagonist is trying to grasp onto a memory of his son:

Now he casts his thoughts out for Henry and all he gets is the usual clamour of data. Henry after Helen’s death, running across the field behind the Coach House with a carving knife, following the wing lights of a plane.... Some might say this is not a happy memory, but he would object that it is not the happiness of the memory he is looking for, it is the memory itself; the taste and touch of it, the proof it brings of himself.¹¹

In many ways the structure of the book is performative – echoing the confusion and lack of certainty that the main character feels. The text is full of repetitions, returns and reversals, and as the novel progresses, the boundaries between real and imagined, accurate and distorted become more and more permeable. Indeed, it has been argued that Harvey “substitutes lyrical description for narrative certainty, a kind of lace-making around the holes in the weave.”¹² While I find the structural experimentation thought provoking, there is also something unnerving about Harvey’s beautifully crafted literary descriptions. Jacob’s experience often becomes a kind of distant object that the narrator seems to be singling out for our attention:

What frightens him is this – the way objects rush and trip over themselves to support his confusion. He looks around his car and tries to remember what make it is; he cannot. He opens the window to feel what month it is. It isn’t a month. There aren’t months. There are just happenings, a lack of signposts.¹³

Her writing has been described as ‘extremely controlled prose... peppered with vivid images that are recalled with haiku-like clarity’.¹⁴ One of the distinguishing features of dementia is the gradual loss of language and the ability to express oneself. Even when describing Jacob’s struggle to hold onto words, the narrator does so in a way that demonstrates a consistent capacity for linguistic control:

All the while he repeats: discard, devolution, demolish, dish, decrepit, drone, dynasty.... It sets his brain into a loop, and... he finds that forgetfulness, having wilder gardens to explore, does not bother with him.... There is a satisfactory quality about gathering the words into his mind, filling him like stones filling his pockets.¹⁵

In this sense, as Jacob’s memory deteriorates the disparity between his verbal struggles and the narrator’s linguistic virtuosity becomes more and more apparent. At one point the narrator tells readers that Jacob “feels to be the supremely unconfident narrator of his own life”, but the voice that articulates this is one of continual precision

⁸ Genova: 270.

⁹ Sontag: 65.

¹⁰ Halpern.

¹¹ Harvey: 1-2.

¹² Davies.

¹³ Harvey: 26.

¹⁴ Webber.

¹⁵ Harvey: 98.

and mastery.¹⁶ In *The Wilderness* events are complicated and as readers we are encouraged to question memories and truth, but I would argue that we are still far from connection and empathy.

If third person narratives seem to foreground problems of identity and representation, then perhaps the solution is to attempt to represent dementia from the inside. But this approach is fraught with just as many complications. Is it ever possible to narrate from within a disintegrating consciousness without descending into textual chaos? How do you represent the loss of language when language is your only tool?

Turn of Mind by Alice La Plante is a recent, prize-winning novel that attempts to answer the first of these questions. It is narrated by Dr Jennifer White, a retired surgeon with Alzheimer's disease. She is also the prime suspect in a murder case, an unreliable witness to a crime and an even more unreliable narrator. In an interview about the difficulty of narrating the experience of dementia, LaPlante points out that she deliberately chose a mystery as something for everything else to "hang off" arguing that a literary book about dementia could be off-putting and alienating for readers.¹⁷ It is arguable that there is a constant tension throughout the text between a mystery that must be solved and the attempt to immerse readers in the chaos of Jennifer's experience.

The book is structured in short bursts or episodes, fragmented moments of consciousness with varying levels of clarity, verbal exchanges between Jennifer and her children, her carer and various doctors and lawyers, police officers, letters, articles and excerpts from Jennifer's notebook – a device she acknowledges as "a way of communicating with myself.... My bible of consciousness."¹⁸ The story begins, rather appropriately with indeterminacy:

Something has happened. You can always tell. You come to and find wreckage: a smashed lamp, a devastated human face that shivers on the verge of being recognizable. Occasionally someone in uniform: a paramedic, a nurse. A hand extended with a pill. Or poised to insert a needle.¹⁹

As readers we are plunged straight into the narrative, to a moment of sudden awareness. Something has happened, but what? We are told of, as well as momentarily feeling the lack of ability to grasp onto specific details, to anchor ourselves in a context. The second person "You" complicates things further. The statement "You can tell" is both specific and general, implicating both narrator and reader and distancing the narrator strangely from herself and the present unfolding moment. The passage as a whole is a strange mix of immediate, arguably performative linguistic confusion and carefully controlled literary description. I would argue that this is a struggle maintained throughout the novel, between competing forces within Jennifer's narration. On one hand the centripetal moments of linguistic vagueness, drawing readers into the moment, implicating them in confusion and struggle and the other, more distanced and coherent descriptions, a kind of centrifugal force drawing us out of her experience and enabling the narrator as well as readers to evaluate and construct our own wider version of events.

While it is quite possible for Jennifer to remain, to some extent, articulate while struggling to hold onto memories, her status as narrator and protagonist often seems to open up strange ontological gaps demonstrated in the contrast between her actions and her telling of them. This is evident in a scene where Jennifer gets distressed by a discussion topic at an Alzheimer's support group:

Hatred. Hate. The word resonates. My stomach contracts, and bile rises in my throat. *I hate.* I find my hands clenched into fists. Faces turn to look at me....

It is becoming hard to breathe. What is that noise. Is it me. Who are you staring at. [sic]²⁰

The narrator is at first very articulate about her physical reaction to a word that seems to trigger some unbidden trauma. Her stomach contracts, bile rises, but in the next sentence she *finds* her own hands clenched as if her body is momentarily lost, as though her physicality and her consciousness have separated. This slippage highlights the ambiguous nature of identity, perception and sensory experience, but also the problems of first person narration. In the first part of the extract the narrator emphasizes the resonance of the word hate with italics, but a few sentences later has abandoned question marks, as though her voice has moved beyond the reach of proper punctuation. There seems to be a constant pull between linguistic fragmentation and experiment to represent the shifting nature of Jennifer's experience, and the need to hold the narrative together, to keep it polished and coherent. This struggle becomes more intense as the novel progresses. Jennifer continues to describe her mental and physical deterioration in consistently articulate ways. In this extract she is being questioned by a police officer:

¹⁶ Harvey: 200.

¹⁷ Flood.

¹⁸ LaPlante: 5.

¹⁹ LaPlante: 3.

²⁰ LaPlante: 27.

Dr. White. Jennifer. Do you know where you are?

I do, but it is in pictures. No words. I am on a porch, sitting on the top step. A brisk morning in late October. The trees are golden. There is a line of pumpkins on the porch gazing at the world with horrified expressions.²¹

By drawing our attention to her lack of language, the narrator also highlights the limits of the narrative she is part of. There are no words, but she has nothing to give us *but* words. Indeed, the words we are given come from a persistently articulate and reflexive inner consciousness, as though dementia has affected only her ability to communicate and perceive but somehow left her ability to think logically and inwardly about it intact. In this sense she seems to be both extra and intradiegetic narrator, and when at the end of the novel there is a shift to third person it does not come as a shock, it seems rather to confirm that someone else has been narrating and arranging things from elsewhere all along.

Despite the risks and difficulties I am still invested in the idea that texts can be performative and if reading is, as Wolfgang Iser claims, an act of performance where “we are both ourselves and someone else”, then it is possible as readers, however briefly, to feel our sense of time and place shifting and our linguistic confidence begin to crumble.²² Reading these and other narratives has informed my own writing. When I initially decided to write about dementia I conceived the project as a sequence of short stories, some narrated by May – a housewife, mother and grandmother in the mid-stages of Alzheimer’s, alongside other voices and connected characters. Perhaps part of this decision was an attempt to write against the professional/privileged gaze of the doctor, and to question the idea that the only people with dementia worth writing about are those with exceptional brains. It was also to do with the idea, as Helen Small suggests, that “our lives are misunderstood if we conceive of them as separate units, or isolated stories disconnected from the lives of others.”²³

Early in the writing process it began to feel false to craft her narrations into polished, autonomous stories. I began to experiment, to allow the language to be messy, to let go of many of the personal pronouns, to try to plunge readers into an immediate approximation of her consciousness:

Not a hospital, not a holiday, not a hotel, not a school, not *home*. This is nowhere. These people aren’t my people. Not my husband, not my gravy, not my – haven’t paid for this food, can’t find my purse can’t find my –

if I eat it they’ll charge me and there isn’t any and there simply isn’t any way.

These people are not my people.²⁴

I also experimented with the aesthetic layout of the text on the page. At one stage of development May’s narratives became right-justified, full of large gaps, unexpected line breaks, spilling out chaotically across the page while the other voices in the book retained their story titles and conventional formatting. My supervisor commented that while I was passionate about trying to reduce the distance between May and readers, to complicate the inevitable othering – the relationship of the voyeur and the tragic figure slowly descending into darkness – what I had actually done was create a kind of visual and textual annexe for May. One of the most difficult things in writing the novel has been balancing this desire to question the way we position ourselves in terms of dementia with the desire to make the text in some way performative. There is a constant pull, perhaps appropriately, between chaos and harmony, connection and disconnection.

David Shenk suggests the possibility that greater knowledge of dementia can help us “revise our very sense of ourselves” and “acknowledge a new-found vulnerability.”²⁵ What role, if any, do fictional representations of dementia have in this? Joe Moran argues that the “problem in all dementia narratives is that the illness can never be narrated adequately – part of it will always slip through the discursive sphere into raw experience...”²⁶ If the aim of a fictional representation of dementia is to plunge readers into an imagined consciousness and allow them to experience dementia for themselves then it is doomed to failure. Any attempt to echo this in structural or linguistic fragmentation will also inevitably foreground readers’ ability to use complex memory processes to partially overcome these difficulties – make predictions and fill in gaps. Complete immersion is never possible. What is valuable, however, is that these narratives have the potential to make readers more aware of the way they

²¹ LaPlante: 216.

²² Iser: 244.

²³ Small: 116.

²⁴ Kruger.

²⁵ Shenk: xii.

²⁶ Moran: 258.

regard people with dementia, aware of their own fears and assumptions. Any text that destabilizes the position of self/other, even temporarily, has the power to dilute fear and open up space for empathy and connection.

I am not seeking to trivialise the experience of dementia by pointing out that we all have moments of confusion, that we all know what it feels like to have a word on the tip of our tongue just out of reach, that we all have questionable memories. By positioning May among other voices, other characters who struggle with these things, by allowing her to speak for herself rather than presenting her as a medical specimen, I am trying to look differently at dementia, to re-position myself, and readers, to challenge the inevitable construct of “us and them” and move towards a kind of solidarity between reader and character.

As David Clegg (an artist who spent hours recording and collating the stories of dementia patients) asserts, “we are all unreliable narrators; we all consciously and unconsciously change our stories all the time and we all lie.”²⁷ We are not so very different as we like to think.

Bibliography

- Behuniak, S. M. (2011) The Living dead? The construction of people with Alzheimer’s disease as Zombies. *Ageing & Society* 31, 74.
- Clegg, D. (2010) *Tell Mrs Mill her husband is still Dead: More stories from the Trebus Project* (Trebis Publishing).
- Davies, S. (2009) *The Wilderness*, By Samantha Harvey [online] *The Independent*. Available from:
<http://www.independent.co.uk/arts-entertainment/books/reviews/the-wilderness-by-samantha-harvey-1632983.html> [Accessed 10 September 2012].
- Flood, A. (2011) *Alzheimer’s is a hard thing to frame* [online] *The Guardian*. Available from:
<http://www.guardian.co.uk/books/2011/nov/22/alice-laplante-alzheimers-turn-of-mind> [Accessed 10 September 2012].
- Genova, L. (2010) *Still Alice* (London: Pocket Books).
- Halpern, S. (2009) *Permanent Ellipses* [online] *New York Times*. Available from:
http://www.nytimes.com/2009/02/15/books/review/Halpern-t.html?_r=1 [Accessed 10 September 2012].
- Harvey, S. (2009) *The Wilderness* (London: Jonathon Cape).
- Iser, W. (1989) *Prospecting: From Reader Response to Literary Anthropology* (Baltimore: John Hopkins University Press).
- Jolley, D. J. and Benbow, S. M. (2000) Stigma and Alzheimer’s disease: causes, consequences and a constructive approach. *International Journal of Clinical Practice*, 54, 117.
- Kruger, N. (2013) extract from *May* (novel-in-progress). Department of English & Creative Writing. Lancaster: Lancaster University. PhD Thesis.
- LaPlante, A. (2011) *Turn of Mind* (London: Harvill Secker).
- Moran, J. (2001) Aging and identity in dementia narratives. *Cultural Values* 5, 258.
- Shenk, D. (2001) *The Forgetting* (London: Flamingo).
- Small, H (2007) *The Long Life* (Oxford: OUP).
- Sontag, S. (2004) *Regarding the Pain of Others* (London: Penguin).
- Tallis, R. (2012) An imitation of life is better than no life at all. *The Times*, 3 April, p. 21.
- Webber, T. (2009) *Memories, memories* [online] *The Observer*. Available from:
<http://www.guardian.co.uk/books/2009/apr/05/wilderness-samantha-harvey> [Accessed 10 September 2012].

²⁷ Clegg: 12.

