

Alzheimer's Disease: Personhood and First Person Testimony

Paper for CDSRN

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I want to talk today about the political and ethical dimensions of Alzheimer's first person testimony. I'm referring here to first person accounts of living with Alzheimer's dementia – a small but significant body of texts written in conditions of intense contingency in the face of a progressive and incurable illness. As reflections upon a condition characterised by profound cognitive decline, behavioural difficulties and the erosion of memory, these texts speak from a subject position that is usually perceived to preclude first person narration. Indeed, they speak from a place which is popularly perceived to represent the ends of meaningful personhood per se. The prevailing perception of Alzheimer's disease is of the death that leaves the body behind, of the pathological destruction of selfhood prior to the physical demise of the body. Dominant tropes of dementia describe the person with Alzheimer's as a denuded zombie or the living dead – spectral figures at the limits of life, meaning and social recognition. Alzheimer's, as Elizabeth Herskovits notes is culturally elaborated as a monstrosity. This is something we see in a whole range of metaphors that discursively strip those with dementia of their personhood and humanity by constructing them as animals or vegetables – cabbages, 'lower functioning primates', dogs -- are just a few examples I've come across. Such tropes express deeply embedded psycho-social fears around our vulnerability to impairment and decline, the loss of bodily control and self-awareness, and the "horrors" of dependency. Alzheimer's describes a condition whose threat lies in its perceived violation of the boundaries between the human and the non-human, personhood and non-personhood, life and death. In generic terms, if cancer narratives are often quests, Alzheimer's is a form of gothic horror.

I want to focus in particular upon two texts: Diane McGowin's *Living in the Labyrinth* and Cary Henderson's *Partial View*. I do so because I think they are two of the most interesting examples of this genre, and ones which raises some difficult questions. My interest lies in the ways in which first person accounts of living with

Alzheimer's relate to current ethical debates around personhood and the relationship between definitions of a person and constructions of the human. I want to think about the ways in which we read and evaluate their ethical and political dimensions in the context of the wider political agendas of disability rights. I want also to think about the ways in which first person testimony engages with and problematises particular autobiographical conventions. To what extent does the scripting of Alzheimer's push the autobiographical project to its limits or demand a new kind of lifewriting?

In wider terms, my paper concerns the ways in which we think about forms of cognitive impairment and of personhood and our evaluation of the definition and limits of meaningful life. I guess this can be framed in two related ways. First, in what ways do condition such as Alzheimer's fall beyond the critical orbit of particular models of personhood and second, in what ways does Alzheimer's demand that we rethink these models in order to develop an ethics of personhood that can accommodate our collective vulnerability and interdependency? Forms of cognitive impairment sharply focus questions that resonate across the whole domain of disability politics – namely what it means to be human, the evaluation of meaningful life and the social treatment of those with atypical needs.

Part One: The Critical field

Alzheimer's disease has been strangely neglected in the body of critical work that has emerged around the recent proliferation of illness and disability narratives. I say strangely because in so many respects, Alzheimer's is everywhere. Its lived experience is narrated in hundreds of thousands of Google hits, in blogs and websites, in the publications of local community presses, and in published literature. It is both at the centre and at the margins of numerous novels, films and television programmes. It haunts the hospital corridors and waiting rooms of *ER*, *Greys Anatomy* and *Casualty*. It is embodied as a site of profound social and psychological disturbance in the knee-jerk violence of Junior Soprano, and played out as tragedy and sometimes as farce in documentaries, television dramas, soaps and sitcoms. Every taxi driver to whom I've ever mentioned my research can tell an Alzheimer's joke. At every paper I've ever given on the subject at least half the audience know or have known someone with Alzheimer's. Hardly a week goes by without some news report

on the social and economic implications of the predicted epidemic of dementia now facing the baby boom generation, on hopes invested in emergent technologies such as stem cell research and genetic mapping, and on a range of preventative measures we are encouraged to adopt. In a culture increasingly obsessed with an ethics of personal responsibility, bodily perfectibility and death denial, the evasion of dementia has become an increasingly complex and prescriptive expression of the powers and limits of self and bodily discipline – injunctions to consume green tea, blue berries, omega oils, and Su Doku puzzles point to a whole economy of evasive strategies.

My point is that Alzheimer's – unlike say chronic obstructive pulmonary disease – is embedded in the contemporary cultural imaginary. It has come to stand for dementia, rather than simply describing a particular pathology of cognitive decline and it operates across the cultural domain as an attribution that focuses a range of anxieties around aging, vulnerability, the burdens of caregiving, dependency and familial responsibility. Yet for all this, there is comparatively little critical scholarship on Alzheimer's literature and lifewriting in contrast to say that on HIV/AIDS, cancer and increasingly that on autistic spectrum conditions.

The model that has dominated critical discussions certainly of illness narratives or pathographies is one which sees significant illness or sudden disability as a traumatic event that radically disrupts the canonical life narratives that constitute self identity. Rupturing the fictions of a narrative continuity between past, present and future, serious illness or injury has been explored by numerous scholars as profoundly alienating. This is firstly on the grounds of its capacity to wreak havoc upon the person's sense of embodied selfhood or indeed in its capacity to speak to our embodiment in ways that may not previously have been apparent. It is also tied to (what in the West at least) is an unavoidable confrontation between the rich and particular life narratives of an individual with the discursive and institutional practices of modern medicine. As Foucault points out in *The Birth of The Clinic*, this is an encounter in which the medical gaze places the person in parenthesis in the diagnostic quest for the generic signs and symptoms of disease. Thus for Arthur Frank, the illness narrative is borne out of a impulse to reclaim a sense of self in the face of the what he describes as the colonising imperatives of modern medicine. It is also, he argues, a reparative form that serves as an act of witness, a testimony that seeks to

expose our shared bodily contingency, to make sense of pain and suffering, and to reorient a life interrupted.

A central pillar of scholarly works on illness narratives (and indeed on current scholarship on life-writing in general) is the notion of subjectivity as embodied. Grounding identity in the irreducible materiality and particularity of the body, this paradigm foregrounds the integral relationship between mind and body. Oliver Sacks' *A Leg to Stand On* is often cited as an exemplary exploration of the psychological rupture that follows from bodily suffering. Yet despite this emphasis upon embodiment, the locus of selfhood for scholars such as Franks, Sacks and Eakin remains the mind. Their work assumes a model of subjectivity that is predicated upon the possession of full cognitive function and an ability to construct stories out of the narrative wreckage of serious physical illness. Franks argues that the wounded body begets narratives but is, itself, silent or mute. Eakin argues that subjectivity is contingent upon a capacity to produce narratives and explicitly refers to those with Alzheimer's as 'non-selves'. Sacks questions the very humanity of those without the capacity to remember.

I'm happy to say more about the significance of the body and embodiment within the field of dementia studies later. However, for now, these examples simply highlight the extent to which conditions that involve cognitive impairment fall beyond the normative models of subjectivity (embodied or otherwise) that underpin much of this work. This is perhaps one of the reasons that Alzheimer's first person lifewriting has received comparatively little attention. Not only is the illness supposed to preclude the production of life narratives, there are few critical mechanisms in place that enable one to conceptualise the scripting of damaged subjectivity. For all that critical scholarship on illness and disability narratives emerges to speak to various forms of physiological impairment, certain capacities are often assumed –for instance, full participation in a language community, memory, awareness and so on. Those who do not possess these attributes are easily displaced from the critical scene – figured as non-selves or simply bare but mute lives beyond any form of self-representation.

Personhood at the limits of Life

I raise this issue of the relative marginality of Alzheimer's to current scholarship within the field of disability studies in order to highlight the ways in which the kind of critical paradigms we work within may actually collude with the stripping of personhood of those with profound cognitive disabilities. Within current bioethical debate Alzheimer's has emerged as a key limit case in evaluations of the meaning of personhood and our ethical obligations towards human life. Part of what Paul Rabinow describes as the 'problematization of life itself', these debates turn upon what constitutes a life deemed worthy of living, recognising and protecting, where meaningful life begins and ends, and whether the concepts of 'person' and 'human' (as a designation of species) should be distinguished. Theodore Fleischer distinguishes between two key positions in what he terms the current "personhood wars". First personalism. Here a human being achieves a claim to life and medical resources only if he possesses certain capacities, primarily cognitive abilities and self-consciousness" (1999, 309 and Leibing, 246). Second, "vitalism". Here "every human being, even one who lacks capacities is entitled to have a life" (309, 246).

An example may help here. An advocate of personalism, the utilitarian philosopher, Peter Singer, argues against the ethical principle of the sanctity of human life on the grounds of its incompatibility with new medical techniques and changing public opinion. Describing the belief in the 'equal value of all human life' as 'paradoxical' and 'incoherent' (p.189), Singer argues that the principle of 'equal worth' should be replaced by a new set of ethical maxims that are responsive to contemporary medical technologies and shifts in consensus with regards to practices such as abortion, euthanasia, organ donation, and living wills etc. He thus suggests that rather than founding ethics on the basis of the sanctity of human life per se, the test or criterion for decision making with regards to life and death should be based upon whether the human in question can be described as a 'person'. He defines personhood by way of Locke, as the capacity to 'see [oneself] as existing in different times and places' by having 'wants and plans for the future', 'rationality' and 'self awareness' (n.Locke p.197-8).

For Peter Singer, 'brain failure' and 'person failure' are indissolubly connected and central to a process of adjudication as to which lives are, and are not, deemed to be worth living. This is a process, as Giorgio Agamben would have it, of designating and distinguishing bare lives – the merely human -- from those worthy of legal recognition and protection. In arguing that personhood is that which can be empirically determined by way of a test (as if that might resolve the ethical difficulties that the necessity for such a test presents), Singer's position is founded upon an investment in biomedical discourse as that which provides a neutral and disinterested 'base' upon which the rethinking of traditional ethics and the boundaries between life and death may take place. For him, personhood is an individual property whose value is contingent upon the possession of particular attributes to be determined by the biopolitical apparatus of the state – the institutions of medicine and the law.

In the field of dementia studies, much discussion has focused upon the ethical consequences that follow from the adoption of a model of the person that views cognitive abilities and consciousness as the determining attributes of personhood. Many have pointed out that the boundaries between so-called normal ageing and 'pathological' ageing in Alzheimer's elude precise definition.(Esiri and Nagi). "Lines can be drawn, but their exact location is a matter of evaluative judgement based on correlations between neuropathology and symptoms and signs".(Hughes, 2) In this light, sociological research on dementia by scholars such as Karen Lyman and Jaber Gubrium (amongst others) has demonstrated the powers of medical diagnosis to effect a kind of ontological transformation of the person manifesting the symptoms of memory loss and cognitive decline into Alzheimer's sufferer. The argument is that far from neutral, the process of diagnosis itself is instrumental in producing the impaired subject, condemning them to what Lyman terms 'a self-fulfilling prophecy of impairment' (Lyman,). 'Descriptions' such as "Alzheimer victims, demented, elderly mentally infirm", Tom Kitwood argues, "devalue the person, and make a unique and sensitive human being into an instance of some category devised for convenience or control' (p.7) In this scenario, all behaviour ('normal' and otherwise) becomes flattened out and made sense of primarily in terms of the perceived characteristics of the disease.

This kind of critique of the biomedical paradigm, foregrounds the iatrogenic powers of discourse to produce, and to devalue, the subject it purportedly describes. As such, it places questions of language, discourse and representation – the paradigms through which we ‘know’ and construct dementia – at the centre of ethical debate. Postmodern ethics – and our current uncertainty as to the meaning and value of particular kinds of human life – is characterised by the fracturing of previously inviolable presumptions about the sanctity of life and an absolute boundary between living and dying. In this context, the powers of discourse are considerable – the kinds of arguments that are made, the ways in which conditions and those who suffer them are construed and evaluated not only matters but materialises those bodies in particular ways. It goes without saying that to construct someone as a lower functioning primate or a non-person is hardly ethical neutral and has a significant bearing upon the ways we might treat those with the signs and symptoms of dementia.

First Person Testimony

It is in the context of these personhood debates that we can begin to recognise the political and ethical significance of Alzheimer’s first person testimony. This is perhaps best described as a subgenre within Alzheimer’s lifewriting, the vast majority of which is produced by family members – children and spouses. It is arguable that the interest and appetite for the majority of AD memoirs lies with the fame of either the writer (Jonathan Franzen, Sue Miller, Linda Grant) or the person with dementia (Reagan, Murdoch). First person accounts of living with the disease represent a relatively small number of texts, only a few of which have gained any kind of mass recognition. (McGowin and De Baggio). All the first person testimony I have read is written by those with early onset AD (people in their fifties) and much of it is driven by the need to work through the trauma of such a diagnosis, a sense of the therapeutic benefits of writing, as well as a desire to assert the continuation of selfhood in the face of the diagnosis and the profoundly negative cultural representations of the disease.

Life narratives by those with dementia necessarily write back to dominant assumptions about Alzheimer’s and the ease with which people are consigned prematurely to a form of biosocial death. To write is to align a person with a narrative voice, and to make a claim for social recognition and personhood. Every text

challenges the assumption that those with Alzheimer's disease have no 'self' to realise. Diane McGowin's Alzheimer's memoir *Living in the Labyrinth* (1993) is often cited as a key text within the personhood movement in dementia studies (Leibing). Writing back against the grain of prevailing third person Alzheimer's illness narratives in which the person with dementia was largely eclipsed by descriptions of familial suffering, McGowin writes powerfully of her continuing needs and wants as a woman, rather than simply as an "Alzheimer's sufferer"[n]. Her book challenged the pervasively negative representations of Alzheimer's that emerged in the 1980s, encapsulated in the schlock horror of a range of 'zombie' tropes and in titles such as *Alzheimer's Disease: Coping with a Living Death* (Woods, 1989) and *Stolen Mind: The Slow Disappearance of Ray Doernberg* (Doernberg, 1986). Far from acceding to what remains the dominant popular cultural construction of Alzheimer's as "the death that leaves the body behind", McGowin writes of living with dementia. She describes her book as the embodiment of this claim to personhood; "To you", she concludes, "you are holding a book in your hands. To us, you are holding our lives." (140).

We can see here why G. Thomas Couser argues that this kind of autobiographical text models the "agency and self-determination" for which the disability rights movement campaigns by speaking from *within* a particular condition and thus writing back to a legacy of negative cultural representations. Yet the correlation between a capacity to produce life narratives and personhood is not unproblematic, nor is the framing of such a connection in terms of notions of political agency and self-determination. For if self-realisation through writing is to be tied to social and political recognition we are still working within a paradigm that potentially robs those unable to produce their own narratives of their personhood. What is interesting about the critical reception of McGowin's text is that commentators tend to focus on its eloquence and articulacy as if this in itself is a measure of her right to stake a claim for her continuing personhood. This raises the issue of whether or not notions of agency and self-determination are the most appropriate ways of construing the politics of first person representation in this kind of disability lifewriting. For it is precisely these fictions of autonomy that render the vulnerable and disabled beyond the pale of social, political and often legal recognition. In this context, the question of narrative form – of how the subject is realised through writing – is significant to the degree that particular autobiographical modes construct selfhood as more or less interdependent or relational.

Before I pursue this point further I'd like to take a brief detour around Martha Nussbaum's recent work *Hiding from Humanity*. Here Nussbaum explores the ways in which socially marginalised groups, the vulnerable and the disabled are stigmatised in order to manage deeply rooted psychosocial fears of our own animality and the inevitability of impairment and decline. Her primary concern is with the social extension of forms of shame and disgust. In what, quite typically of Nussbaum, is a lengthy and meticulously argued work, she traces the ways in which disgust expresses a "refusal to ingest and thus be contaminated by a potent reminder of one's own mortality and decay-prone animality" (97). This basic fear of contamination is extended socially through what she calls the practice of "disgust-based social subordination" by which she means the identification of groups of humans to whom the threat of contamination and contagion can be attributed. She focuses in particular upon the interaction between disgust, stigmatisation and the law in the treatment of gays and lesbians, racial minorities and the physically and mentally disabled. The social production of groups of "subordinate humans", she argues, serves to demarcate "a 'buffer zone' between the dominant humans and the aspects of their animality that trouble them" (97). What we see in the stigmatisation of the disabled, and indeed of the terminally and chronically ill is thus an attempt to manage the visceral reality of human embodiment and its limitations through the designation of abject types whose bodies bear the signs of difference and vulnerability.

Nussbaum goes on to develop her argument in the context of socio-legal notions of individual autonomy and a prevailing cultural investment in self-sufficiency and independence. She argues that the "myth of the citizen as a competent, independent adult" (311) is predicated upon a form of constitutive exclusion of those who manifest the signs of our collective fragility:

Most forms of social-contract do, of course, make provision for "normal" human needs, but they do screen from view, in the initial design of basic political principles, all the times of asymmetrical or unusual dependency, even those that result from childhood or old age, stages of life through which all citizens pass. In that way, as Goffman observes, there is a public fiction that a sharp line divides the "normal" from the stigmatized; in reality, the normal and the stigmatized are a part of one another.

Thus the fiction of the independent adult becomes a version of the fiction of perfection, and is itself a vehicle through which those with atypical needs are regarded as dependent, lacking in competence. (311-312)

Nussbaum's point here is that those with "atypical needs" are used to police the 'fictional' boundary between the "normal" and the "unusual". Dependency on others is a characteristic of human life, but one which is placed in parenthesis in political and legal models of citizenship and the ideological fictions of agency and self-determination that they underpin. Forms of physical and cognitive impairment are transformed into disability and those with disabilities are then annexed and managed as distinct and problematic constituencies. They serve to demarcate a realm of imagined 'typicality' – the ideal, independent, fully functioning citizen.

As Nussbaum notes, those with severe forms of cognitive impairment or mental disability are typically excluded from the social contract *per se*. They are divested of legal rights and often excluded from meaningful participation in the social world often as a consequence of institutionalisation and so on. In the context of an analysis of prevailing cultural perceptions of those with Alzheimer's, her argument raises important questions about the usefulness of any model of rights and socio-legal recognition based upon the independent, competent individual. She suggests that a model that recognises our collective interdependency and neediness would be more appropriate to speak to the inevitability of "asymmetrical" dependency at some point in our lives. "Good thought" about both the profoundly disabled and the non-disabled she argues, "requires revising the idea of the citizen as independent bargainer and replacing it with a more complex image of a being both capable and needy, who moves from helplessness to "mutual interdependence", and, unfortunately, often back to helplessness again." (313).

The achievement of this ethics of interdependency is, of course, no easy matter. Nussbaum's discussion of shame and disgust is precisely directed towards an analysis of the profound psychosocial barriers that stand in the way of the social inclusion of stigmatised groups. Her arguments – amongst other recent calls for a more relational or interdependent models of the legal subject --- raise important issues for the way we might approach the political and ethical dimensions Alzheimer's first person

testimony. The impulse to link the production of autobiographical narratives with the expression of agency and self-determination is seductive, but it may be less than helpful in thinking about the politics of representation of this kind of condition.

I guess my problem is really one about how we go about reading and evaluating this kind of writing and the extent to which the realities of impairment are realised or contained within the first person narrative voice. I say this in part because the claims to personhood made in these texts are not simply matters of content or argument but ones which are often tied to appraisals of the articulacy or eloquence of the writing. Of course to make such a judgment runs the risk of placing the realities of cognitive decline under erasure, subsuming the disability in the comforting normalcy of standard English and a coherent narrative voice. To what extent are available autobiographical conventions appropriate to the expression of cognitive impairment – how far does the dissemination of texts in which the narrator passes as ‘neurotypical’ at the level of voice and style, collude with precisely those norms that underpin the stigmatisation of dementia in the first place?

It is worth anchoring these comments in relation to a piece of text. Here is a passage from McGowin’s *Living in the Labyrinth*:

My behaviour was often repetitive as I checked and rechecked the date, the time of day, the location of my purse and other belongings. I was rapidly developing fetishes or mannerisms indicative of slipping capacities. I would ask my husband the date repeatedly. My language became saltier. I ceased driving at night or out of my immediate neighbourhood, yet became anxious and frantic when I was a passenger as someone else drove. However, my laundry might remain in the washer or dryer for an inordinate period of time, usually until discovered by my husband. (100)

This text is indicative of the narrative style of other first person testimony, (Christine Boden and Larry Rose). What troubles me about it is the disjunction between the coherence and stability of the narrative voice and the incoherence and fragility of the matter of narration. It is difficult to square the voice of the narrator with the incidences of memory loss, confusion and misery that are the subject matter of the texts. This introduces a level of epistemological uncertainty as to what is concealed by

these narratives in the process of their production. Of course, this is a problem with writing itself once we recognise its mediated, edited and revised qualities, but it takes on a particular significance when narrative coherence becomes the grounds upon which claims to recognition are made. For McGowin the stability of the narrative voice is tied to the redemptive intent of her text as a whole. But how far does the narrative voice operate as a form of dementia denial in its encapsulation of loss as a thing of the past – separating the subject matter, from the subject of the narrative itself.

[As a reader this may of course be comforting – a way of assimilating the profound unthinkability of dementia, but whose needs does this really serve?]

It is here that I would like to turn to Cary Henderson's *Partial View* as a text that acknowledges the collaborative dimensions of the lifewriting project and the mediation and production of the text itself.

The text combines the transcript of diary entries and reflections upon his illness that he recorded on tape, with photographs by Nancy Andrews. The title encapsulates a range of meanings. First and foremost, it speaks to the diminishing of Henderson's view, and of the difficulties of accessing memories and language: "Just keep in mind" he notes, "that everything you can say or do is partial – you're probably never going to get a sentence – a nice clean sentence that says everything you want to say." (18) It is thus a statement of the difficulties inherent in any Alzheimer's lifewriting project, of the struggle to express oneself in coherent language. The title also relates to Andrews' images themselves – partial views in every sense. It is important to note that there is not a single image of Henderson (bar the 1970s portrait on the final page) in which he engages eye contact directly with the camera. To this degree we are never given the illusion of full unmediated contact with him. He is generally shot at an angle, looking away or down at the ground or off to the side. There are a number of images in which he is shot alongside people but rarely engaging with them. These images suggest a kind of parallel play in which he occupies a shared space but does so alone. In one powerful image his grandchild stands at the window, partly concealed from the rest of the room by the curtains he is about to pull around him and stares directly at the camera. His expression is one of interest and that indefinable thoughtful defiance that only small, resolute children possess. His Grandfather sits in an armchair. His

gaze is empty, barely directed anywhere, but certainly not towards the camera. We see only one side of him. His arm stiff against the arm of the chair, fingers slightly tensed in a partial grip. The light from the window that touches his grandchild, glances off the sleeve of his shirt but the rest of the room is dark, obscured. The position of the child by the window speaks of a connection with the outside world, as does his engagement with the camera. Henderson, meanwhile, is separated from the child by the position of the curtain that serves to divide the image.

Of course, there is much more to say about these images, but at this point it is simply important to establish that they too iterate the sense of partial access. In a literal sense, he is available to see, but in other respects, he is unavailable. In visual terms, at least we are denied the sense of connection conferred by a direct portrait.

The written text relates the process of recording his thoughts as well as his reflections upon Alzheimer's itself:

So if you can get the ideas down, you can communicate better, you can keep your ideas long enough so somebody else can hear them, which may be a very valuable thing.

It's very much worth having – a memory device – an electronic memory device.

I still haven't mastered this, apparently very simple thing of – uh – pushing down the two sides to get the machine to work. Pushing two buttons ought to be the easiest thing on earth. I don't know, I must have another problem besides Alzheimer's. I don't know. (7)

In contrast to the seamless narrative we are offered by McGowin, there is no attempt here to conceal the signs of his dementia. Henderson's description of the tape recorder as "an electronic memory device" reveals both his word finding difficulties and his reliance upon prosthetic devices in his lifewriting project. The text is made sense of for the reader by the accompanying photographic image of his tape recorder. In this sense Andrews' images collaborate in the autobiographical project. Indeed it is only through the dialogue between text and image that our partial view emerges. Some of the images seek to convey a sense of his perspective. The blurring of his feet, for instance, is constructed in such a way as to suggest that Henderson himself is author of the image, recording his own disorientation. It conveys a perception of unstable

ground – and speed, as well as visual disturbance. Andrews also attempts to encapsulate his anxieties about climbing the stairs: “I’m very tentative when I go up a stair, down a stair. I’ve got to hold on pretty tightly, then I’ll go screaming meemies, the uncertainty of one’s footage.” Her image is one that emphasises the steep and relentlessness of a large flight of stairs, with a diminished Henderson at the bottom, almost defeated by the prospect.

Also unlike McGowin’s memoir, Henderson’s text is repetitive and perseverative, returning again and again to his sense of anxiety and paranoia, his fears about being a burden and his hope that his caregivers understand that “being an Alzheimer’s person is – just a little bit of hell.” Of course, the extracts have been edited and selected and shaped in the interest of producing a readable book. (This is stated clearly in the preface by Henderson’s wife). But the text has not been purged of the confusion, slips and ellipses of which Henderson speaks. There is a sense in this text of an alignment of narrative voice and the subject of the narration. The text speaks of dementia at the level of form and content. Henderson’s personhood is asserted in the very act of narration, but his profound difficulties are recognised too.

I think that *Partial View* is an important contribution to Alzheimer’s lifewriting, firstly in its refusal to submerge difference and in its avowedly collaborative nature. The view of which the title speaks emerges through the interaction of image and text, the former illuminating and adding to the latter. Writing of the illness narrative in general, Arthur Franks speaks of the ethical importance of telling a good story of an illness. This does not necessarily imply a kind of unmediated or authentic testimony – but a story that speaks to the complexity and the difficulties of an experience. There is no doubting the impulse to tell such a story on the parts of the writers I have discussed. Yet I believe that to write of Alzheimer’s – to tell a good enough story – may require a different genre – a new set of conventions – fully to speak to the damage wrought by the condition and to the significance of relationships and intersubjectivity to the illness experience. Collaborative texts raise their own ethical difficulties – raising what are perhaps insoluble problems around the different roles and contributions of each author. However, they raise these problems explicitly, rather than subsuming them behind what has always been a fiction – that of the autonomous, independent subject.

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