‘I will not be soothed’: Care, Advocacy, Affect and the Use of Genre Tropes in Refiguring Dementia

Abstract

We currently find ourselves within a ‘therapeutic void’ regarding neurodegenerative conditions resulting in dementia, the suffering of which is only compounded by the contemporary valorization of the ‘hypercognitive’ subject. Similarly, amidst popular discourses of dementia we find ourselves wedged between ‘apocalyptic demography’ and other damning, bleak, and fatalistic representations, or alternatively overly moralized and romanticized perspectives, each of which comes packaged with its own stigmas and harmful assumptions. In this paper I highlight innovative means by which fictional works can partially alleviate these discords through sensitively rendered refiguring of persons with dementia. Drawing primarily on Paul Ricoeur’s threefold mimesis model and idem/ipse typology of identity, combined with Teresa Brennan’s characterization of the ‘transmission of affect’, this paper explores three novels that focus their narratives on female protagonists living with dementia: Emma Healey’s Elizabeth is Missing; Fiona McFarlane’s The Night Guest; and Alice LaPlante’s Turn of Mind. Specifically, this analysis traces the subversive use of genre tropes of the ‘detecting’ novel, observing how the use of mimetically speculative point-of-view and the shift to ‘empathic sleuthing’ helpfully elucidate possible phenomenologies of living with dementia. Furthermore, the discussion unpacks the idea of ‘affective residuals’, which feature prominently in all three of the novels discussed, and demonstrates how these induced feelings and overflows of inexpressibility can be alleviated by forms of affective labor. In this way, the affordances of fiction may open up possibilities of realizing new forms of ‘more-than-body’ care for cognitive ‘others’, and may gently persuade us to consider alternative modes of recognizing cognitive being.

Keywords: dementia, neurodegeneration, affect, Ricoeur, detecting fiction, emotional labor

Introduction

In an essay discussing caring for her dementia-suffering mother, anthropologist Janelle Taylor lamented that when asked about her mother’s wellbeing the most pressing question was always a variant of ‘does she recognize you?’.

1 Implicit within this question, observed Taylor, was also

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an inverse assessment of whether her mother was herself still worthy of ‘recognition’. But perhaps, Taylor suggests, we should focus less narrowly on ‘recognition’ as a quality afforded only to the higher cognitive capacities of the subject, and instead embrace a model of recognition, mutuality, and reciprocity across greater affective and empathic terrain. The difficulty, of course, comes in understanding how we may best realize these modes of affirming accord with one another.

With this important ‘moral challenge’ of reframing perceptions of dementia toward a more expansive model of recognition\(^2\) – and certainly an urgent task given the ‘therapeutic void’ we currently find ourselves within\(^3\) – this paper considers what fictional depictions may offer in elucidating the complex entanglement of sociality, identity, memory, corporeality, temporality, and volitional being. Specifically, this study closely analyzes three novels – Emma Healey’s *Elizabeth is Missing*\(^4\), Fiona McFarlane’s *The Night Guest*\(^5\), and Alice LaPlante’s *Turn of Mind*\(^6\) – that each explore the interiority of dementia through their respective female protagonists.

This paper draws on Paul Ricoeur’s threefold model of mimesis and *idemlipse* typology of identity and temporality, combined with philosopher Teresa Brennan’s influential articulation of the ‘transmission of affect’, along with related ideas sourced from hermeneutics and narrative theory, affect theory, and the medical humanities. In doing so, the discussion will outline how these novels persuasively elucidate the affirming value of affective exchange, and the paralyzing outcomes that can occur when an ‘affective residual’ is forcibly induced within a person.

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\(^4\) E. Healey, *Elizabeth is Missing* (London: Viking, 2014)


\(^6\) A. LaPlante, *Turn of Mind* (Toronto: Bond Street Books, 2011)
suffering from dementia, a subject who may not be afforded the means by which to otherwise unburden themselves of a diminishing state of being.

To further ground the discussion with empirical rigor the analysis is woven throughout with supporting findings from clinical and ethnographic studies of dementia care. This interdisciplinary approach will in turn demonstrate the instructive role that carefully researched and sensitively rendered novels of neurological difference can provide to both professional health practitioners and lay subjects in practicing forms of ‘narrative medicine’. Furthermore, this paper adds to wider discussion of ‘neuronarrative’ works. This genre comprises an emerging body of literature that looks to wrangle with the increasingly influential cognitive neurosciences and their accompanying injunctions upon our conduct and wellbeing, thereby offering a compelling voice within the humanities toward upholding ‘neurodiversity’ and duly recognizing the cognitive ‘other’.

While cognizant of the ways in which scholars of the humanities can both overstate the possibilities of narrative – while simultaneously neglecting other promising avenues – this paper suggests that these novels sensitively articulate that prior to any total debilitation caused by

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dementia there persists a desire to be affirmed as an agent still capable of affective exchange. These fictional works can therefore serve as a form of gentle instruction and advocacy, aiding those persons who live with a form of neurological difference that renders them more dependent on others for positive affirmations of identity and selfhood.

Rethinking Dementia in a Hypercognitive World

There is perhaps no condition that contrasts more strikingly with the contemporary valorization of the ‘hypercognitive’ subject than dementia. This umbrella category encompasses a range of symptoms resulting from neurodegenerative diseases and other disorders (eg. Alzheimer’s disease, Lewy’s body dementias, Parkinson’s disease, cerebrovascular trauma, among other causal agents), and today has a prevalence never before seen, with a predicted quadrupling of Alzheimer’s cases worldwide by 2050, afflicting 1 in every 85 people globally. In many ways, dementia is the exemplar of the double-edge of progress and rationalization, for after either eradicating entirely, curing upon onset, or otherwise reducing the incidence of many once terminal afflictions, we now find ourselves undone by an insidious neurological process for which we lack effective therapeutic interventions, and instead only possess meagre measures by which we can trace its course.

13 A brief qualifier on terminology adopted for this paper: Long-debated considerations of categorical nuance and perceived stigma have led to the DSM-5 largely eschewing the term ‘dementia’, replacing the previous diagnostic ascription with ‘minor’ or ‘major’ neurocognitive disorder. This is arguably a welcome development given that ‘dementia’ has a battery of ingrained connotations that may perpetuate harmful presumptions. However, this change may also prove unhelpful, for the vagueness and lack of cultural cachet of the new designation may render advocacy and other political engagement all the more difficult. That stated, for the following discussion I retain the umbrella term of ‘dementia’, despite its accumulated discursive baggage and its etymological origins of being ‘without mind’. As Margaret Lock notes, for better or worse, ‘dementia’ has ‘symbolic power’ worth protecting while we
Furthermore, it is regrettable that popularly prevailing considerations of dementia are rather limited in scope. Public policy discourse has framed the rise of neurodegenerative disease as an urgent crisis, a forthcoming ‘expenditure time bomb’ that raises the pressing need for ‘participatory biocitizens’ to take personal responsibility ‘to prevent the wastage of their mental capital’. Such ‘apocalyptic demography’ can dominate discursive spaces to the detriment of comparably weighty considerations around autonomy, agency, care, and the importance of ‘emotional labor’. Moreover, efforts to develop therapeutic interventions have proven immensely difficult. Dementia, as a medical category, ‘oscillates uncomfortably between neurological and psychological referents’; usually diagnosed and managed through behavioural and cognitive measures, but only confirmed post-mortem in the brain’s neurofibrillary tangles, plaques, and erosions. Attempts to precisely categorize types of dementia are likewise beleaguered by highly variable manifestations of pathology, such that neurodegenerative disease is ‘expressed more clearly in text than in tissue’. Similarly, clinicians and laboratory scientists alike posit that the aetiologies and causal agents of dementia are a function of complex heterogeneous interactions, almost impossibly difficult to disentangle from processes of age and degeneration, mental illness, and still fuzzy theories of a ‘cognitive reserve’. Adding to simultaneously labor to remove its associated stigma, see M. Lock, The Alzheimer Conundrum (Princeton: Princeton University Press, 2013: p.241). I think it unlikely that the terminology of ‘minor’ and ‘major’ neurocognitive disorders will be taken up in wider usage, and for this reason I maintain that scholarly and advocacy interests are better served by retaining ‘dementia’ as a rallying term, and from this categorial foundation working toward adjusting popular misconceptions. However, while I retain the use of the category of ‘dementia’ there will be little reference to those living with dementia as ‘victims’, ‘sufferers’, or the ‘demented’. Rather, in accordance with typical guidelines from advocacy groups, less evocative and reductive language is used throughout this paper.

21 Especially depression, another ailment of our neoliberal age, see A.F. Jorm, ‘Is depression a risk factor for dementia or cognitive decline?’, Gerontology, 46:4 (2000): pp.219-227
dementia’s formal categorical problems are problematic social constructions of ageing and accompanying assessments of agency and capacity.\(^{23}\) Medical practitioners are also acutely aware of causing unnecessary distress and inadvertently enabling stigma through diagnosis, one effect of which may be an underestimation of actual rates of prevalence.\(^{24}\)

Indeed, dementia raises an array of ethical quandaries, for principles of beneficence, avoidance of harm, and the just accordance of autonomy take on complexities not typically present in comparable conditions.\(^{25}\) For example, already hotly contested considerations of end-of-life processes become even knottier with the added complication of cognitive deficits.\(^{26}\) Also, prior to this end-of-life stage, a person with dementia typically finds herself reckoning with a life stripped of its narrative drive. Once fulfilling and self-affirming occupations and activities are relinquished, further disaggregating one’s sense of identity and narrative as social engagement becomes increasingly difficult.\(^{27}\) Objects lose their previous referents and temporalities clash and collapse, shrinking the temporary coalition that makes up the self into ever smaller windows of coherency.\(^{28}\) Once casual displays of vivacity become strained undertakings, punctured with


increasing failures in ‘passing’ as neurologically ‘normal’.\textsuperscript{29} Ascribed stigmas stick and wound, with all behavior now framed through the new master status of being ‘demented’.\textsuperscript{30} Moreover, dementia ranks as the most feared ailment among lay subjects, which undoubtedly contributes to perpetuating stigma.\textsuperscript{31}

Complicating matters further, neurodegenerative diseases are incredibly idiosyncratic in manifestation and rarely run a smooth course of decline, hence such conditions are not easily amenable to precise, rationalized programs of care.\textsuperscript{32} What manifests is a gradual – but never uniform – disorganization of the self, which in turn requires negotiating a ‘structuring and destructuring’ of the self and its changing relation to the world.\textsuperscript{33} A more expansive articulation of the diverse experiences encountered through living with dementia is therefore crucial. In particular, we should consider how fictional texts might serve to rescue framings of neurodegenerative disease from the current wedged position between: a terminal illness for which we forlornly hope for laboratory breakthroughs; a parlous, maligned state as the seeming antithesis of our ‘hypercognitive’ society; and the resulting sufferance of those who must contend with these conditions in a state of ongoing ontological purgatory.

Fictional works, I argue, can provide insights that can partially alleviate these discords, guiding readers toward richer practices of recognition and refiguring of persons with dementia. Furthermore, thoughtful and well-grounded fictional works may provide instructive and productive speculations on the elusive ontology of living with dementia. This is a pressing task, as characterizations of dementia in popular discourses have long unduly skewed toward monstrous, tragic and nightmarish framings of neurodegenerative disease, in part as an

\textsuperscript{29} Fontana and Smith, ‘The unbecoming of self and the normalization of competence’, (above, n. 27)
inadvertent outcome of early advocacy efforts that strived for gritty realism.\textsuperscript{34} One consequence of these representations has been the imposition of disabling stigmas, whereby we too readily ‘lean on’ presumptions of incapacities, resulting in a ‘discrediting effect’ that may bear no fair relation to a person’s actual functioning.\textsuperscript{35} The identity of the stigmatized person is thus, as Goffman notably put it, ‘spoiled’, with little means available by which it can be repaired.\textsuperscript{36} This is especially noticeable among those in early to moderate stages of dementia progression, where forms of ‘malignant social psychology’ can be unnecessarily imposed, with subsequent self-fulfilling impacts on social engagement.\textsuperscript{37}

Of course, there is no denying that bearing witness to your own or a loved one’s ontological undoing is a harrowing prospect, and – for the most part – the novels to be discussed here certainly do not sidestep such grave considerations. However, these novels also instruct us that sympathy alone ‘misevaluates what is actually important in human life, placing material suffering over spiritual independence’, and so can counter-productively further wound the suffering other.\textsuperscript{38} Note, for example, the ‘ghoulish interest with the extremities to which dementia can lead’ propagated by popular media, producing accounts that are grossly skewed representations of the wide spectrum of life with dementia.\textsuperscript{39} These narratives of dread are cruelly ironic outcomes of popular rhetoric that aims for hard veracity but instead generates either hollow lament or sensationalist horror, edging the source of its concern further across the threshold from subject to object, person to patient.\textsuperscript{40} The regrettable outcome is that dementia


\textsuperscript{36} Goffman, \textit{Stigma}, (above, n. 30)


\textsuperscript{38} Berger, \textit{The Disarticulate} (above, n. 9), p.175


\textsuperscript{40} Zeilig, ‘Dementia as a cultural metaphor’, (above, n. 39)
‘seems to act as a very powerful solvent on many kinds of social ties.’\textsuperscript{41} Persons with dementia commonly suffer a form of ‘social death’, while their primary carers may be wracked with wrenching ambivalence, ‘compassion fatigue’ and even, in many cases, homicidal and/or suicidal ideation.\textsuperscript{42} There is, as Beard, Knauss and Moyer observe, a frustratingly dominant ‘discourse of loss’ that invariably presents dementia in damning, bleak, and fatalistic ways that ultimately serve no productive end.\textsuperscript{43} A ‘disease double’ thus becomes apparent, where persons suffer not only from the disease-in-itself – however it may manifest – but also ‘the layers of stigma, rejection, fear, and exclusion that attach to particularly dreaded diseases’.\textsuperscript{44}

Persons with dementia will eventually lose the referents of themselves as a unified agent, and this disaggregation of self is undeniably awful for all involved. Thus, though it need not be stated, I have absolutely no intention to romanticize neurodegenerative disease in this discussion.\textsuperscript{45} But nonetheless we should reconsider our dominant focus in public discourse on the very latter stages of neurodegenerative disease, for such narrow perspectives may actually hasten the unravelling of selfhood.\textsuperscript{46} It is therefore worth reframing the problem ‘in a way that cuts across the dimension of cognitive impairment’.\textsuperscript{47} One means by which we might achieve such refuguration is by including the voice of the person living with dementia wherever possible,

\textsuperscript{41} Taylor, ‘On Recognition, Caring, and Dementia’, (above, n. 1), p.319; see also P. Werner, ‘Social distance toward a person with Alzheimer’s disease’, (above, n. 28)
\textsuperscript{43} Beard et al., ‘How we reframe dementia through personal narratives’, (above, n. 23)
\textsuperscript{45} See S.R. Sabat and R. Harré, ‘The construction and deconstruction of self in Alzheimer’s disease’, (above, n. 27) for a comprehensive overview of this dissection of selfhood
\textsuperscript{46} T. Kitwood, ‘The dialectics of dementia’, (above, n. 37); T. Kitwood, Dementia Reconsidered (above, n. 37); Lyman, ‘Infantilization of elders’, (above, n. 27)
as firsthand accounts remain relatively rare.\textsuperscript{48,49} One benefit is that including the views of those in early stages of dementia progression allows them to better articulate preferences for the future, thus potentially alleviating some dilemmas of end-of-life care. This pragmatic adjustment also provides a potential source of comfort, for persons with dementia can now exercise a form of agency that extends their temporal being, allowing a greater sense of control over their own narrative.\textsuperscript{50}

Similarly, fictional explorations may contribute to a better understanding of how we may labor to re-align the affective volitions of those living with dementia with their remaining capacities. We are custodians of each other’s selfhood in almost any context of life, and especially so for those living with dementia, who are dependent upon others in realising an accord between cognition, emotion, body, environment, and temporality.\textsuperscript{51} In turn, this shift holds promise for a productive and expansive reconfiguring of selfhood:

‘We may need to stop looking only to individuals as the bearers of “selfhood,” and start looking more at how “selfhood” is distributed among networks, sustained by supportive environments, emergent within practices of care.’\textsuperscript{52}

Through this refiguration we may dismantle prevailing measures of ‘wellbeing’ that insist upon an unrealistically unified, contained, rational subject. We may therefore breathe new vitality into our approach to the neurological subject more generally. As Kitwood observes in this regard:

\begin{itemize}
  \item 48 Many popular biographies of life with dementia, for example, argue persuasively for refigurations that afford more autonomy to the subject. However, though welcome developments, many of these works ‘inevitably put the subjectivity of the carer at the centre, rather than that of the person experiencing dementia’ (see J. King, ‘Fiction as a gerontological resource: Norah Hoult’s \textit{There Were No Windows}, \textit{Ageing and Society}, 29:2 (2009): 297). Curiously, some early works striving to correct this imbalance were authored by carers, who would look to ‘translate’ into poetry or prose what communicative urges they believed resided within those for whom they cared (see Gubrium, ‘Structuring and destructuring the course of illness’, (above, n. 27); Herskovits, ‘Debates about the “self” and Alzheimer’s disease’, (above, n. 34)). Some academic studies now also feature authors or research co-designers who are living with dementia, see Beard et al., ‘How we reframe dementia through personal narratives’ (above, n. 23); J. Knauss and D. Moyer, ‘The role of advocacy in our adventure with Alzheimer’s’, \textit{Dementia}, 5:1 (2006): 67-72; D. Tanner, ‘Co-research with older people with dementia: Experience and reflections’, \textit{Journal of Mental Health}, 21:3 (2012): pp.296-306.
  \item 50 V. Cottrell and R. Schulz, ‘The perspective of the patient with Alzheimer’s’, (above, n. 49); J.N. Clarke, ‘Alzheimer’s disease in mass print magazines’, (above, n. 34)
  \item 51 King, ‘Fiction as a gerontological resource’, (above, n. 48), p.297
  \item 52 Taylor, ‘On Recognition, Caring, and Dementia’, (above, n. 1), p.326
\end{itemize}
‘… one of the crucial factors is the extent to which the “experiential self” has or has not been well-developed: that is, an integrated centre, grounded in feeling and emotion. For this can remain when the “adapted self” (derived from role-performance and meeting others expectations) declines – as is very often the case for people in later life.’

Narrow, coolly objective clinical gazes can often result only in a needless denuding of the self, inadvertently depriving other ways of maintaining and affirming being. Fictional explorations are thereby one means by which we may get closer to elucidating the quotidian (ar)hythms of living with dementia. Perhaps, as King suggests, ‘only imaginative reconstruction can hope to explore the experience of memory loss beyond the point when the very attempt to write fails’. To this end, the fictional characters living with dementia discussed herein are presented as precariously teetering in a ‘liminal state’; neither as capable as they once were, nor past a point where forced reductions in autonomy will not harm self-esteem. These elusive, shifting subjectivities are the central focus of these novels, explored with a depth and knowing that allows for empathy, rather than just sympathy, and so proves both consoling and gently instructive.

Sadly though, not all creative works presenting neurodegenerative disease adhere to such a mandate. Popular films, for instance, can be especially susceptible to exploiting dementia as a lazy trope or convenient plot device. Block also observes a similar trend in the incorporation of dementia in some works of literary fiction:

‘Nearly every novel I’ve read that attempts to depict the internal experience of Alzheimer’s also attempts to fit the disease’s retrogenic symptoms to one sort of sentimental trope: a reckoning with a repressed or unacknowledged truth that must come before acceptance is possible.’

Such practices introduce an unnecessarily moralized quality to depictions of terminal illness, and this tiresome troping and inane sentimentalizing of dementia can prove grossly unhelpful. The

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54 King, ‘Fiction as a gerontological resource’, (above, n. 48), p.297
56 Segers, ‘Degenerative dementias and their medical care in the movies’, (above, n. 34)
popular proffering of melancholy and pity without the offer of genuine consolation, empathy, and alleviation of suffering risks becoming unwittingly exploitative, reducing those with dementia to objects of pity through which we contemplate the fine margins of life.

However, some fictional works feature characters living with dementia in ways that are plausibly woven into wider contexts. Novels, in addition, can more capably access interiority and depict subjective states with a depth that other media cannot readily equal. Moreover, the slow, nuanced unravelling of a novel allows for a slow-burn form of advocacy, for readers can bear witness to protagonists at their most vivacious selves, pre-dementia, and then travel with these characters as they are steadily ontologically reconfigured through their ailing brains. Given that we enter into a novel by making what Paul Ricoeur described as a ‘wager’ – ie. we actively enter ourselves into a form of alterity and stretching of empathic capacities – then fictional works hold great potential in opening up new avenues for how we might approach neurological difference.

**Residuals and Transmissions of Affect**

Central to this discussion is first noting that these novels take great care in illustrating the paralyzing harm of ‘affective residuals’. To elaborate on this term, observe how Emma Healey, author of *Elizabeth is Missing*, articulates her primary motivation in writing the novel:

‘The misconceptions about the illness upset me more than anything, the idea that you can be less than pleasant to somebody with dementia ‘because they won’t remember’,

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whereas in fact the feelings evoked are residual. They know something is wrong, that something bad has happened, and they don’t always forget that.61

Bruising encounters thus create lingering stings, which can become a discomfiting and disabling ‘affective residual’ once the trauma is shorn of its original context. This observation of suffering through affective residuals is a shared interest in all of the novels to be discussed, and demands further explication for what it may offer in refiguring the demented subject. Certainly, as Healey touches upon above, recollection encompasses far more than simply the descriptive, semantic content or event-oriented ‘plot’ of an encounter. Rather, remembrance is always laced with affective import, lest we would otherwise have no inclination to ponder upon it at all, and as we cannot ‘rationally’ parse all matters that enter into our orbit some shortcuts of affective valence are required.62 Hence we viscerally recall the affective imprints left by others through our interactions with them, gathering together a contextualized reverie of embodied dispositions, corporeal volitions, and their accompanying narrative thrust. Contrary to those harmfully ignorant assumptions highlighted by Healey, affective wounds can be even more harmful when their aetiology is lost, for the inability to connect the injury to its source may leave one in a state of crippling dissonance. I should note as clarification that the recent affective turn in critical theory carefully distinguishes between ‘emotion’ and ‘affect’, so as to open up an ontology of the latter that is irreducible to personal identity, hence we must be careful not to harm conceptual utility in conflating the two.63 That said, while residual affects are not constitutive of identity

and intentional being in the way emotions may be characterized, their very quality of being contained and rendered inert within a single subject through the diminishing actions of others is their key defining attribute in this discussion.

To clarify this further, the work of Teresa Brennan provides an account of affect that convincingly conceptualizes the injurious residual felt by many persons with dementia. Brennan’s *The Transmission of Affect* offers a useful entry point toward reframing cognitive being, demonstrating how properties of the self typically considered intangible, elusive, and ineffable can instead take on a highly visceral quality, a motion and causal agency, but only if we can resist pre-emptively excluding them when assembling the idealized modern subject endowed with ‘high’ cognition. Brennan describes the ‘transmission of affect’ as ‘a process that is social in origin but biological and physical in effect’, with ‘enhancing or depressing energies’ that emerge as they move between volitional beings. Regrettably, argues Brennan, we have typically assumed that ‘to be a worthy object of study, the individual has to be severed from affective connections with the surrounding environment and others in it’. Such hypothetico-deductive constructions speak to ‘primarily modern and Western approaches … that assume that the individual is an energetically self-contained or bound entity, whose affects are his or hers alone’. This insistence on the ‘bounded’ subject brings with it normative expectations of conscientiously managing one’s affective state so as to avert its undesired intrusion into everyday life. Those who are deemed neglectful in managing their affective state in ways aligning with overarching

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65 Ibid., p.3
66 Ibid., pp.18-19
67 Ibid., p.24
expectations will be ascribed a ‘borderline’ status, seen to be ‘susceptible as well as liable to “leakage”’, 68 or to being ‘taken over’ by affect-laden dispositions. 69 Yet these ascriptions fail to recognize that such an ethic of self-care is a ‘culturally specific idea’ that ‘presupposes a self-contained individual’. 70 The emerging cognitive sciences, suggests Brennan, are so enamored with importing prevailing societal dictates into the neurological terrain that they risk becoming ‘caught up in the very process it should be analyzing’ . 71 The result is the valorization of the subject capable of conscientiously quelling their affects, and thus ‘self-containment is not only a delusion but also an achievement’. 72 Undoing these hard ascriptions may allow for refigurations of the cognitive subject less dependent on the tacit assumption that we are ideally realized only when sufficiently ‘hypercognitive’. Before further developing this conceptual framework by discussing possibilities for refiguration, however, the reader may best be aided in following this analysis through brief overviews of the novels addressed herein.

Elizabeth is Missing – Emma Healey (2014)

Maud is an elderly yet still sprightly woman living with dementia, who is generally left alone to while away the hours, watching daytime television with sardonic puzzlement and following (or resisting) handwritten instructions scattered about her home. But something is troubling Maud: her friend Elizabeth is missing. Maud’s own scrawled notes remind her of this repeatedly. However, her concerns are dismissed by others, and so Maud sets out to investigate, gamely attempting to compensate for her lapses of memory through diligent note-taking. As she

68 Ibid., p.26
69 Ibid., p.15
70 Ibid., p.25
71 Ibid., p.63
72 Ibid., p.63
searches for clues the narrative is intercut with Maud’s lucid memories of her sister Sukey, who went missing in suspicious and unsolved circumstances when they were young. These haunting reveries of the past are triggered by sensory stimuli in the present, emerging with such vividness that Maud often finds herself caught unawares by her subsequent behavior. As the novel progresses these two mysteries become further entwined, generating an urgency and escalating tension heightened further by Maud’s steadily declining capacities.

The Night Guest – Fiona McFarlane (2013)

Ruth is a 75 year-old woman, residing in a secluded coastal setting where she and her husband chose to retire. However, Ruth’s husband dies of a heart attack, and she finds herself alone as dementia begins to take hold. By Ruth’s own weary assessment, life has simply seemed to stop. However, one evening Ruth’s ‘blurry brain’ senses the presence of a tiger in her home. Ruth well knows that the tiger cannot possibly be ‘real’, yet its veracity seems undeniable, embodying something of ‘extravagant consequence’. The next morning brings the arrival of Frida, who announces herself as Ruth’s new carer. Ruth soon finds herself equally distrustful and dependent upon Frida, whose own presence is unmistakably tiger-like: playful, powerful, unpredictable, and sometimes fearsome. The two unannounced arrivals stoke a foreboding mood, instilling a deeply felt resolve within Ruth to realize unfulfilled but hazy desires before her remaining autonomy is entirely foreclosed. As Ruth’s dementia worsens the ability to assert herself against the domineering Frida wanes. Ruth thus finds herself in a claustrophobic,

73 McFarlane The Night Guest (above, n. 5): p.107
74 Ibid., p.1
75 Ibid., p.4
threatening space, seeking reconciliation with the world before her volitional unity is irrevocably eclipsed.

**Turn of Mind – Alice LaPlante (2011)**

Dr Jennifer White is a former orthopedic surgeon, specializing in hands. Now retired after dementia has undone her once formidable intellect, Jennifer finds herself bewildered by investigations into the homicide of her both confidant and adversary, Amanda, found deceased with four fingers of her hand removed with surgical expertise. Jennifer’s husband passed away some time ago, though she regularly forgets this, and her two children fill her with discomfitting ambivalence regarding their underlying motives and genuine care for her wellbeing. Jennifer also regularly forgets that Amanda is dead, yet a residual discomfort remains throughout, presumably attached to this loss, and so as her condition worsens Jennifer works feverishly to correct this discord, reassert her autonomy, and to be once again recognized as a being worthy of respect and affection.

Despite their seemingly pat templates note that these novels are not typical examples of the ‘detecting’ genre. Moreover, the resolution sought in these narratives is not one of ‘finding the killer’ or otherwise revealing the true intentions of some nefarious figure hiding in plain sight. Rather, though these familiar genre tropes certainly help to orient the reader through the text, rather more pertinent is the protagonists’ quest for a form of reconciliation with the world, of realizing an ontological mode that can enable them to navigate the liminal state of living with a neurodegenerative disease.
Furthermore, the point of view chosen in these novels is notable, for they each reflect an aspiration to accord greater narrative voice to persons living with dementia. Emma Healey ambitiously adopts a first-person perspective of life with dementia throughout the entirety of *Elizabeth is Missing*. Fiona McFarlane adopts a slightly less demanding third-person limited view, with interiority restricted to her protagonist, Maud. Alice LaPlante, alternatively, while funneling most of the narrative through the first-person perspective, later shifts into the rarely-used second-person and then briefly into close third-person in the novel’s epilogue. Within each perspective though, it is clear that Jennifer’s authorial voice is our sole window onto proceedings, even if she cannot comprehend the import of what she witnesses. The implication embedded in these distancing shifts in point-of-view is to demonstrate how Jennifer is becoming estranged from herself as her neurodegeneration worsens.

These three novels also share some remarkably similar characteristics. Most obviously, each features a female protagonist living with dementia, who find themselves charged – of their own accord – with detecting something of immense gravity. Katsura Sako, in her own analysis of *Turn of Mind* and *Elizabeth is Missing*, deftly highlights this critical reconfiguring of the detective novel, shifting away from the patriarchal model of the cool, rational, dissecting male protagonist to the watchful female protagonist, who alternatively detects through reading the affective state of others.⁷⁶ Our three protagonists do not piece together clues from bloody fingerprints and matchboxes left at the scene, nor through dubious leads given by seductive femme fatales, but rather through their capacity for empathy. These neuro-atypical protagonists

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search faces, surveil hands, and attend closely to voices in their quest to uncover the hidden truths in others. Like Sako, I am interested in the ways that genre tropes may be subverted in service of a reparative advocacy for the subjugated ‘other’, thereby dismantling constrictive ways of imagining subjective being. However, while Sako persuasively focuses on how such novels undo the stale gendered premises of detection, I am more concerned here with what these novels of dementia may offer to better understanding the problematic ways in which persons living with dementia – particularly women – are subjected to ‘banned emotions’ and other affective regulation, and yet it is these very valances that give the protagonists an affirming sense of identity and intentionality: a will to remain with us.

Refiguring Dementia Through the Affordances of Fiction

The exploration of subjective experiences of dementia by subverting genre tropes raises productive possibilities of refiguring harmful depictions of the ‘demented’ subject, and of how we represent idiosyncratic conditions so often characterized by their inexpressibility. Here we may turn to the work of Paul Ricoeur, philosopher and literary theorist known particularly for operating between phenomenology and hermeneutics. Ricoeur’s core philosophical outlook is relational, tracing how affordances, vulnerabilities, and perceptions of self are shaped through our interpretations of the world and subsequent extensions of ourselves into this terrain. The

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idealized Ricoeurian thrust of literature is to extend an interpretative circle, building hermeneutic bridges between subjects through narratives informed by an ethic of reciprocity and recognition. This, for Ricoeur, is a ‘restorative’ criticism, capable of resurrecting texts by unfixing them from their set contexts, opening them up to reincorporation into new settings, and thereby potentially ‘restoring’ subjects otherwise dismissed or maligned.\(^{80}\)

Ricoeur is also interested in the relations between narrative, temporality, and ethical potentials within these imbrications. Ricoeur affirms the sociological truism that our identity is a function of our engagements with others, and thus while we can doggedly attempt to self-sculpt it is ultimately others who are the ‘custodians’ of our selfhood.\(^{81}\) The crucial measure of ethical being may therefore not be those markers of virtue gained by way of personal asceticism or adhering to prescribed principles, but rather those more elusive and performative extensions of seeking communion with others in whatever ontological space we can find them, willfully reconfiguring oneself in service of another. This ethical labor takes on greater urgency where dementia is concerned, for we must seek to maintain the narrative grounding of another in ways that require creativity and vulnerability; both are necessary in order to ‘get into the world’ of those for whom language and other higher cognitive functions are no longer viable.\(^{82}\)

With restorative hermeneutics in mind I should note what may appear to be a crippling contradiction in these fictional explorations of dementia. A form of this critique was articulated by Andrea Gillies in her *Guardian* review of *Elizabeth is Missing*, wherein Gillies expressed

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\(^{81}\) Ricoeur, *Oneself as Another* (above, n. 79), and this is especially apparent in cases of dementia, see M. Hepworth, *Stories of Ageing* (Buckingham: Open University Press, 2000); King, ‘Fiction as a gerontological resource’, (above, n. 48); Taylor, ‘On Recognition, Caring, and Dementia’, (above, n. 1)

incredulity regarding the novel’s point-of-view, suggesting that the slippery interiority presented becomes steadily more implausible as the cognitive capacities of Maud declines, yet the reader is presumed to consider her somehow ‘secretly articulate’. There is perhaps some bite to this critique, for Maud certainly maintains a richly eloquent stream-of-consciousness prose style despite her waning capacities, as does Ruth in *The Night Guest*. Alice LaPlante’s *Turn of Mind* foresaw this criticism of the demented-yet-articulate point-of-view, cleverly sidestepping this contention while simultaneously acknowledging the elusive, unavoidably speculative quality of representing neurodegeneration. LaPlante achieved this by, firstly, blurring the distinction between speech and thought, and secondly (as noted earlier), steadily shifting the point-of-view as Jennifer’s undergoes a dissociation from self. Throughout the entirety of *Turn of Mind* no usual markers of punctuation are used to signify speech. The intention of this is to obscure – from both Jennifer and the reader – whether she is speaking or merely thinking. This communicative blurring mirrors the conflation of thought and speech that can occur among persons with dementia, who often find it much harder to navigate usual social decorum due to this slippage. Likewise, the speech of other characters in *Turn of Mind* is denoted by italicized writing (rather than any quotation marks). This subtly undermines the veracity of whatever is ‘heard’ by Jennifer, and so deftly acknowledges the declining ability of many dementia-sufferers to follow the semantic content of other’s speech.

However, Gillies’ criticism unjustly reduces point-of-view to a tame function of depicting only the semantic and neatly denotive ‘internal monologue’ of characters, which in itself is an implausible,

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hopelessly a-mimetic construction of our interiority. Furthermore, part of the very telos evident in various techniques of narrative voice is to render communicable that which may otherwise seem inaccessible and inexpressible, enabling the text to serve as a hermeneutic bridge between subjects. Entering into any narrative requires this willing suspension, of recognizing this liminal space of the ‘secretly articulate’, where ‘we must understand in order to believe, but we must believe in order to understand’, willingly ‘exposing ourselves to the text and receiving from it an enlarged self’.86 This, for Ricoeur, is a ‘wager’ we are asked to make, giving our credulity in good faith, laboring together to liberate what may at first appear opaque and impenetrable. Ricoeur thus construes mimesis and creative hermeneutics not as an attempt at reproducing the world-as-is, but rather seeking to illuminate the meaning behind action for an expanding interpretive circle, rendering a phenomenological state accessible and affectively salient to a greater number of others.88 These imaginative labors extends the ‘possible theatre of my liberty’, for to discover new means of seeing oneself as another is to unshackle those binds of deadening solipsism.89

Ricoeur proposed a threefold or ‘triple’ model of how mimesis may be achieved, aspects of which take on curious nuances when applied to novels of dementia.90 Firstly, both reader and protagonist must be suitably prefigured through the presentation of a willful agent operating in a recognizable context. This agent need not necessarily be ‘high functioning’, but we must be sufficiently clued into their capabilities and their relation to the presented social terrain, so that

86 Ricoeur, The Symbolism of Evil, (above, n. 60), p.351
88 Simms, Paul Ricoeur (above, n. 87), pp.61-85
90 Ricoeur, Time and Narrative Vol. I: (above, n. 79), pp.54-76
we may duly adapt to this interiority. Through this adaptation to the cognitive ‘other’ we can avoid hasty interpretations that flattens character’s motivations into nothing more than misfiring synapses, and instead align ourselves with another ontological space where our protagonist still remains ‘finely aware and richly responsible’, a quality Henry James deemed necessary for any worthwhile drama.\footnote{H. James, The Princess Casamassima, (New York: Penguin, 1977): p.133} As such in all three of the novels featured here we are introduced to fiercely independent and intellectually acute protagonists seeking urgent ends, before gradually adjusting our figurations of them as we bear witness to their cognitive decline, suffering greatly in societies that expressly valorize the high functioning cognitive subject and fear the degenerating one. Prefiguration in this highly particular context of the ‘detecting neuronovel’ also requires recognizing the authors’ deployment of common plot templates, followed by their respective subversions of genre. We can then align these genre adaptations toward better understanding the lived experience of Maud, Ruth, and Jennifer’s cognitive disorders. For example, while the reader will soon be aware that Maud’s friend ‘Elizabeth’ is not ‘missing’ at all, this in no way diminishes the narrative as supposedly dependent upon an unoriginal trope within the mystery genre. Instead, we, quickly recognize that the primary aim of using this genre template is to delicately explore something far more urgent and elusive, rather than simply propel a thrill-by-numbers plot. Similarly, while The Night Guest – which frequently uses fugue-state, surreal elements – may set itself up as yet another entry into the already crowded claustraphobic psychological thriller canon, we quickly understand that such titillation is certainly not McFarlane’s main objective. Ruth knows the tiger is not materially real, but that does not preclude the phenomenological reality that Ruth is witnessing the tiger as some avatar
of portent that is otherwise inexpressible. We are therefore asked only to accept that the internal state of someone with dementia could plausibly manifest this spectral being.92

The second part of Ricoeur’s threefold mimesis concerns configurations: the lines of possibility open to the protagonist (and the reader, who likewise imagines these paths), the varying urgency of their realization, and the means by which the protagonist is compelled toward enacting these ends. For Maud, Ruth, and Jennifer to be suitably configured to action thus requires the reader to buy into the import of the mysteries they each feel compelled to solve, respectively: ‘Where is Elizabeth?’; ‘What does the sudden appearance of the tiger and Frida signify?’; and ‘Who killed Amanda?’, mysteries which in turn are placeholders of greater, but more elusive drives for reconciliation with the world.

Lastly, Ricoeur posits that mimesis requires acts of refiguration. We, the reader, must find a way to accommodate what the text might afford us in our own lives and the lives of others, thus expanding the text’s hermeneutic reach. Our labor of willing suspension also requires considering how the text may helpfully instruct, advocate, and petition us to action, stretching our empathic capacities beyond just this specified context. If we cannot imagine such refigurations, the utility of the narrative is diminished, with potential affective transmissions now inert and trapped within its bindings, and the means to effect change lost.

Inevitably, those with dementia will reach a stage where it appears they can no longer be reached by even our most dedicated efforts of care, and these novels certainly do not indulge romantic

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tendencies by avoiding these hard realities. Catherine Malabou describes such unfortunates as ‘figures of the void’, with whom we can no longer find communion through our therapeutic endeavors, and thus they steadily, irrevocably, slip into abysmal alterity, one marked by the absence of self:

‘The worst dissensions of the subject with the self, the most serious conflicts, do not even look tragic. Paradoxically, they are signaled by indifference and coldness.’  

Through dementia the synaptic self is slowly suffocated, neuronal networks steadily unwound, and with it the range of cognitive capacities the sufferer might still perform. This degeneration may occur without any outward change, save for the gradual subduing of dispositional displays, eventually leading to this seeming ‘indifference and coldness’. Our collective ingenuity has solved the maladies of old, never before have we been more resilient to the decomposition of our bodies, but now we must contemplate the disintegration of subjectivity itself. How can we find our way to these ‘ontological refugee[s]’, who themselves are only partial witnesses to their ongoing dissonance and dissension of self?  

Here, Dutch author J. Bernlef attempts to capture this precarious, melancholic liminality in his own novel of dementia, Out of Mind:

‘I am being split open from inside. It is a process I cannot stop because I myself am that process. You think "I," "my body," "my mind," but these are only words. They used to protect me… But now there is a greater force holding sway in me, which is not to be gainsaid. I don't want to think about it any more.’  

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94 Malabou, Ontology of the Accident, (above, n. p.94)  
Observe here the suggestion of internal betrayal, and of ‘mind’ and ‘body’ as occluding constructs of language, concepts once protective and dependable, but now shown to be mere facades. A former unity is lost amidst dementia, one to which Malabou invokes Spinoza, who remarks:

‘Here it should be noted that I understand the body to die when its parts are so disposed that they acquire a different proportion of motion and rest to one another. For I dare not deny that—even though the circulation of blood is maintained, as well as other [signs] on account of which the body is thought to be alive—the human body can nevertheless be changed into another nature entirely different from its own. For no reason compels me to maintain that the body does not die unless it is changed into a corpse... And, indeed, experience seems to urge a different conclusion. Sometimes a man undergoes such changes that I should hardly have said he was the same man.’

As Spinoza observed, certain biological mechanisms can still operate for extended periods after a trauma is inflicted, but they may do so without ever again coalescing to form a whole concert of volitional being, and consequently an escalating discord takes hold. Through neurodegeneration we witness the cleaving and disassembly of life’s ratio and motion that begins with a series of small betrayals. A name is forgotten, an appointment missed, or we find ourselves lost in a familiar place. Temporalities flatten, overlap, become otherwise distorted, or we feel trapped within a body rendered alien by odd motor function. Ricoeur has his own adaptation of Spinoza’s ratio, specifically a ‘ratio of fallibility’, wherein a disjuncture or disproportion can

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occur between what is willed or conceivable in the universal (logos), and what is possible of a physical being bounded in the spatiotemporal (bios). This ratio of fallibility is measured by the varying accord or discord between one’s imagination, character, and feeling. Of course these measures can never entirely align and reconcile with each other, for this would suggest an inert homeostasis. Rather, it is the constant churn of imbalances and corrections that propels this Spinozan motion; a self constantly at work between what seems willed by the indexical ‘I’ and what volitions appear to simply arrive from the ether to compel the subject one way or another. The difficulty, as will be shown below, is when ‘imagination’, ‘character’, and ‘feeling’ can no longer be reconciled to each other at any point in time. With this theoretical framework and empirical grounding now in place, the following sections will explore the ways in which these novels of dementia achieve forms of mimesis through the delicate, variegated constructions of identity and volition, corporeality and affirming touches, and the relation of temporality to overflows of inexpressibility.

Identity, Volition, Pleasure, and Purpose

Ruth, Maud, and Jennifer are each imbued by their respective authors with a sense of great urgency. Some momentous end must be realized before they no longer have the requisite wherewithal. However, these longings for a kind of reckoning are not clearly demarcated tasks of the typical hero’s journey, nor do they represent the aforementioned moralistic making-amends-for-past-mistakes narrative hooks that Block justly abhors. Instead these ‘conatic

99 Simms, Paul Ricoeur, (above, 88): p.16
100 Block, ‘The literature of Alzheimer’s’, (above, n. 57)
hopes are more elusive, capturing something inexpressible that seeks to be freed from the confines of slipping minds. For Ruth, this is signified by the tiger, ‘her consequential visitor’, to whom she is both fearful and ecstatic:

‘A tiger! Ruth, thrilled by this possibility, forgot to be frightened and had to counsel herself back into fear.’

The tiger is not intended to signify any single thing – McFarlane herself has admitted as much – but rather gives visceral form to the heady confluence of memory, longing, fear, and sheer possibility that Ruth feels as her ontological composition shifts into a state of alterity and dissolution. This tiger is a nonchalant, untamable predator, coming and going and doing as he pleases. Ruth is dramatically reinvigorated by this presence, one she desires to emulate, adopting the tiger’s demeanor to counter the domineering presence of the new carer, Frida. Ruth knows the tiger is some portent of change and finds this marvelously enlivening after previously lingering in numb isolation. The arrival and portentous threat of both the tiger and Frida instils a fevered urgency within Ruth, a desire to regain control of her narrative and to project herself into the future with a clear sense of personal identity. This self-projection includes pondering desirable affective states, such as mulling over a forthcoming visit from an old flame:

102 McFarlane, The Night Guest (above, n. 5), p.23
103 Ibid., p.2
104 F. McFarlane, ‘Interview with Caroline Baum’, Booktopia, available at https://www.youtube.com/watch?v=7AunZbsfL2Y
105 Frida herself is partially mirrored in the avatar of the tiger, with her large but graceful and skulking presence, and brightly colored hair.
‘Ruth sat still with the idea of Richard. She was surprised by how much she wanted to see him, and also by the pleasure of wanting. He would be an arrival – one that she had asked for, that she had planned.’

This ‘pleasure of wanting’ – and the capacity to plan for its fruition – is clearly significant to Ruth’s sense of identity. Likewise, Ricoeur suggests that identity is retained through the ability to place oneself in a propulsive mechanism of narrative, where identity denotes not simply idem or ‘sameness’ over time, but ipse, a form of constancy through change. That is, identity is affirmed through the motion of a ‘plot’ that allows for constant but steady, coherent refiguring of self. However, both idem and ipse are threatened by the onset of dementia. For one, the ‘sameness’ of idem is clearly undone by neurodegeneration itself, with physiological changes taking place that undermine those capacities which enable ‘fixed’ aspects of identity. These degenerative processes will steadily erode short term memory, language capabilities, problem solving capacities, regulation of mood and emotion, and eventually long-term memories and basic motor functions. Under this new regime, ‘sameness’ is simply impossible, for its requisite mechanisms are no longer present. However, the more narratively relevant ipse – ie. those ontological shifts found to be contributory to self-actualizing – can remain tenable for those with dementia. Ruth’s ‘pleasure of wanting’, then, is felt as an intensely satisfying projecting of herself across time through a future-oriented narrative; thus re-affirming the steadying comforts of idem while expanding the volitional possibility of ipse. Unfortunately, Ruth’s pained desire to maintain an indexical and pleasure-seeking unity runs counter to carer Frida’s attempts to quell and dull her vigor in routine habits. Consequently the novel’s unfolding follows a tense descent

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106 McFarlane, The Night Guest (above, n. 5): p.64
of increasingly claustrophobic and delirious encounters, as each woman looks to impose their will on a subjectivity becoming untethered from reality.

Alternatively, in Healey’s *Elizabeth is Missing*, Maud’s coherency of self is tightly affixed to her search for Elizabeth, whom Maud believes is missing. However, the reader will soon grasp that Elizabeth is not actually missing, yet will also understand that Maud simply cannot retain this otherwise indisputable knowledge of Elizabeth’s whereabouts. Instead, ‘Elizabeth’ is felt as a constant lack, a gnawing absence within Maud. When Maud cannot attach the fitting signifier to this affective gap her handwritten notes serve as a reorienting reminder that Elizabeth is ‘missing’, and so reconciles Maud with a clear narrative foothold and imperative to action. Maud’s family patiently try to reassure her that Elizabeth is *not* missing and – in a good faith attempt – Maud tries to yield to their pleas by dutifully writing herself a note to persuade her distrustful mind of the ‘truth’.108 However, this does not reconcile the deeply felt lack, for soon thereafter the affective gap re-opens:

‘Not that again,’ Carla says. ‘I thought you’d given it up?’ She points to the sign on the wall. [Whereon Maud has written a note to herself: ‘Elizabeth is not missing.’]

‘Oh yes,’ I say, laying down my pen. I feel disappointed, as if I’ve lost something valuable.109

What is ‘valuable’ but lost here is the volitional unity that comes through narrative propulsion. If Elizabeth remains ‘missing’, the affective residual Maud feels is no longer inert but flowing in

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108 Healey, *Elizabeth is Missing* (above, n. 4), p.81
109 Ibid., p.83
an affirming course, providing an intentionality that extends Maud into the world through the desire to effect some positive action upon it:

‘I have a nagging feeling that there’s somewhere I’m supposed to be. I put on my coat and walk out. I can’t think where I’m going, but that doesn’t matter, I’m sure I’m supposed to be somewhere and I must come to it eventually.’\textsuperscript{110}

‘The next street is just as strange and my heart gives a thud in my chest. I’m running out of time. I’ve got to get somewhere, or to someone. It’s urgent.’\textsuperscript{111}

Maud is so utterly beholden to transmitting this affective residual that her narrative of self cannot be maintained without this definite task that compels her to action. This ‘detecting’ task, therefore, is generative of a consolation that – though strictly speaking based upon a falsehood – is Maud’s best means of persisting in the world. Without it she is stricken and stranded, completely undone. Gillies’ aforementioned review of Elizabeth is Missing unfortunately missed the importance of recognizing that these distresses of desiring to intervene upon the work can actually prove enlivening and affirming, skeptically noting that:

‘It’s tempting to wonder why a woman constantly writing herself notes – and still able to read them – hasn’t also written down the solution to the Elizabeth mystery, which, it transpires, Helen [Maud’s daughter] has explained to her over and over again.’\textsuperscript{112}

But this is the very point: the mere ‘solution’ to the ‘mystery’ cannot, in itself, resolve a lack Maud registers within herself, for the ‘missing person’ is an avatar of some greater resolution Maud is seeking but cannot yet contextualize into recognizable form. Regrettably, Gillies’ query

\begin{itemize}
\item \textsuperscript{110} Ibid., p.89
\item \textsuperscript{111} Healey, Elizabeth is Missing (above, n. 4), p.140
\item \textsuperscript{112} Gillies, ‘Elizabeth Is Missing review’, (n. 83)
\end{itemize}
is analogous to instructing a person with phantom limb syndrome to constantly gaze upon the amputated appendage in order to confirm that, yes, the missing-but-still-felt limb has not yet returned. If executive cognitive capacities fail to align with felt volitional imperatives then a discord is inevitable. Affective residuals thus emerge, yearning for empathic ‘transmission’, rather than the impossibility of rational ‘correction’. Again, the mode of ‘detection’ presented in these novels is significant; our protagonists are empathic sleuths, not coldly deductive private dicks.

The readers thus recognizes that Elizabeth’s ongoing status as ‘missing’ instils a momentum that keeps Maud reconciled with the world. Indeed perhaps it is the only thing maintaining her narrative unity, and thus Maud seems desperately compelled to retain this propulsion to action. In every instance where others attempt to convince Maud of the truth she immediately slips into a void, bereft of meaning, only to be brought back by the eventual act of forgetting this correction. In a telling scene, Maud is undertaking a diagnostic assessment of her cognitive capacities in which she fails every measure except for one: when asked to write a complete sentence Maud neatly jots ‘My friend Elizabeth is missing’. It is this desire to effect a positive action upon the world that enables Maud to retain her capacities in the face of radical ontological transformation, personal loss, and callous treatment by others (see below).

**Corporeality and the Affirming Touch**

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113 Healey, *Elizabeth is Missing* (above, n. 4), p.156
Explorations of embodiment also feature prominently in these three novels, occasionally as felt absences, other times as affirming expansions of self. Indeed, often it is an uncanny combination of both, such as when Ruth contemplates her shifting mode of being:

‘When she woke early the next morning, Ruth couldn’t remember falling asleep. More than this, she couldn’t remember her own body; it seemed to be missing. Nevertheless, she was able to move… Ruth was standing, without quite knowing how she came to be on her feet. She felt nothing. This might be the true weight of age, she thought, without feeling her thought; it was weightless, everything was, but not in a light way. That might be pleasant. This weightlessness was all absence … Then there was a noise in the room, which finally she recognised as her own voice – she wasn’t sure what her voice was saying, but the existence of it, and its definite sound, returned sensation to her back and legs.’\textsuperscript{114}

Again, the liminal state of dementia draws into focus the complex entanglement of embodiment and our accompanying sense of ontological cohesion. Yet the body has been strangely absent from typical analyses of dementia, reduced only to a set of motor functions in decline, or a set of parts to be arranged in the provision of personal care.\textsuperscript{115} Yet we are not brains in a vat, and our body is inextricably imbricated with our psyches and neurological compositions in ways we are still far from comprehending.\textsuperscript{116} Thus these novels remind us that we should not neglect to recognize that ‘the most basic form of consciousness, is not symbolic or linguistic. It is bodily, a sense of at-homeness in the body … the sense of one’s body as one’s own’.\textsuperscript{117} To exclude the

\textsuperscript{114} McFarlane, The Night Guest (above, n. 5), p.152
\textsuperscript{117} Berger, The Disarticulate (above, n. 9), p.132
body from such encounters is therefore to reduce the provision of care to a hopelessly narrow ledger of wellbeing. The ways in which our volitions are distributed through the body must be considered, and so it seems aptly significant that Ruth does not begin to emulate the tiger – and its particular ethical disposition to the world – until her own body begins to unshackle its previous bounds.

Of course, in this creeping porosity of corporeality and temporality not all experiences will be pleasant. To be thrown back and forth through memory and accompanying shifts in self-conceptions – along with being similarly ejected from one’s own body – can be immensely distressing and disorienting for the already fragile subject. Simple motor functions become complex processes requiring taxing deliberation. Cycles of ‘natural’ processes, such as sleeping patterns and meal times, are lost, with ‘sundowning’ and odd eating habits quite common. Maud, for example, regularly forgets to eat and drink or alternatively consumes too much, but finds a comforting habit in the quotidian routine of making multiple cups of tea or endlessly purchasing canned peaches. Further forms of body dissociation can occur, sometimes felt as uncannily pleasant reckonings:

‘Ruth hadn’t thought about her feet in some time. She was mildly surprised to find them intact at the end of her legs…’

At other times, though, this combination of body dissociation with temporal collapses can render self-perception a terrifying ordeal. Ruth begins to no longer recognize her reflection – another

119 Healey, Elizabeth is Missing (above, n. 4), p.5,121
120 McFarlane, The Night Guest (above, n. 5), p.81
common symptom of neurodegenerative disease\textsuperscript{121} – and her disaggregating ontological makeup here marks a falling action for the novel.\textsuperscript{122} Ruth now becomes susceptible to being thrown back and forth through temporalities with greater speed and force, while other actors she perceives take on increasingly fantastical qualities, altogether ramping up the tension toward \textit{The Night Guest}’s denouement.

Alternatively, these novels also take care to emphasize that such discord can be alleviated simple by the physical touch of another. This can be a powerful means of (re-)affirming the subjectivity of persons living with dementia.\textsuperscript{123} Sadly, however, this is often lacking in rationalized regimes of care, where finite resources often cannot be stretched to accommodate these intangibles of emotional labor.\textsuperscript{124} Nevertheless, these novels repeatedly reinforce the importance of physical contact that affirms another as worthy of recognition, rather than a patient to be efficiently managed toward death. These are tender acts of figuration in understanding that ‘existing is being caressed and touched’.\textsuperscript{125} To simply be held by another reaffirms oneself as a desiring – and desirable – entity, a confirmation Ruth begins to yearn for following the tiger’s arrival:

‘Ruth went back to the lounge room and listened for some time. Every noise she heard was ordinary, and the cool room was stiff and airless. She lay on the sofa, turned her back from the lace of the windows, and waited. It seemed important that something

\begin{footnotesize}
\textsuperscript{122} McFarlane, \textit{The Night Guest} (above, n. 5), p.211
\end{footnotesize}
might touch her, and crucial that she not open her eyes to look for whatever that thing might be.\footnote{The Night Guest (above, n. 5): p.52}

In contrast, as Sako observes in *Turn of Mind*, hands and their forms of communicative touching serve as arbiters of truth for Jennifer – the former orthopedic surgeon – and signify varying levels of trust and intimacy.\footnote{Sako, ‘Dementia and Detection’, (above, n. 76), p.13} Jennifer focuses intensely on the hands of others to best determine their underlying motives, and the central motif of hands as revealing or concealing devices recurs throughout the novel.

Other kinds of corporeal pleasure are also evident in these novels, such as Ruth and Maud’s undertaking of single, simple tasks, including the tearing and breaking of small objects.\footnote{A relatively common behavior among persons with dementia, see B. Draper, H. Brodaty, L. Low, V. Richards, H. Paton and D. Lie, ‘Self-destructive behaviors in nursing home residents’, *Journal of the American Geriatrics Society*, 50:2 (2002): pp.354-358} Maud also finds satiation in digging dirt with her bare hands, which Healey deftly uses to foreshadow the plot’s resolution. Jennifer, however, prefers tactile satiation of a kind more befitting her former profession, which in this case is visualizing – and, as the novel implies early on – literally disarticulating a hand through precise work with a scalpel.\footnote{The dual-meaning of ‘disarticulate’ is of course intended by LaPlante, for Jennifer retains this desire to practice her vocation even as she loses her capacity to communicate this aspiration (see James Berger’s *The Disarticulate* above, n. 9, for a comprehensive study of these tensions between language, disability, and narratives of modernity).} Altogether these acts are emphasized by the respective authors as sustaining means for the protagonists of proving their presence upon the world through a form of therapeutic haptics. McFarlane suggests that even the most seemingly banal of acts can be immensely satisfying when they affirm an accord of body and mind:
‘Ruth nodded again. It felt good to nod, so she continued to do so; yes, she said with her pendulous head, and yes and yes again; she was a clock, she thought; she was generous and wise.’

Similarly, the mode of detection used by all three protagonists is decidedly emotional and embodied. Ruth’s ‘detecting’, for example, consists of adopting the traits of the tiger by prowling around her house with an air of nonchalant impunity, and through this she experiences a radical transformation in herself. Hence what was once ‘only the silly clamour of her beating blood’ later becomes ‘the distant roar of her own blood’. Whether this Ricoeurian refiguring may be a symptom of worsening neurodegeneration is certainly plausible, but ultimately beside the point given the lesson these novels wish to impart to us. Neurological mechanisms will inevitably degrade in a person with dementia, but what matters is stoking and satiating the vitalizing capacities that remain.

**Temporality and Overflows of Inexpressibility**

However, compounding this difficulty of realizing still felt volitions is the frequent blurring and collapse of temporalities. Part of sustaining a unity of identity against Ricoeur’s spiral of fallibility is the capacity to be multiply present in different temporalities; to stretch one’s present self into the past in a way that coalesces into a clear narrative, but also to extend into the future and thus affirm oneself as an autonomous agent. For our protagonists living with dementia this proves incredibly difficult, for they are repeatedly thrown into reveries of the past, while also

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131 Ibid., p.2
132 Ibid., p.169
lacking the means to project themselves into the future. The result is that their temporal existence either shrinks to a pinprick of the present or is stuck in a fugue state of the past, dredging up affective residuals that cannot be transmuted into a clear imperative to action. Maud, for example, is constantly dropped into a well of childhood memories around the unsolved disappearance of her sister. Frequently Jennifer does not remember that her husband has passed away, while Ruth also regularly forgets that her husband, Harry, has died, resulting in a resurfacing of anguish as the loss is felt over and again in a looping, unending bereavement:

‘Frida sank into the catless end of the couch. ‘Ruthie,’ she said, with unexpected softness, ‘Harry’s dead.’

‘I know that,’ snapped Ruth, and she did know it; she had even known it a moment ago when she suggested they consult him. And she was disgusted with him, because nobody could be really, truly dead; nobody could stand it. It was one thing, maybe, to die – and Ruth held his head as Harry died, she remembered that now, she saw the sand on the pavement at the bus stop and Harry’s shaking dying head – but it was quite another to go on being dead. That was obstinate; it was unkind.133

Ruth, Maud, and Jennifer all endure a constant churn of emotion-laced memories butting up against blunt realities, and when the two become entangled this clouds the protagonists’ present intentions. The result is a dizzying confluence of affective overflows and residuals, which requires the labor of others to help render shifting, deteriorating interiorities toward a new figuration and accord with the world.

133 McFarlane, The Night Guest (above, n. 5), p.211
Consider, for example, that as Maud’s cognitive faculties unravel she repeatedly loses the narrative thread of her affective volitions, which then become untethered, resulting in trapped residuals that swell a reservoir of distress. In *Elizabeth is Missing*, Emma Healey is quick to establish to the reader the lasting impact these affective residuals have on Maud. In the opening chapter, Carla – Maud’s tactless carer – breathlessly recounts a news report of a mugging of an elderly woman, later found “‘with half her face smashed in’” (Healey, 2014: 3). Maud laments to herself ‘I wish Carla wouldn’t tell me these things; they leave me with an uneasy feeling long after I’ve forgotten the stories themselves’. Even though – or indeed because – this referent is lost in the act of forgetting, the induced fear of this story lingers discomfortingly within Maud, expanding and looping upon itself without end. MacFarlane’s Ruth and LaPlante’s Jennifer are equally prone to such disabling residuals, and thus the lesson here is that what is carelessly induced by another may be retained and soon thereafter found to be distressingly inexpressible for whom it is implanted within. This affective transmission generates a potentiality that seeks re-affixing in a coherent narrative. For instance, when Ruth considers the new presence of the tiger she cannot help but revel in the possibilities it engenders:

‘… and pictured, as she did so, the headlines: ‘Australian Woman Eaten by Tiger in Own House’. Or, more likely, ‘Tiger Puts Pensioner on the Menu’. This delighted her; and there was another sensation, a new one, to which she attended with greater care: a sense of extravagant consequence. Something important, Ruth felt, was happening to her, and she couldn’t be sure what it was: the tiger, or the feeling of importance … She felt something coming to meet her – something large, and not a real thing, of course, she

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134 Healey, *Elizabeth is Missing* (above, n. 4), p.3
wasn’t that far gone – but a shape, or anyway a temperature. It produced a funny bubble in her chest.’

McFarlane, 2013: 4

Hence a life that had once descended into whiling away the hours now takes on an expansive urgency and a sense of ‘extravagant consequence’. With the powerful dual presence of Frida and the tiger, Ruth’s days become ‘thick’ and ‘crowded’ with a ‘strange hothouse heat’.135 Ruth knows not the why or wherefore of this atmospheric change, but its sensate veracity promises reckoning and reconciliation with the world.

Maud’s affective residual, on the other hand, is laced more with panic and disquiet, tethered to her still ‘missing’ friend, Elizabeth. Note this is not a disinhibiting residual, rather it propels Maud to action, yet still her anxiety often holds a charge that knows not where to dissipate. Maud repeatedly finds herself stuck in a narrative disjuncture, with volitions surging through her body for which reconciling referents cannot be found:

‘… but I can’t sit down, I must keep on. I must do the thing I came to do. For a moment I can’t think what it is. My mind is blank. My arm starts to shake and my heart beats in my stomach.’136

These fizzing affective charges manifest themselves in ways almost akin to a fight-or-flight response, but due to their neuro-atypical state our protagonists often cannot locate the source of their unease. When these discords of volition and narrative are finally reconciled, however, the realized comfort is palpable:

135 McFarlane, The Night Guest (above, n. 5), p.40
136 Healey, Elizabeth is Missing (above, n. 4), p.75
‘I fold a stalk over itself until it snaps. ‘Tell me. Tell me who it is. Who’s missing, Helen? Who am I looking for?’

She says Elizabeth’s name, and hearing it is like falling into a soft bed. Bits, bits fall from the stem of a hydrangea as I run my hand down it.’

This desire for narrative accord creates powerful somatic markers, corporeal pangs of a subject struggling to persist. We repeatedly bear witness to trapped residual affects, often emerging thereafter as overflows of inexpressibility. These overflows manifest themselves through: cursing and other minor normative transgressions; the aforementioned habitual breaking of small objects; and occasionally impotent fits of rage born of sheer frustration. Healey, LaPlante, and McFarlane all take great care in establishing that these behaviors are clearly out of character for their respective protagonists, but neither are they purely physiological symptoms of atrophying neuronal assemblies. Rather, the overflows are entangled phenomena, for cognitive decline is tied to status ascriptions. Thus, for example, flashes of anger are caught between varying causalities: either attributed to the disease modifying the sufferer’s personality; a reaction to personal frustrations of dwindling capacities; or a rational response to perceived personal injustices resulting from statuses ascribed by others. Note, for example, how the normally prim and proper Ruth becomes increasingly frustrated with being corralled, dominated, and patronized by others, such that swearing provides a newly discovered cathartic release:

137 Ibid., p.166
139 Verbal and physical aggression is relatively common among nursing home residents living with dementia. The difficulty of managing affective states combined with the loss of autonomy that comes with life in a total institution can understandably manifest in outbursts of frustration, see A.S. Schreiner, ‘Aggressive behaviours among demented nursing home residents in Japan’, International Journal of Geriatric Psychiatry, 16:2 (2001): pp.209-215
‘… she swore again, with greater pleasure this time, as if the word *fuck* could increase in beauty the more care she took to say it.’

Jennifer is likewise subjected to domination-through-care, stripped of her autonomy to indulge those purportedly ugly and unbecoming aesthetic impulses that we regularly find to be therapeutic balms to hopeless situations. Instead, Jennifer’s exhortations are wholly read as symptomatic of her neurodegeneration, thereby ironically rationalizing even further strictures upon her sovereignty. In *Turn of Mind*, various others assess Jennifer’s condition while she gamely attempts to follow along:

‘*The stories I could tell you. The situation is deteriorating.*

*That’s what Dr. Tsien says. He says she’s entered the worst stage. The next one will be easier. Much sadder, but easier. It’s almost time. Our options are running out.*

I listen carefully, I think this is important, but the words disappear into the ether the moment they are spoken. I accept a cookie from a plate. I bite into its sweetness. I drink the hot wet liquid in the cup that is in front of me. And I ignore the two women who are in my kitchen, two of the multitude of half-familiar strangers who have been intruding, who take such liberties with my house, my person. Even now, one is leaning over my chair, hand outstretched, trying to pat me on the head. Pet me. No. Stop. I am not a wild thing to be soothed by touch. I will not be soothed.’

Like Jennifer, many persons who live with dementia have suffered the belittling and disheartening experience of becoming simultaneously ‘invisible’ and ‘smothered’, both ‘soothed’

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140 McFarlane, *The Night Guest* (above, n. 5), p.165
142 LaPlante, *Turn of Mind* (above, n. 6)
and ‘dismissed’, and ultimately left to linger in relative solitude.\textsuperscript{143} Also, as noted earlier, note how speech in the above passage is signified only by italicized text, the effect of which is to imply the blurring of these actors, voices, and their intents from Jennifer’s point-of-view. It is thus made clear here that despite her best efforts Jennifer has not been able to follow the semantic content of this exchange. However, the affective content has been transmitted to Jennifer, even if only unwittingly. These figures will determine the extent of Jennifer’s ever-dwindling liberty, and will do so in her very presence, with impunity. The manner of this discussion and the accompanying use of hands – as, recall, hands prove for Jennifer the best indicators of true motives – swells the resulting affective overflow: Jennifer is deeply hurt, and refuses to be ‘soothed’ in the face of such dehumanizing treatment. Maud is similarly prone to these affective overflows in being constantly thwarted by others in her attempts to search for Elizabeth, generating waves of anxiety only partially alleviated through expressive overflows that, in turn, only serve to further confirm her ‘demented’ status. Thus, in exploring the importance of recognition and reciprocities of affective flows for sociality, friendship, and authenticity, these novels ask whether we might consider these seemingly odd behaviors as no longer – or, at least, not just – the strange habits of the ‘demented’, but rather urgent expressions of isolation and longing, and corrective attempts toward catharsis and self-actualization.

Affective overflows endured by the protagonists are usually triggered by some event that disorients or inhibits, repeating on itself once it becomes shorn of any discernible context. As carers well know, therapeutic interventions against these overflows often requires a labor of mutually constructed and performed narratives that are mimetically resonant for those living with

dementia. Arlie Russel Hochschild’s *The Managed Heart* provides a thorough analysis of the demands of this emotional labor. Such labor often requires an act of ‘transmutation’, achieved by making the affective state of another commensurate with your own. This requires inducing a compatible feeling within oneself through various entraining strategies, which can serve to alleviate any sense of dissonance within oneself. That is, we adopt techniques of ‘deep acting’ in order to cultivate the required feeling that renders our performances as sincere engagements with others, rather than mere veneers of fellow-feeling. Hochschild’s ethnographic research demonstrates that when a required act of emotional labor proves demanding, a common method of subduing any potential dissonance is to reframe the narrative of the subject for whom they labor. In this way the rude customer in a retail/service industry setting is reconfigured as someone who is perhaps under great stress, or the disruptive child in school has an unsettled home life, or the senile, demented person was once (and should still be recognized as) a figure of great stature, the central protagonist of a rich narrative, and clearly deserving of whatever forms of recognition we can achieve through the affordances of care available.

This custodial duty, this tending to another’s narrative grounding and desire for affective transmission, is of great significance. As Anne Vittoria observes, this care goes far beyond ‘bed and body’ work – in itself an immensely taxing and oft-underappreciated labor – that we may erroneously assume captures the totality of our collective obligations for those with dementia.

Likewise, the three novels discussed in this paper all argue that inattention to affective

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144 See Orr and Teo’s (2015) study of popular works largely presented from the perspective of carers for a thoughtful discussion of dilemmas of identity, care, and of sacrificing one’s own narrative thrust in service of another.
145 Hochschild, *The Managed Heart* (above, n. 18)
146 Ibid., p.19
147 Ibid., pp.33-54
148 Vittoria, *Preserving selves* (above, n. 82), p.105
transmissions can needlessly damn the cognitive other, and we should therefore hone our capacities for performative exchanges of ‘identity work’.

As affective residuals within dementia can expand and repeat upon themselves it can take only seemingly minor acts to shift dispositions dramatically, for better or worse. Demonstrative of the importance of fostering positive, agency-affirming exchanges is a scene in *Elizabeth is Missing* where Maud wishes to report her friend Elizabeth to the police as a ‘missing person’. The officer she encounters initially seems kind, obliging and indeed somehow already aware of Maud’s concern. Maud begins to feel ‘tears of relief’ knowing that her fears are being heard with seeming sincerity, but is soon devastatingly undone when it is revealed that the officer is cruelly mocking her:

“‘This’ll be the … let me see …’ he clicks at the computer a few times ‘… fourth time you’ve been in.’

Fourth time. ‘So,’ I say. ‘Is someone looking for Elizabeth already, then?’ I know as soon as the words are out of my mouth that it’s hopeless.

He laughs. ‘Oh yeah. I’ve got every man on the force out. Sniffer dogs, forensics, flying squad. They’re all out there’ – he pauses to skim a hand through the air – ‘looking for your friend Elizabeth.’

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149 Ibid.
150 Schreiner, Yamamoto, and Shiotani, ‘Positive affect among nursing home residents with Alzheimer’s dementia’ (above, n. 125), for example, note the importance of structured recreational activity in care facilities as a producer of positive affect, whereas affectless or ‘null’ displays were 2.5 times more likely to be present at any given moment when residents were simply left to their own devices (see also L. Teri, ‘Identifying Pleasant Activities for Alzheimer's Disease Patients: The Pleasant Events Schedule-AD’, *The Gerontologist*, 31:1 (1991): pp.124-127).
I got hot at his words. My armpits prickle. I can see what he thinks of me now, and I feel sick. The tears spill over, finally, and I turn away so he won’t see them.”

Again, note the somatic markers here of the body going ‘hot’, armpits prickling, of feeling ill, and of tears ‘finally’ arriving once the felt disquiet is confirmed as damning. A deep hurt lodges and lingers within Maud after this encounter, despite the ‘plot’ of the encounter being forgotten within moments. The belittling transmission continues to dog Maud, dragging her into a depressive state. That this is callous treatment is obvious enough. More precisely though, the instructive lesson here regards how such wounds may be retained as incapacitating residuals. The lazy gratification of the policeman comes through an affective ‘dumping’ onto Maud.

Yet, in return for this cheap thrill to the policeman’s perhaps otherwise dull day, Maud must now contend with the depletion of her own sense of agency and volition created through an act of belittlement and mockery. There is thus a gross disequilibrium here, for the pleasures enjoyed by the officer are certainly not inversely equivalent to the paralyzing distress felt by Maud, hence the resulting creation of an inert, residual affective state.

To clarify, care and recognition does not require ‘humoring’ or infantilizing those with dementia, rather it simply requires the willing labor of co-constructing mutual narratives and exchanges of affective reciprocity. Healey makes this clear in juxtaposing Maud’s depleting encounter with the police officer with a later scene, wherein Maud attempts to place a classifieds advertisement to aid her search for Elizabeth. In this scene the receptionist assisting Maud is well-meaning and

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151 Healey, Elizabeth is Missing (above, n. 4), p.77
153 Brennan, The Transmission of Affect, (above, n. 64), p.30
154 Lyman, ‘Infantilization of elders’, (above, n. 27)
patient, but mistakenly assumes ‘Elizabeth’ is a cat, resulting in a comical extended miscommunication. This scene comprises a carefully directed humor, generated not through the disparagement of another, but rather in two equal persons acting in good faith and mutual care, with results going harmlessly awry in ways easily mended.

**Conclusion**

Through Ruth’s urge to prowl around her home and be touched by another to confirm her corporeal presence, to Maud’s hope for someone to recognize and share her concern for her missing friend, and finally Jennifer’s desire to know that she is loved and can trust those around her, these novels demand of us that we open ourselves to the more-than-body labor that dementia care requires, and to reconsider what this labor can further reveal to us about neurological difference and wellbeing. We are called to recognize that maintaining affective flows essential to identity and agency requires understanding that we are the scribes of one another’s selfhood, and far less the autonomous authors of our own than we may assume, regardless of how ‘hypercognitive’ we presume ourselves to be. I have thus argued that these fictional representations provide a much needed ‘epistemology of humility’\(^\text{155}\) in depicting the interiority of subjects undergoing a radical transformation of being-in-the-world, rather than merely reducing persons to their ascribed condition. These exploratory and experimental narratives are imbued with requisite sensitivity necessary to ‘resuscitate the humanity’ of those living with dementia, and challenges hardened categories of the normal and the pathological by

\(^{155}\) S.G. Post, ‘Comments on research in the social sciences pertaining to Alzheimer's disease: A more humble approach’, *Aging and Mental Health*, 5:S1 (2001): p.18
demonstrating the complexly entangled qualities of neurodegeneration, ageing, identity and sociality.¹⁵⁶

These novels compel us to recognize that any principles of ethical care worth upholding and defending will not be realized in the intensive rationalization of quelling affective states and the oppressive actuarial management of the demented subject, but rather in acts of reciprocity and mutual affirmation of being. Their protagonists remind us that what unites us all is not some conception of our species-unique capacity of rational morality, but rather the desire for narrative accord and affirming transmissions of affect with one another, forms of recognition and reconciliation that can only be realized through the co-constitutive efforts of authoring each other into being.

¹⁵⁶ Herskovits, ‘Debates about the “self” and Alzheimer’s disease’, (above, n. 34)