

Communication

## Making Sense of Senselessness: Contemporary Literary Commentaries on Dementia

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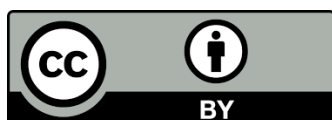
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### Abstract

Alzheimer's Disease is increasingly seen as the major health problem in developed countries supplanting cancer and heart disease. The terror with which we respond to dementia, is grounded in a view of dementia as a monstrous descent, ambushing our healthy ageing through an incursion of pathology. The pervasiveness of this view can mean that other perspectives and even the views of those most touched by the challenges of dementia remain unheard.

Part of the cultural conversation around dementia is informed by contemporary literature. Novels such as *Still Alice*, *The Corrections*, *The Madonnas of Leningrad* and *Tinkers* include vivid images of the dementia journey. They provide a variety of responses to the disruptions of this illness, as well as the possibility of finding meaning within the undeniable losses of



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dementia. These works and others like them extend the dialogue around the experience of dementia beyond the convenience of simplistic caricatures of the people affected by dementia. Engaging with these perspectives will assist clinicians' understanding of the deeper implications of dementia for us all.

### **Keywords**

Dementia; ageing; cultural studies; literature

Years into the battle against cancer, heart disease and diabetes another affliction is now stalking us. This is not a novel pandemic infection but something more terrible and more insidious, seemingly poised to consume all of us in our old age. The spectre of Alzheimer's Disease is the new fear that has come to haunt modern societies, threatening to undermine the improvements in life expectancies once proudly proclaimed as the crowning triumph of medical science.

Wherever populations are ageing, the prevalence of dementia increases sharply [1]. This is not limited to rich countries: wherever you are, ageing is inseparable from diminishing capacity, failing memory, lost autonomy and disintegrating personhood. For many older people, the menace of dementia hangs as a dark shadow, its presence constantly suggested in the ordinary slips and lapses of daily life. The sense of threat is intensified by a popular press replete with stories of almost unmitigated pessimism—of hopelessness, decay and isolation, where the expression "Alzheimer's Disease" is automatically linked to the words "tragic", or "cruel". Indeed, dementia is often presented not as an illness but as a descent into a terrifying, subhuman nether world, a continuing living death [2].

It may come as a surprise that this bleak image of dementia is a relatively recent construction. Representations of both ageing and cognitive decline have evolved rapidly over the last few years [3-5]. Here, the roles of television, the Internet, film and social media are obvious; the influence of the subtle infiltration of language and the reshaping of the signs we employ in ordinary cultural life might not be so apparent. And the consequences for the deep lifeworld experiences for older people and their loved ones remain largely unknown.

The changes in the cultural representations of dementia and the great fluxes of meaning and hope generated by them have also become a focus of recent literary works. Of these, contributions from developed countries, particularly the United States, warrant attention as they arise within the milieu of this region's significant cultural impact on responses to dementia over the last four decades [6]. In this review examples of literature from the United States, chosen due to their popularity, critical acclaim, influence and the nuanced interpretations enabled by their descriptions of the dementia experience will be discussed and supplemented by sources from other developed countries. More than academic theorising these works illustrate a process of exploring and mapping the social and conceptual transformations signified by the new force of dementia and of seeking out novel narrative forms that can make sense of them. This process might help clarify not only what it is about the contemporary context of ageing that terrifies us but how we can start to come to terms with it.

## 1. Images of Dementia

A major task of some recent works of fiction is how to talk about the losses associated with dementia. Dementia might well be a “cruel” “enemy”, but this is not always the whole story, as shown by Lisa Genova’s popular novel *Still Alice*. Alice is a young mother and professor of neuropsychology who chronicles systematically her experiences from the shocking first manifestations of her illness. Her story is punctuated by progressive losses, and endured with varying degrees of resilience. Early on Alice laments pathetically against the monstrous injustice of the disease [7]. She wishes hopelessly for a condition with a less complicated medical narrative, such as cancer. However, dementia asserts itself as the enemy that cannot be fought: it is rather an overwhelming natural force, a beast, a hunting “predator” with “no weapons that could slay it” [7]. Later in the novel, Alice returns to her imagery of the elemental power that is now not stalking but enveloping, drowning her. Dementia becomes the “unstoppable, ferocious, destructive” force of the ocean dragging the self away into its depths.

In Jonathan Franzen’s book, *The Corrections*, the imagery around the dementia that is progressively taking over the proud and difficult patriarch, Al, has a more furtive and elusive force. It is a darkness that snatches at him as he winds his way through a forest of words and actions, a “sinister decay” that steals his bearings [8].

This view of dementia as a tragic, monstrous descent, however, is not universal. In Debra Dean’s *The Madonnas of Leningrad* Marina, the protagonist acquires increasing mystery for her family as her decline progresses [9]. Family members encounter the weight of her words and struggle to balance them against the assumed non-sense of a person living with dementia. Dean’s heroine becomes immersed in a beautiful interplay of rich memories and the live, fresh world around her. Marina’s dementia is pictured as an ephemeral openness that causes havoc in the present but allows Marina to unearth meanings through a creative exploration of her past, and ultimately a frail but transcendent self-discovery. Dean challenges us to search for a hidden beauty and mystery within the delicate fragility of narratives of desolation.

Yet other works go even further, presenting dementia as a possible site for genuine transformation. In Paul Harding’s *Tinkers*, Howard’s father fades from the world owing to his dementia, or rather the world fades from him, becoming no more than his dream. Although no longer solid, but insubstantial his presence endures in the “brief disturbances of shadows or light” [10]. He seems to be made from “planets and wood, diamonds and orange peel” with the “iron in (his) blood ... once the blade of a Roman plough” [10]. Through this perplexing process, Howard’s father’s illness becomes more than just a source of sad discomfort for his family; it is also a link to the mysteries of time, and life’s fecund and fleeting inter-subjective connections.

## 2. Responding to Disruption

Recent fiction offers a richness of possible responses to the challenges arising for both the persons with dementia and those around them. Al (*The Corrections*) sees himself as acquiring different selves. He becomes at once a rational adult and a “panic-stricken” boy, “thoughtless” and “crashing” around, searching for a clearing in the confusion [8]. It is this “rational” Al who, in the book’s final stages, asks his son Chip to end his life. Chip’s pathetic refusal echoes Al’s failures to act earlier, his clear wish for death triggered and ironically defeated by dementia’s decline.

Meanwhile, Enid (Al's wife) recognises that amidst the tempestuous changes of dementia Al retains a core identifying trait: "(t)he one thing (Al) never forgot was how to refuse." [8]. Dementia for Franzen lies within the ecology of illness and complex relationships, but it is also tragic, in its ironic status as an agent of uncorrectable change, ceaselessly dynamic yet obdurate and mute to our desires.

"Correcting" dementia with suicide is also a theme in *Still Alice*. Alice wishes to die but stays her hand early in the book buoyed by her professional and social worth. Later, self-negation gives way to a recognition that the fundamental relevance of her experience extends beyond her ability to remember it. For Alice, remembering gradually becomes less important than the present moment of experience and connection with those around her and, while not sufficient for all, some of her family are able to connect deeply with the vibrant, emotionally present person their mother has become. While these portrayals continue to represent dementia as tragic, they suggest that it is not limited to loss and devastation, that the person with dementia is not completely annulled and denuded.

### **3. Finding Meaning in Loss**

There are no more potent investigations into the possibility of finding meaning in dementia than those conducted by people with the condition. An increasing variety of these are now available as both as published works and periodic blogs. A forerunner to this tradition was the dementia auto-narrative of Dianna McGowin. She describes visiting her home town to "touch again the Diane ... who had once been, before she was no more" [11]. McGowin describes her unfolding response to the exquisite frailty of her memory as her story gradually transforms—before her own eyes—into the story of a stranger. The connection to one kind of past fades; the sheer possibility of an embodied voice, eerily perdures. A similar sense of the changing relationship with self-experience is conveyed by Wendy Mitchell's elegantly titled blog "Which me am I today?" and book "Somebody I used to know" [12, 13]. Mitchell discovers that her relationship with her sense of time is evolving. She feels that her past is lost to her and the uncertainties of her future make it too confronting for comfort. Mitchell finds herself residing in a present time, reflecting on the beauty and transience of her momentary experiences. Here her observation that "... even as our memories fade, it's not to (sic) late for new ones to be made." reminds us of the persistence of self-experience in dementia and with this the possibility of new meaning and flourishing [12].

Dementia fiction exhorts us to give up the idea of an untouched person residing underneath behind a sad veil [14]. It shows how dementia touches many beyond those with the diagnosis. Often, it describes personal experiences – as in the cases of Genova and Franzen – thereby endowing the works with a sense of deep authenticity. As testaments to the multiple ways the illness affects the people it touches, and to our ability to make sense, even as darkness is closing in. Literature written by those who care for those with dementia about their experiences reflects on similar territory. The deep and existential challenge of this role is often juxtaposed with revelations of joy, wonder, learning and hope. In the blog "Dementia Diaries: A Journey With Dementia" Cassandra Jones speaks of her mum's dementia as a new epoch in the lives of those around her, everything else is "B.D" (before dementia) when hope was easy to find, but nonetheless there is wonder, personal growth and joy within sharing this journey [15]. No-one

denies the tragedy of dementia. What we are in the process of learning is how it can also take us on a journey of exploration, renewal and growth, where fragile new possibilities can emerge as the old ones wither away.

When we have moved beyond the caricature of the person with dementia as a monster, drained of his or her moral content and personhood, there will still be a lot of work to do. Literature can show us some things—and recognising that persons with dementia are changing beings with rich experiences arising out of painful loss is an important insight. This perspective resists the injudicious simplicity of reducing dementia and those with the diagnosis to dichotomous notions of independence and dependence, illness and non-illness, being and non-being or worth and non-worth. The benefits of this kind of engagement with dementia through literature are not just inter-subjective. Accounts of those with the diagnosis and those who care for them suggest enhancements in personal appreciation of social identity, interpersonal connections, healing, and a variety of capacities from their involvement in telling their story [16, 17]. Stories compel both the teller and the audience [18]; exposure to dementia narratives that subvert monophonic, assumed understandings of this experience as tonally wretched can be politically and culturally influential [19] and enabling this interchange is an empowering act. The biomedical discourse likewise has much to gain from a sensitivity to the multifarious, rich and nuanced representations of the dementia experience in literature. Medicine while responsive to culture, may recognise a need for deeper consideration of dementia than just a quest for a cure arising from these perspectives.

How society will manage the increasing numbers of old, and cognitively impaired people, how we handle our own transitions to the twilight worlds of insight built on the frailty from which no traveller returns—this is an important ongoing work of culture and medicine, a process with no easy solutions.

### **Author Contributions**

All authors contributed equally to the planning and authorship of this manuscript.

### **Competing Interests**

The authors have no potential conflicts of interest to disclose.

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