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# ENTERTEXT

Storying Alzheimer's Disease in Lisa Genova's *Still Alice*

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## **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.

## Storying Alzheimer's Disease in Lisa Genova's *Still Alice*

Sarah Falcus

The value of the Humanities to gerontology has been recognised for some time now, with much work in the last twenty years, in particular, on inter-disciplinary and multi-disciplinary approaches to ageing. The work of critics such as Sara Munson Deats and Lagretta Tallent Lenker, Kathleen Woodward, Anne M. Wyatt-Brown and Janice Rossen, and Margaret Morganroth Gullette has carved out a valuable place for the Humanities in ageing.<sup>1</sup> This contribution is acknowledged by Sally Chivers:

Humanities scholars who have turned to age studies, rather than merely mining cultural products for evidence of attitudes toward the elderly, have exposed theories of – “modes of conceptualizing” – old age, opening the door for new models. They acknowledge and encourage the social construction of age and work toward understanding the processes behind it.<sup>2</sup>

Significant amongst this work is the attention paid to literary narratives of ageing. Chivers argues that this field – often called literary gerontology – “can balance social and cultural narratives of aging with the physical dimensions of aging to develop rich models for new understandings of late life.”<sup>3</sup> And, as part of this, there is significant interest in the relationship between ageing, illness and disability. Chivers's own work on fiction and film is a case in point. This paper seeks to extend this work by examining the literary depiction of a disease that is very much associated with ageing in the cultural imagination: Alzheimer's disease. I will argue that literary narratives allow for the exploration of the contradictions of the relationship between ageing and disease. Not always unproblematic or progressive in their depictions, novels of Alzheimer's disease can nevertheless encompass these contradictions in a way that non-fictional narratives may not. They therefore have much to offer the discourse of Alzheimer's disease, and, by extension, that of illness in later life.

Rob Dillman argues that “The demarcation of AD is intimately connected with the question of whether it is different from aging.”<sup>4</sup> Though it is the case that Alzheimer's disease does proportionally affect more people over 60 than below 60, Dillmann makes clear the difficulties of linking Alzheimer's disease so ineradicably with age. He argues that age is something we use to discern difference and not therefore a cause of changes that occur. However, it is clear that in our cultural imagination Alzheimer's disease is inexorably associated with age. As critics such as Anne Davis Basting, Margaret Cruikshank and Sally Chivers recognise, cultural representations of Alzheimer's disease, and dementia more widely, yoke together ageing and Alzheimer's disease to produce images that inspire fear and horror of both the disease and the ageing process.<sup>5</sup> As Chivers argues:

In mass media, literature, and film, Alzheimer's disease offers a cunning demotic for late life because it magnifies what people fear most about how age could manifest itself.... Alzheimer's thereby becomes a quick way to symbolise not just other forms of dementia but also old age more generally.<sup>6</sup>

This stereotyping and reliance upon Alzheimer's disease as a metonym for the general decline narrative of old age is, according to Anne Davis Basting, under-researched:

Little research has been done that specifically explores the stigma of and bias against people with dementia. There isn't even a good word to describe the expression of bias against someone with dementia, other than the general term “ageism,” the demonstration of bias against older adults. The general categories of “healthism” and “ableism” get some play among people who study disabilities. There are the awkward terms “athazagoraphobia” (fear of forgetting) and “dementophobia” (fear of insanity), but “athazism” and “dementism” don't exactly roll off the tongue.<sup>7</sup>

This lack of research into the way Alzheimer's is stigmatised in its association with a negative understanding of old age is particularly problematic when its effect on both Alzheimer's disease sufferers and their carers is acknowledged. Like many critics,

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.<sup>8</sup> 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."<sup>9</sup> 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."<sup>10</sup> 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 the process of meaning-making on which narrative depends? One way in which texts that tell Alzheimer stories deal with the challenges the condition poses to narrative is to offer the caregiver's perspective, something found in fictional works such as Alice Munro's "The Bear Came Over the Mountain" and Jane Rule's *Memory Board*, and in biographical work on Alzheimer's, such as John Bayley's *Iris* or Andrea Gillies's *Keeper*.<sup>11</sup> However, even these texts must deal with the difficulties that the disease poses. As John Wiltshire argues in relation to biographies of illness and disease, which he calls pathographies:

The need to create meaning, prevalent in the pathography in any case, becomes pressing when the patient, the very subject of the narrative, while apparently physically well enough, incarnates the disruption or bafflement of normal meaning-making activity, and seems in fact to be a different 'self' or to have lost the self that they were. The challenge of all illness experience may then perhaps be said to confront the pathographer of Alzheimer's with particular intensity.<sup>12</sup>

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.<sup>13</sup>

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."<sup>14</sup> 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."<sup>15</sup> 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.<sup>16</sup> 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?<sup>17</sup>

This more questioning approach can be seen in a therapeutic context (as Freeman's work with his mother demonstrates), where much work has been done which suggests that a form of narrative can be maintained in those with dementia, where narrative becomes not about loss of self, but about the exercise of a form of agency:

Indeed, narrative gerontology helps to undo the "warehousing" of persons with dementia by seeing them as still biographically active, as still having narrative agency, even if they can no longer tell their stories in ordinary language or in words at all.<sup>18</sup>

As these debates suggest, the notion of narrative (often in relation to autobiography) is central to much work on the cultural representation of Alzheimer's disease. But it is not straightforward and a more postmodern understanding of the narrative self may actually lead to less reliance on a coherent and unified model and therefore a space where the Alzheimer's 'self' can be articulated. As Roberta Maierhofer argues:

In these terms, Alzheimer's disease patients can be seen as extreme paradigms of this postmodern condition, where memories and the past only exist in a [sic] unstructured, fluid condition. Like the decentered subject that is in Lacan's term of the mirror stage defined as constituted in and by its language, Alzheimer's disease patients use language without any referential meaning in order to establish relationships and connect to others.<sup>19</sup>

Whilst not seeking to minimise the effects of the disease on Alzheimer's disease patients, this view of the disease does offer a less restrictive way of approaching the self and narrative in Alzheimer's disease. Basting, like Maierhofer, sees value in the articulation of selfhood in postmodern terms – drawing here on the work of Baudrillard, Gergen and de Certeau – but she warns against the dangers of using illnesses such as Alzheimer's disease as a way of representing postmodern selfhood.<sup>20</sup> Basting therefore prefers the notion of the relational self as a way to conceptualise a self with Alzheimer's disease, a self "that is formed through interaction with others."<sup>21</sup> Wary of the dangers of reducing Alzheimer's disease to a form of the postmodern condition, Basting's notion of the relational self offers a way

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.<sup>22</sup> 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 the narrative remains in the third person and is not entirely given over to Alice's perspective. This is one way to address the tension between the self of Alzheimer's disease and the demands of narrative, allowing the novel's structure to remain coherent whilst nevertheless tracking and offering access to Alice's confusion. Also important to this reading of *Still Alice* is that it is a popular novel (though initially self-published, it entered the *New York Times* Bestseller list at number five and has won a host of awards) whose depiction of Alzheimer's disease has generally been received positively by both critics and those with personal and professional experience in the field of dementia.<sup>23</sup> *Still Alice* therefore walks a line between the coherence and chronology demanded of the form of the popular novel and the exploration of the effects of Alzheimer's disease, which disrupts coherence, organisation and aspects of meaning-making. This is in many ways a fairly conventional narrative, rather than a more avant garde or experimental text, and yet, I argue, it manages to offer significant imaginative access to Alzheimer's disease and insist upon the maintenance of a form of selfhood and (albeit limited) agency for its protagonist.

This is not, however, to argue that *Still Alice* is a revolutionary story of Alzheimer's disease, resolutely challenging cultural scripts of ageing and disease. Analysing representations of dementia in popular culture Basting argues that there are two main types of tragic dementia stories:

First, there is the one in which dementia is represented as a calamity that can only be eliminated if scientists are given enough time and money to find the



cure. Second is the tale of the loss of an accomplished, inspiring person, a person slowly emptied out by a devastating illness. How do these stories work? And what experiences do they leave on the cutting room floor?<sup>24</sup>

*Still Alice* clearly fits into the second of these, though it also incorporates aspects of the first in the scientific 'subplot' of Alice's husband desperately trying to find a drug that will cure her of Alzheimer's disease. The tragic model of the loss of an inspiring person is made more acute in this novel by the fact that Alice has early-onset Alzheimer's disease and so is diagnosed in what is clearly presented as the prime of her life. This allows the novel both to make Alice's Alzheimer's disease seem more tragic and to distance Alice's illness from ageing, but to do so in a way which both reinforces ageist stereotypes *and* exposes the way that Alzheimer's disease and ageing become inexorably linked in terms of decline in the cultural imagination. Similarly, the scientific subplot in the novel allies the story to the quest for a cure narrative, but this is in the end a narrative thread that is subjugated to the more crucial depiction of Alice's experience of the disease and science is seen here to be both knowing and blind. As this suggests, *Still Alice* maintains a dialogic approach to Alzheimer's disease, sometimes reiterating limiting cultural scripts of disease and ageing, and sometimes insisting in meaningful ways on the personhood and agency of the Alzheimer's disease sufferer. In these ways, it illustrates the value of literary and literary gerontological approaches to the study of ageing and disease: both allow for the exploration of the uncomfortable contradictions in our cultural constructions of aged and ill bodies and selves.

*Still Alice* runs from September 2003 to September 2005 and the dated chapters give the novel a structure that eventually comes to have no meaning for Alice herself. Therefore, even as the narrative becomes more fragmented and repetitive, representing Alice's increasing memory loss and difficulties with language, it retains an order and coherence. This readerly understanding is also ensured by the fact that the novel begins when Alice is only experiencing mild confusion, forgetfulness, linguistic slips. By the time Alice does not know her family and struggles to follow conversation, the reader, though still given access to Alice's point of view, is also able to place her within a secure family and social context, and so

does not fully experience her confusion with her. In this way, the ordering and logic of the narrative always provide a context for Alice's increasing misperception, allowing the reader to experience this while not becoming lost within Alice's world. Therefore, the novel does not go as far in its narrative style as it might; it does not allow the reader to become almost as confused about place and time as the protagonist in the way that a novel such as Samantha Harvey's *The Wilderness* does, for instance.<sup>25</sup> However, in crucial ways the narrative voice and structure do allow the reader experience of Alice's world.

As the novel progresses the narrative becomes more fragmented and repetitious, expressing aspects of Alice's condition. Despite the clarity provided by the chapter titles, the sense of time becomes uncertain and the narrative moves from episode to episode with little sense of causality. This loss of linear temporality is further expressed by the repetition. So, for example, in the middle of the night Alice gets up and walks downstairs to find sleeping pills; the chapter begins: "It was dark, still middle of the night. She wasn't confused. She knew she should be sleeping. John lay on his back next to her, snoring."<sup>26</sup> When her husband John confronts her she is unable to remember what she is looking for and returns to bed, only to wake again: "It was dark, still middle of the night. She knew she should be sleeping. John had fallen back to sleep without ceremony and was already snoring."<sup>27</sup> Such repetition of similar, if not identical, phrases and sentences occurs more and more as the novel progresses, drawing the reader into the cyclical nature of Alice's temporality. The uncertainty that such repetition instils is further emphasised in the narrative's lack of omniscience in relation to key events. For example, Alice's husband says that they have discussed moving to New York and she claims not, but there's no way of verifying this since we tend to stay with her point of view. Taken together, these narrative techniques, whilst not leaving the reader as confused as Alice about time and memory, provide some access into the changes she is experiencing as a result of her Alzheimer's disease.

As this might suggest, the most important way in which the text represents Alice is through focalisation. Alice's perspective dominates in this novel and the reader is rarely given access to the thoughts and feelings of her family or others

around her. The reactions of others always tend to be refracted through Alice's understanding. This means that, although the third-person voice presents a largely coherent narrative of events and dialogue, Alice's perceptions of these things dominate. This allows the text to mark Alice's understanding and the progress of her Alzheimer's disease in various ways. One significant way in which this is done is through naming. As the novel goes on, Alice's daughter Lydia becomes "the actress" – she is the first family member whose name Alice cannot remember – and later her daughter Anne becomes "the mother." In the final part of the novel, her husband becomes "the kind stranger." This naming makes clear Alice's lack of memory of key relationships in her life. But, more crucially, the use of focalisation means that Alice does not become the diseased and suffering other to the reader. Even as she lies in a state of semi-consciousness in her bed, Alice is, as the title suggests, 'still Alice'. This is not to suggest that this is a static and unified version of selfhood. Indeed, this is a challenge to the 'loss of self' narrative that, as I will show, is dominant at other points in the novel. Here the self is very clearly akin to Basting's 'relational' self, with Alice remaining Alice because of the recognition of her selfhood and her agency by her family and friends, and by the reader.<sup>28</sup>

These formal interests in the Alzheimer's disease experience of language and memory are echoed in the thematic exploration of language in the novel. The latter is centred on the fact that Alice is a psycholinguist. On one level, Alice's job makes her Alzheimer's disease all the more tragic, in the sense Gillian McColgan et al argue: "For one engaged in intellectual pursuits, experiencing Alzheimer's disease is presented as a double tragedy."<sup>29</sup> As their article shows, this is very much the way that the case of Iris Murdoch was read, and in a parallel, though fictional, manner Alice's loss is seen as more tragic here since she'll lose the language that has been central to her research: "Everything she did and loved, everything she was, required language."<sup>30</sup> And Alice is proud of her memory and her ability to offer a coherent narrative in her research, "filling in the holes" in her PhD student's "narrative [and] creating a more contiguous picture" within his research project, for example.<sup>31</sup> Ironically, one of the first words she is unable to recall is lexicon. Alice's loss of narrative is made clear in the memory tests that she undergoes; in a recurring test that requires her to remember the details of a story her increasing memory loss and

confusion are evident. This all suggests that in its plot the novel presents Alice's language loss as a personal and individual tragedy, a loss of self in the loss of language and narrative. And, to an extent, this is the case, with Alice reflecting on this herself as her illness worsens: "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."<sup>32</sup> The links made between ageing and Alzheimer's disease in the novel tend to support this reading, as both are seen as conditions of inevitable decline and irretrievable loss.

In this novel Alice is only 49 when she first experiences the symptoms of Alzheimer's disease and her resistance to the link between Alzheimer's disease and ageing is very clear, bearing out the idea that in the cultural imagination Alzheimer's disease is synonymous with old age. As Cruikshank puts it, "Today, Alzheimer's stands for aging in America."<sup>33</sup> I'm not suggesting that this text critiques the way that Alzheimer's disease comes to function as an image of ageing as decline; Alice's early-onset Alzheimer's disease tends to work to opposite effect by implying that she is unusual in not being both aged and ill. However, close attention to the way the link between ageing and Alzheimer's disease is explored in the novel makes clear how contradictory and problematic it is, as the novel both reinforces ageist stereotypes and yet also exposes the way that Alzheimer's disease is constructed to be metonymic of ageing as decline.

Alice's own reaction to her diagnosis makes clear the way she has previously understood Alzheimer's disease. Her first response to being told that she has Alzheimer's disease is to say that "this can't be possible, I'm only fifty."<sup>34</sup> Ironically, however, it is to ageing that Alice attributes many of the early symptoms of the disease, before she receives the Alzheimer's disease diagnosis. She sees her memory loss and confusion as linked to turning fifty and being menopausal: "Nothing life-threatening. Nothing abnormal."<sup>35</sup> The menopause is here constructed as natural, in opposition to the invasion of the monster that is Alzheimer's in the text. The close links Alice immediately makes between Alzheimer's disease and ageing are also seen in her reflection on the 'Activities of Daily Living' questionnaire that her husband is to complete about her once she is diagnosed with Alzheimer's disease.

This rates the functions of daily living from 1 to 3, with 3 the most severely impaired, including lack of bladder and bowel control, lack of ability to feed oneself. Alice considers: “How much of this list was due to the progression of Alzheimer’s disease and how much was confounded by the overwhelmingly elderly population it described? Were the eighty-year-olds incontinent because they had Alzheimer’s or because they had eighty-year-old bladders?”<sup>36</sup> Associating bodily decline (and disability) with ageing, Alice uses this as a way to stereotype and other both Alzheimer’s disease sufferers and those older than herself. On visiting a care facility for Alzheimer’s patients it is the fact that most are over eighty that disturbs her and is a great part of her feeling that she doesn’t belong. This scene, in particular, more generally reinforces the idea that Alice is not the ‘usual’ Alzheimer’s patient, not elderly, not yet infirm. By insisting that most of the patients in the facility are over eighty, and by presenting a condescending vision of elderly care (making bird houses), the text actually reinforces the link between Alzheimer’s disease and ageing, representing the former as synonymous with the latter, and allowing Alice herself to appear to be an exception.<sup>37</sup> Alice’s later home care further reinforces this idea – she will not join the elderly in the institution, but will be looked after by loving daughters and have contact with new grandchildren.

As the text continues Alice’s increasing dependence does position her more firmly as an older woman, again reinforcing the link made between Alzheimer’s disease and age, but also exposing how the two become intertwined, with Alice beginning to see herself as an old woman, an old and an ill woman. This is made clear in the various mirror moments in the novel (the mirror moment is a trope found in very many novels that explore ageing). In the first few pages of the novel Alice sees herself and her husband in a mirror and describes them as: “a distinguished-looking, tall man with white-flecked brown hair and glasses; a petite, curly-haired woman, her arms crossed over her chest.”<sup>38</sup> A little later in the text Alice invests in a response to her mirror image which bears out Mike Featherstone’s and Mike Hepworth’s argument that many older people feel that they wear a ‘mask of ageing,’ in which their sense of self-identity is hidden beneath an imprisoning ageing shell.<sup>39</sup> Here, Alice appears to subscribe to this Cartesian dualist version of self: “The reflected older woman’s face didn’t quite match the picture that she had of herself in

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."<sup>40</sup> 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?*"<sup>41</sup>

This scene reads as a denial of the aged body in much the way that Kathleen Woodward reads ageing mirror moments, as a rejection of the mirror stage of old age, where "the ego finds it more difficult to maintain its defences" in the face of an image of bodily disintegration.<sup>42</sup> Unlike the mirror stage of infancy, however, Woodward sees this latter stage as "more obviously rooted in the social and economic theatre of a given historical moment," based upon an assumption of "the elderly as alien to ourselves."<sup>43</sup> This final mirror scene makes very clear the way that Alice brings together Alzheimer's disease and ageing, seeing her ill self as an aged self, which she then rejects in order to try to maintain her own "defences." As a result of this image, Alice paints the mirrors white, symbolically erasing her aged self because of the threat it presents.

These examples suggest that the novel subscribes to the tragic story of Alzheimer's described by Basting. Even whilst the links between Alzheimer's and ageing can be read as exposed in the novel, it nevertheless does not undermine

these in any sustained way. And Alice's Alzheimer's is presented as a loss of self, something even more tragic in a younger woman. However, many aspects of the novel mitigate this simplistic reading and make clear that the novel presents a more multifaceted portrait of selfhood and agency in Alzheimer's disease. For example, there are key points – almost 'moments of being' – in the novel which emphasise Alice's sense of self and ability to enjoy her life in the present. She sits with John eating ice cream by the river and, though she cannot accurately answer John's questions about her location in time and place, she is happy to be there and her attention is taken by her immediate surroundings: "He held her hand. His was warmer than hers. Her hand felt so good in his hand. Two of the geese waddled into the calm water. There were no people swimming in the river. It was probably too cold for people."<sup>44</sup> At this point John asks Alice if she still "want[s] to be here," an ambiguous question that could refer to John's desire to move to New York or to Alice's earlier suicide plans (as readers, we cannot be sure how much John knows about these). Alice understands John very literally and replies that she is happy and has not finished her ice cream. Other moments, such as Alice listening to a busker with her carer, are similar in their emphasis on Alice's continuing ability to both feel pleasure and enjoy moments in which she is 'still Alice'.<sup>45</sup> These moments challenge the reader to reconsider the very nature and value of the construction of self in illness; since we see these episodes from Alice's point of view, the reader is encouraged to value what she does in the present and experience her pleasure intimately as self-affirming. According to some extent with a more postmodern reading of selfhood, being Alice at this point is not just about relationality and the recognition of identity and agency by friends and family (and reader), but about the awareness of pleasure in the present, where 'moments of being' support a sense of self. Narrative point of view is therefore used again in this novel to underline agency and the nature of Alice's continuing selfhood, even as she would be unable to articulate this in language.

Throughout the novel, this focalisation allows the reader to experience with Alice the ways in which she is treated by others, and the ways in which they construct her as an Alzheimer's disease patient. Dominant in the reactions of others are feelings of fear: Alice recognises that Lauren, her neighbour, looks "baffled and

scared” when Alice tells her that she has Alzheimer’s disease, and Alice similarly feels isolated by the reactions of her Harvard colleagues, feeling that they are avoiding her after she has admitted to her condition.<sup>46</sup> This is something she fears early on in the novel, recognising the way that culture constructs mental illness: “Even the well-intentioned and educated tended to keep a fearful distance from the mentally ill. She didn’t want to become someone people avoided and feared.”<sup>47</sup> The novel makes very clear the ways in which Alzheimer’s disease inspires fear in the non-sufferer and the effects of this upon the Alzheimer’s disease patient. This extends into the heart of Alice’s family where her daughter Anna, though not rejecting her mother, initially fails to try to understand and empathise with her position. Instead, she confronts her mother with her memory loss and insists upon Alice fighting this rather than using strategies to circumvent it and retain a form of independence. When Alice asks the time of the performance of her daughter Lydia’s play, in order to put this into her Blackberry, which she relies upon as a memory aide, Anna tries to force Alice to remember the time without looking in the Blackberry. The lack of understanding in this approach is clear to the reader, something underlined by the satisfaction the reader experiences when Alice, knowing that “poor Anna needed to be put in her place,” asks Lydia for the time and the scene ends with Alice stating: “It’s at eight o’clock, Anna.”<sup>48</sup> Scenes such as this expose the harm done to Alice by misunderstanding and culturally-inspired fear, but the novel also suggests the possibility of another approach, one that can support an on-going sense of selfhood.

The plea for a self in Alzheimer’s disease is emphasised in the novel through Alice’s speech to a Dementia conference. Still able to articulate clearly – though only by keeping her eyes on the page – Alice delivers an impassioned plea for recognition and respect for those with Alzheimer’s disease. A clear voicing of the politics of the novel, and strongly emotional in its situation within Alice’s story, this speech articulates a vision of selfhood in Alzheimer’s that is supported by approaches to care that are based upon empowerment and not limitation.<sup>49</sup> And this vision of a different form of care, based upon a relational understanding of selfhood, can be seen in Alice’s relationship with her daughter, Lydia. Though Lydia is the first family member Alice does not recognise, she is nevertheless the person who represents



the promise of a sort of Alzheimer's disease care that is based upon relationality and respect for the selfhood of the sufferer. This is evident in lots of moments in the novel, from Lydia's patient answers to Alice's questions (how old she is, is she married) to the comforting physical contact she provides. Though at times these scenes do tend to be sentimental and even slightly melodramatic in the pathos conjured up by the shadow of the loss of such mother-daughter contact as Alice's illness progresses, the insistence in these moments on Alice's need to be recognised as a person and a loving mother, even when she does not remember her daughter, prevents the objectification and distancing of Alice as an Alzheimer's disease patient. Lydia is an actress and her interest in the relationship between the physical and the mental in performing identity provides a further link between her and her mother, and provides a metaphor for Alice's social interaction with increasing symptoms of Alzheimer's disease. Alice's Alzheimer's disease is inhibiting the successful performance of her identity, literally in the sense that she is increasingly unable to understand verbal communication and engage in social dialogue (though, for a time, she retains the ability to read non-verbal communication, something Lydia praises as an enviable skill). But, together, Alice and Lydia read plays, engaging in a dialogue that Alice finds fulfilling: "They passed eager questions and answers back and forth, their conversation two-way, equal, fun. And because Alice didn't have to compete with John to complete her thoughts, she could take her time and not get left behind."<sup>50</sup> The plays give Lydia and Alice a topic of conversation which is based in the present and does not rely on Alice's memories and past context. And Alice is able to enjoy the sense of performativity in the present in both the readings of the plays and the discussions about them. Not involving the details of her own life, and not relying on longer-term memory, Alice is able to express a sense of agency and selfhood in a situation where she is not under pressure to 'perform' to someone else's construction of 'Alice'.

As the above makes clear, *Still Alice* is concerned with the issue of care for Alzheimer's disease patients. And, like many other narratives of dementia, this includes an exploration of the science and medicalization of illness and disease. *Still Alice*'s author, Lisa Genova, has a PhD in neuroscience and this tends to suggest an authorial reliability about the science of Alzheimer's disease that lies behind the text.

The italicised scientific narrative that interrupts the fictional narrative at key moments echoes this sense of scientific authority. The scientific context is developed in this novel by Alice's career in psycholinguistics and her husband's research career. It is the latter that symbolises the scientific narrative, as Alice's husband invests all of his energies into researching Alzheimer's disease and potential new drugs. And on one level this novel therefore follows the common depiction of science in Alzheimer's disease narratives, as a hope that in the end fails the sufferer (though it may provide hope for the future, as it does here for Alice's children and grandchildren). However, this novel tends to play down the scientific advances that may 'save' Alice in favour of exploring her psychological and emotional responses to treatment and the way she is positioned as an Alzheimer's disease patient by the medical profession. In this way, the text suggests that the medical and scientific approach to Alzheimer's disease may indeed be blinded to the selfhood and the need for relationality of the Alzheimer's disease patient.

John may be seeking a cure for Alice's Alzheimer's disease, but this does not play a large part in her story. And since her perspective dominates, the reader tends to see John's exertions in the way Alice does: as a distraction that stops him having to address her needs and care for her in the way she desires. We therefore view John's drive for scientific answers as, to some extent, a fool's errand that results in poorer care and support for Alice. More generally, John himself comes to embody the scientific quest – with his single-minded determination to succeed at his experiments and his long hours in the lab. The distracted scientist, he takes refuge in empiricism and refuses to relate to his wife as a suffering woman. It is worth noting that John's own scientific work is into a cure for cancer. And Alice sets this up as a binary opposite of Alzheimer's disease, making clear the very different ways in which the two diseases are read: "She wished she had cancer instead. She'd trade Alzheimer's for cancer in a heartbeat... With cancer she'd have something that she could fight.... Her family and the community at Harvard would rally behind her battle and consider it noble."<sup>51</sup> Alice emphasises here the ways in which illness is culturally constructed, something we of course see in her case, as she is marginalised by her Alzheimer's disease. The fact that John is researching a cure for cancer suggests his preference for physical disease over mental illness, his choice of labs and test-tubes

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?"<sup>52</sup> 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."<sup>53</sup> 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 tests of the fictional drug, Amylix, the trial of which Alice chose to enter. This seems to suggest the loss of Alice, as she disappears in favour of John's perspective, and the assertion of the biomedical model of the disease, where science cannot yet save Alice from Alzheimer's disease. However, science does fail here and the scientific answers that John relies upon, for Alice and in his own research into cancer, are seen to have effaced his wife; in his case, he has prioritised his scientific work over caring for her, and so lost much of the time he could have had with her. Of course, this is also problematic since it seems to suggest that care itself should be about self-sacrifice and promotes a certain vision of homecare over institutional support. Nevertheless, the representation of John weeping at the failure of the trial drug symbolises both the way that the novel presents the loss of Alice as a tragedy and also the novel's insistence that one-dimensional and biomedical approaches to care overlook the self that can be maintained in Alzheimer's disease.

The epilogue is crucial here, since it ensures that the final image of the novel is not John's sorrow – which would of course suggest that Alice has indeed disappeared. Instead, we have an image of Alice with her family and, in particular, a scene in which she listens to her daughter recite a monologue:

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 filled Alice and moved her to tears.<sup>54</sup>

As in other significant moments of pleasure in the novel, here there is an emphasis on emotion over knowledge, something that is outside of Alice's previous reliance on language and narrative. Unable to follow the meaning of the words her daughter speaks, she is nevertheless able to track emotion and to feel this. Whilst the text makes clear that Alice's memory and ability to understand language are seriously impaired (as the reference to her daughter as "the actress" shows), meaning is still gained fleetingly here, though it is a meaning of a different sort. This accords with the work done by some narrative gerontologists who evince a form of narrative care for dementia patients. As Marie-Elise van den Brandt-van Heek demonstrates, dementia patients can be encouraged to speak for themselves through "asking the right questions".<sup>55</sup> This extract seems to embody this approach, since Alice is not asked for knowledge by her daughter, but for her opinion and for how she feels (in opposition to this, there are many moments in the novel where Alice is made angry and confused by being asked questions which require memory and knowledge to answer). In this final scene in the novel, Alice is indeed still Alice.

Being Alice is not straightforward in this novel. The title suggests, on one level, the danger of loss of self that Chivers argues is found in many stories of dementia and this narrative is prominent in parts of the novel, in particular in Alice's own fears of her loss of language and other capabilities, and the way the novel links Alzheimer's disease and ageing in a story of decline.<sup>56</sup> *Still Alice* could indeed be read as the stilling, or end of, Alice. However, as this paper makes clear, the novel is more complex than this interpretation suggests and it includes elements that challenge the unified and individualistic form of selfhood implied in 'loss of self' narratives. One of the primary ways the text does this is through its narrative

perspective; concentrating on Alice's point of view, but ensuring that this is located within a familial and social context with which the reader is quickly familiar, ensures that Alice is always, even as her illness becomes severe, recognised by the reader and interpellated as Alice. The intimate experience of Alice's emotional, physical and intellectual states encourages the reader to construct and reconstruct Alice so that she remains not static, but still Alice. This process is very acute in Alice's 'moments of being', where Alice experiences a pleasure in the present that is self-affirming and does not depend upon memory or wider context. This readerly relationality is not dissimilar to the way we see key members of Alice's family, particularly her daughter Lydia, find ways to communicate with Alice and allow her to exercise narrative agency. The novel therefore offers a vision of subjectivity that is not coherent or stable – and indeed may be contradictory - but that can offer agency and recognition in the face of Alzheimer's. This provides possible – and certainly not definitive – answers to Basting's question: "Is a "self" possible when the ability to construct narrative through memory is broken?"<sup>57</sup>

Writing dementia and aestheticizing Alzheimer's disease is not without its risks, ethical and artistic. Nevertheless, fiction has a part to play in the discourse of dementia and novels such as *Still Alice* are able to articulate the moral, emotional and material complexities of illness and ageing. It is because *Still Alice* is such a popular and widely praised depiction of Alzheimer's disease that it is important to analyse its representation of Alzheimer's and ageing. Able to imagine the perspective of an Alzheimer's sufferer, this novel illustrates in an intimate fashion – in a way it is difficult for other forms of representation to do – the physical and mental ravages of the disease, but also explores the way that Alzheimer's is read by others, including the way in which patients are situated by medical science. Reaching a wide audience, and approved of by those working in the field of Alzheimer's, *Still Alice* provides a complex articulation of the possibilities of selfhood and agency in Alzheimer's. Not necessarily escaping the tragic structure that Basting argues determines most cultural representations of dementia – and clearly enmeshed in the often contradictory ways in which ageing and Alzheimer's are understood – popular

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

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### Endnotes

<sup>1</sup> 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).

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

<sup>3</sup> Ibid.

<sup>4</sup> Rob J.M. Dillmann, "Alzheimer Disease: Epistemological Lessons from History?" in *Concepts of Alzheimer Disease: Biological, Clinical, and Cultural Perspectives*, eds. Peter J. Whitehouse, Konrad Maurer and Jesse F. Ballenger (Baltimore: Johns Hopkins University Press, 2000), 171.

<sup>5</sup> Anne Davis Basting, *Forget Memory: Creating Better Lives for People with Dementia* (Baltimore: John Hopkins University Press, 2009); Margaret Cruikshank, *Learning to Be Old: Gender, Culture and Aging* (Lanham: Rowman and Littlefield, 2003), 38-9; Sally Chivers, *The Silvering Screen: Old Age and Disability in Cinema* (Toronto: University of Toronto Press, 2011), 59-61.

<sup>6</sup> Chivers, *Silvering Screen*, 60.

<sup>7</sup> Basting, *Forget Memory*, 26. On ageing and the decline narrative see Woodward, *Figuring Age*, introduction; Gullette, *Aged by Culture*, chapter one.

<sup>8</sup> Basting, *Forget Memory*, 25-30.

<sup>9</sup> Jane M. Scholl and Steven R. Sabat, "Stereotypes, Stereotype Threat and Ageing: Implications for the Understanding and Treatment of People with Alzheimer's Disease," *Ageing & Society* 28.1 (2008): 122, doi:10.1017/S0144686X07006241.

<sup>10</sup> Anne Davis Basting, "Looking Back from Loss: Views of the Self in Alzheimer's Disease," *Journal of Aging Studies* 17.1 (2003): 88.

<sup>11</sup> Alice Munro, "The Bear Came Over the Mountain" in *Hateship, Friendship, Courtship, Loveship, Marriage* (London: Vintage, 2002); Jane Rule, *Memory Board* (USA: Naiad, 1987); John Bayley, *Iris: A Memoir of Iris Murdoch* (London: Abacus, 1999); Andrea Gillies, *Keeper: A Book about Memory, Identity, Isolation, Wordsworth and Cake* (London: Short Books, 2010).

<sup>12</sup> John Wiltshire, "Biography, Pathography and the Recovery of Meaning," *The Cambridge Quarterly* 29.4 (2000): 413.

<sup>13</sup> Mark Freeman, "Narrative Foreclosure in Later Life: Possibilities and Limits," in *Storying Later Life: Issues, Investigations, and Interventions in Narrative Gerontology*, eds. Gary Kenyon, Ernst Bohlmeijer and William L. Randall (Oxford: Oxford University Press, 2011), 13.

<sup>14</sup> Ibid., 17.

<sup>15</sup> Gillian McColgan, James Valentine and Murna Downs, "Concluding Narratives of a Career with Dementia: Accounts of Iris Murdoch at Her Death," *Ageing and Society* 20 (2000): 99. This article does, however, acknowledge that this was beginning to change and we see this in caregiving and therapeutic as well as literary contexts.

<sup>16</sup> Chivers, *Silvering Screen*, 60-1.

<sup>17</sup> Basting, "Looking Back from Loss," 88.

<sup>18</sup> Gary Kenyon, Ernst Bohlmeijer and William L. Randall, eds., *Storying Later Life: Issues, Investigations, and Interventions in Narrative Gerontology* (Oxford: Oxford University Press, 2011), xvi.

<sup>19</sup> Roberta Maierhofer, "Generations Connecting: Alzheimer's Disease and Changes of Cultural Values," *Gender Forum* 28 (2010): 2.

<sup>20</sup> Anne Davis Basting, "'God Is a Talking Horse': Dementia and the Performance of Self," *TDR* 45.3 (2001): 80, <http://www.jstor.org/stable/1146913>.

<sup>21</sup> Ibid.

<sup>22</sup> Lisa Genova, *Still Alice* (London: Pocket Books, 2010).

<sup>23</sup> See <http://lisagenova.com/> for details of the awards won by *Still Alice*. See two typical newspaper reviews here: Beverly Beckham, "Despite Monster: She is 'Still Alice,'" *boston.com*, 2008,

[http://www.boston.com/news/local/articles/2008/03/16/despite\\_monster\\_she\\_is\\_still\\_alice/?page=full](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](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](http://www.alz.org/co/in_my_community_15677.asp).

<sup>24</sup> Basting, *Forget Memory*, 33.

<sup>25</sup> Samantha Harvey, *The Wilderness* (London: Vintage, 2010).

<sup>26</sup> Genova, 191.

<sup>27</sup> *Ibid.*, 193.

<sup>28</sup> Basting, "'God Is a Talking Horse': Dementia and the Performance of Self," 80.

<sup>29</sup> McColgan, Valentine and Downs, 107.

<sup>30</sup> Genova, 74.

<sup>31</sup> *Ibid.*, 28.

<sup>32</sup> *Ibid.*, 270.

<sup>33</sup> Cruikshank, 38.

<sup>34</sup> Genova, 70.

<sup>35</sup> *Ibid.*, 25.

<sup>36</sup> *Ibid.*, 73.

<sup>37</sup> *Ibid.*, 110-6.

<sup>38</sup> *Ibid.*, 5.

<sup>39</sup> 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.

<sup>40</sup> Genova, 35.

<sup>41</sup> Genova, 283.

<sup>42</sup> Kathleen Woodward, *Aging and Its Discontents: Freud and Other Fictions* (Bloomington and Indianapolis: Indiana University Press, 1991) 68.

<sup>43</sup> *Ibid.*, 29.

<sup>44</sup> Genova, 267.

<sup>45</sup> *Ibid.*, 288-9.

<sup>46</sup> *Ibid.*, 196 and 185.

<sup>47</sup> *Ibid.*, 118.

<sup>48</sup> *Ibid.*, 173.

<sup>49</sup> *Ibid.*, 253.

<sup>50</sup> *Ibid.*, 168.

<sup>51</sup> *Ibid.*, 118.

<sup>52</sup> *Ibid.*, 4.

<sup>53</sup> *Ibid.*, 75.

<sup>54</sup> *Ibid.*, 292.

<sup>55</sup> Marie-Elise van den Brandt-van Heek, "Asking the Right Questions: Enabling Persons with Dementia to Speak for Themselves," in *Storying Later Life: Issues, Investigations, and Interventions in Narrative Gerontology*, eds. Gary Kenyon, Ernst Bohlmeijer and William L. Randall (Oxford: Oxford University Press, 2011), 338-53.

<sup>56</sup> Chivers, *Silvering Screen*, 60.

<sup>57</sup> Basting, "Looking Back from Loss," 88.