ENTERTEXT

Storying Alzheimer’s Disease in Lisa Genova’s *Still Alice*
Author: Sarah Falcus
Source: *EnterText*, “Special Issue on Ageing and Fiction,” 12 (2014): 73-94.

Abstract

Taking as its starting point the value of literary studies to work on ageing, this paper explores the contribution of literature to the discourse of ageing and illness, focussing on an illness synonymous with ageing in the cultural imagination: Alzheimer’s disease. This is a condition that poses a challenge not only to narrative and meaning-making, but also to the idea of coherent selfhood. The focus of this paper is the popular novel *Still Alice,* a text praised for its depiction of Alzheimer’s from the perspective of the sufferer. This novel explores the complexity and contradictions of Alzheimer’s disease, ageing and selfhood. It does not always escape the dominant representation of Alzheimer’s as a loss of self that is associated with ageing as decline, but it also contains elements which critique the way Alzheimer’s functions as a metonym for ageing and offers a vision of selfhood that might be called postmodern in its emphasis upon relationality and the fragmented affirmation of self and being. This makes clear that despite the risks – ethical and artistic – in writing dementia and aestheticizing Alzheimer’s, popular fiction has an important part to play in the discourse of dementia.

Basting argues that the cultural construction of dementia (including Alzheimer's disease) is crucial to the way it is experienced, both by patients and those providing care and support.[8] Jane M. Scholl and Steven R. Sabat's psychological review of the literature on stereotyping bears this out and leads them to suggest that those with Alzheimer's disease are "extremely vulnerable to the debilitating effects of negative self-stereotyping and stereotype threat."[9] This makes the examination of representations of Alzheimer's disease crucial: "Understanding how Alzheimer's is perceived and represented can help interrupt and change the experience of the disease for those who suffer, those who anticipate suffering, and those who care for its victims."[10] Understanding that Alzheimer's disease, though a disease with very real and often terrible effects on the material body, is also experienced in relation to its cultural construction and its intimate connection with the representation of ageing as decline, makes clear the urgency of interrogating the narratives that make up this discourse, and this includes literary texts.

Nevertheless, many recognise that Alzheimer's disease poses a particular problem for narrative and for representation. How is it best to represent and explore Alzheimer's disease when it challenges

These challenges become even more pressing when attempts are made to represent the voice of the Alzheimer's sufferer, something that has exercised critics in gerontology for some time. Considering narrative from this gerontological perspective, Mark Freeman argues there may be circumstances where, because of physical or mental illness, the limits of narrative are reached:

> Indeed, in some circumstances, there really *is* no lifestory "to speak of" – not least for the person whose story it was, for there may remain only the most minimal sense of what that life was about. There is not much room for hope here. And we are up against the limits not only of reopening a foreclosed narrative but also of narrative itself.[13]

Addressing the case of his own mother's dementia, Freeman argues that in one sense there is no possibility of "opening up her story," though he does suggest that some sense of narrative progress can be maintained by those around his mother in order that they can support "some measure of meaning and value … in her experience."[14] Perhaps it is this challenge to narrative coherence that means that Gillian McColgan et al could state in 2000 that "People with dementia have been a silent presence. If we hear their voice it is predominantly through others."[15] It is important, however, to interrogate the notion of the selfhood that is being asserted in relation to narrative. Sally Chivers, drawing on the work of Anne Davis Basting, argues that the tendency to view dementia as a loss of stories can be restrictive in its reliance on a selfhood premised upon individualism and coherence.[16] Basting's work is at pains to stress that the experience of the Alzheimer's disease sufferer, rather than simply being cast as a loss of self, may actually cause us to question our understandings of selfhood:

> Understanding the depiction of the self in the crisis of Alzheimer's can also teach us the meaning and value of the ‘‘whole’’ self. Exactly how does one achieve a ‘‘self?’’ Who are we without memory? Is a ‘‘self’’ possible when the ability to construct narrative through memory is broken?[17]

to explore the possibility that selfhood and therefore a form of agency can be maintained in Alzheimer's.

It is in the context of these debates about narrative, selfhood and Alzheimer's disease that this paper examines Lisa Genova's *Still Alice* as one literary response to the challenges the illness poses to narrative and to representation.[22] First published (by a mainstream publisher) in 2007, this novel tells the story of the fifty-year-old Alice and the first two years of her experience of early-onset Alzheimer's disease. What is significant is that in this novel the point of view of a woman with Alzheimer's disease is prioritised, rather than the perspective of her carers, though

her mind’s eye. Her golden brown eyes appeared tired even though she was fully rested, and the texture of her skin appeared duller, looser. She was clearly older than forty, but she wouldn’t say she looked old.”[40] This dualism that we see in many narratives of ageing continues throughout the novel, but is also complicated by the Alzheimer’s disease, since once Alice knows that she has Alzheimer’s disease it is her body that she sees as healthy and strong and her mind as aged and diseased. Nevertheless, by the final chapter, Alice is completely distanced from her physical appearance:

> The girl in the mirror had sunken, darkened circles under her eyes. Her skin looked loose and spotty all over and wrinkled at the corner of her eyes and along her forehead. Her thick, scraggly eyebrows needed to be tweezed. Her curly hair was mostly black, but it was also noticeably gray. The girl in the mirror looked ugly and old.
> She ran her fingers over her cheeks and forehead, feeling her face on her fingers and her fingers on her face. *That can’t be me. What’s wrong with my face?*”[41]

This sc3(b)-3(rowy-3( )-152(h))9(h)-3(d)-3(,)-229(a)-3(s)-81>BDC BT BTpo150.2624 372.55 8v;>

over human beings and relationships. The traditional notion of the myopic and ambitious scientist is here reworked to interrogate the excessive medicalization of Alzheimer's disease and the way that illness is culturally ranked and assessed. As Alice remarks in a seemingly proleptic comment when John is looking for his glasses near the beginning of the novel: "How could he, someone so smart, a scientist, not see what was right in front of him?"[52] This question resonates throughout the novel, a reminder of the marginality and invisibility imposed by the disease.

It is important to note that the novel does not suggest that science has failed Alice. It may indeed not yet have provided a cure, but it has accurately diagnosed her condition (thanks to John's insistence on further tests) and genetic screening has saved her grandchildren from the disease. And Alice acknowledges that, though the drugs she is taking do not seem to have improved her condition, they may indeed be responsible for slowing down the progress of the disease. However, the novel tends not to concentrate upon the treatment of Alzheimer's disease, but upon Alice's experience as a medicalised Alzheimer's disease patient. In this way, the novel demonstrates clearly the effects of medical approaches to Alzheimer's disease on the selfhood of the sufferer. Science makes Alice feel disempowered and lost. She feels shattered by the "professionally uttered opinion" and is aware of the way she is being constructed as 'patient': "If she confessed to John what Dr. Davis had told her, if she gave him the Activities of Daily Living questionnaire, it would all become real. John would become the informant, and Alice would become the dying, incompetent patient. She wasn't ready to turn herself in. Not yet."[53] This questionnaire limits the narrative of Alice's life with Alzheimer's disease to a succession of basic tasks, something the narrative of the novel makes clear is a reductive way to represent her experiences. The nature of Alzheimer's disease makes this patient status even more of a threat to self-determination because the patient is not only subject to the power of scientific discourse, but is also constructed as an unreliable source of information about herself and her life, as the questionnaire, where her husband has to detail her symptoms, makes clear.

The failure of medicine not to cure Alice but to support and care for her fully is made clear when she attempts to form a patient support group at her clinic. She is told that resources are there only for carers and not for a patient group. Though she is later given the names of others, like her, with early-onset Alzheimer's disease, the clinic's reductive approach to her support is clear. Of course, there is another, more ambiguous aspect to this. The reason Alice is given for the lack of a patient support group is that most patients wouldn't be capable of interacting in such a setting, a reminder again of the fact that Alice is unusual in her relative youth and agency as an Alzheimer's disease sufferer.

The penultimate chapter of the novel makes clear this ambiguous approach to the scientific framework and the way it positions the Alzheimer's disease patient and determines the discourse of Alzheimer's as disease. This chapter seems both to prioritise the scientific narrative and yet detail its failure. Significantly, it turns from Alice's point of view to that of her husband, John. This short chapter details his reading of a new report that records the failure of the

> Alice watched and listened and focused beyond the words the actress spoke. She saw her eyes become desperate, searching, pleading for truth. She saw them land softly and gratefully on it. Her voice felt at first tentative and scared. Slowly, and without getting louder, it grew more confident and then joyful, playing sometimes like a song. Her eyebrows and shoulders and hands softened and opened, asking for acceptance and offering forgiveness. Her voice and body created an energy that fille

novels such as *Still Alice* nevertheless have much to contribute to debate about illness, ageing and disease.

Endnotes

[1] Sara Munson Deats and Lagretta Tallent Lenker, eds., *Aging and Identity: A Humanities Perspective* (Westport, Connecticut: Praeger, 1999); Kathleen Woodward, ed., *Figuring Age: Women, Bodies, Generations* (Bloomington and Indianapolis: Indiana University Press, 1999); Anne M. Wyatt-Brown and Janice Rossen, eds. *Aging and Gender in Literature*. (Charlottesville: University Press of Virginia, 1993); Margaret Morganroth Gullette, *Aged by Culture*, (Chicago, University of Chicago Press, 2004).

2. Sally Chivers, *From Old Woman to Older Women: Contemporary Culture and Women's Narratives* (Columbus: Ohio State University Press, 2003), xxxvii

[3] Ibid.

[4]

---

http://www.boston.com/news/local/articles/2008/03/16/despite_monster_she_is_still_alice/?page=full; Carla Lucchetta, "The Memory Thief," *The Globe and Mail*, January 20, 2009, http://www.theglobeandmail.com/news/arts/books/article972362.ece. Anecdotal evidence of the approval of the novel can be found in the reader comments printed in the first British edition of 2009 and also in many online reader reviews and blogs related to Alzheimer's disease e.g. Anne Corbett, "Book Review: *Still Alice,*": http://alzheimers.org.uk/site/scripts/documents_info.php?documentID=674&categoryID=200351&pageNumber=14. The involvement of the (American) Alzheimer's Association in the novel is also significant. *Still Alice* is still one of few creative texts in the Alzheimer's Association's list of Recommended Reading: http://www.alz.org/co/in_my_community_15677.asp.

[24] Basting, *Forget Memory, 33.*

[25] Samantha Harvey, *The Wilderness* (London: Vintage, 2010).

[26] Genova, 191.

[27] Ibid., 193.

[28] Basting, "'God Is a Talking Horse': Dementia and the Performance of Self," 80.

[29] McColgan, Valentine and Downs, 107.

[30] Genova, 74.

[31] Ibid., 28.

[32] Ibid., 270.

[33] Cruikshank, 38.

[34] Genova, 70.

[35] Ibid., 25.

[36] Ibid., 73.

[37] Ibid., 110-6.

[38] Ibid., 5.

[39] Mike Featherstone and Mike Hepworth, "The Mask of Ageing and the Postmodern Life Course," in *The Body: Social Process and Cultural Theory*, eds. Mike Featherstone, Mike Hepworth and Bryan S. Turner (London: Sage, 1991), 377-83.

[40] Genova, 35.

[41] Genova, 283.

[42] Kathleen Woodward, *Aging and Its Discontents: Freud and Other Fictions* (Bloomington and Indianapolis: Indiana University Press, 1991) 68.

[43]