

Forgotten: Narratives of Age-Related Dementia and Alzheimer's Disease in Canada, by Marlene Goldman. Montreal: McGill-Queens UP, 2017. Pp. 472. CAD 34.95 (paperback).

The Poetics and Politics of Alzheimer's Disease Life Writing, by Martina Zimmermann. London: Palgrave, 2017. Pp. 167. Open access through the Wellcome Trust.

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At some point in the late twentieth century, interpreters of Shakespeare's *King Lear* seem to have reached a near-perfect consensus that the play is about dementia. This conviction did not erase Lear's more perennially recognized sources of tragedy (mortality, vanity, the inability to let go) so much as absorb them: in the many performances where the king shuffles directionlessly or forgets daughters' names at key moments, dementia is the definitive instance of the more general human frailty with which the play has always dealt. As well as announcing dementia's sudden prominence as a concern, these neurotragic Lears may tell us something about how we are first disposed to see it. Shakespeare's play does not hide from the uglier aspects of human interdependence, but as a figure for dementia, his troubled hero is a solitary who cuts himself off from kingdom and family when he enters the storm. Very often, we imagine dementia as an existential problem or as a metonym for existential problems generally. That Lear is male, European, and a king should prompt some reflection on the highly partial nature of this supposedly universal prospect.

Perhaps it has. Even if neurotragic Lear remains a popular production strategy, both creative writers and scholars are coming to think of the many dementias as neither private kingly damnations nor encompassing metaphors for the fragility of all life. These illnesses, we are coming to realize, affect innumerable lives, but in ways which are different and whose differences matter. Perhaps most importantly, we are coming to see dementia as a social condition, not as the terminal point of the axiom that everyone dies alone, but

as something which links people in complex nets of obligation and dependence and whose terms we script and stage together. Two recent books, Marlene Goldman's *Forgotten: Narratives of Age-Related Dementia and Alzheimer's Disease in Canada* (2017) and Martina Zimmermann's *The Poetics and Politics of Alzheimer's Disease Life Writing* (2017) exemplify different versions of this increasing recognition. They share commitments familiar to all of us who have learned from Anne Davis Basting's *Forget Memory*, commitments to opposing the widespread, fatalistic, and stigmatizing view of Alzheimer's and related dementias as a kind of death-in-life and the people who live with them as effective non-persons. While they draw on very different archives, these two studies do important and related work in showing how differences in literary representation can contribute to widely different understandings of dementia, different ways of living with it, and different ways of providing care. Taken together, they suggest further questions about how, where, and through which aesthetic representations this kind of social work can be done, questions which will be important for future scholarship.

Zimmermann's book makes a polemical case for the value of life-writing by those with dementia, arguing that this body of texts, along with some instances of relational life writing by caregivers, will counteract damaging stigma, encourage patient-centric care, and secure better institutional support. Zimmermann tenders these life-writing texts as a riposte to more externally focalized understandings of dementia, both in biomedicine (the author has a doctorate in neuropharmacology, and the book is partly framed as a personal discovery) and in popular culture. In curating these expressions of meaningful experience by authors living with dementia, this book itself does laudable work in refuting the sense, still so clearly alive in many areas of popular imagination, that dementia is like death or worse.

As well as taking steps toward this long-held desideratum, *The Poetics and Politics of Alzheimer's Disease Life Writing* offers readers an admirably, indeed exhaustively thorough overview of its chosen genre. Reach alone makes Zimmermann's book an invaluable starting point for anyone working at the interstices of neurodiversity, aging studies, or life writing. Discussions range

from Robert Davis's groundbreaking 1989 *My Journey Into Alzheimer's Disease* to the medically informed narratives of Richard Taylor and Thomas Graboys to the multimodal diary work of Claude Couturier. These are only a few of the writers considered. Zimmermann moves with facility between several languages, and also covers some important instances of relational life writing by dementia caregivers, including Tilman Jens, Reeve Lindbergh, and Rachel Hadas. Via support from the Wellcome Trust, the book is available free from Palgrave's website, a windfall for several fields.

In the strength of its commitment to the voices of those with dementia, however, *The Poetics and Politics of Alzheimer's Disease Life Writing* sometimes relies on a purism that could be further considered. Its chapters follow an implicitly progressive structure. Caregiver accounts, covered in body sections 2 and 3, are said to have prepared readers to think about people with dementia as meaningfully still people and to give writers with dementia a hearing. Chapter 4 surveys writers with dementia who follow traditionally linear narrative norms, overcoming stigma by illustrating their ability to speak for themselves within the conventions their readers recognize. Then, in chapter 5, we meet those finally able to write about the illness in the terms most appropriate to it, for readers prepared to accept dementia's nonlinear and aleatory implications. Zimmermann's archive does indeed give reason to hope for increasing openness with regard to the value of life with dementia. But in its largely uninterrogated premise that people with dementia can finally disentangle themselves from any representative scheme not of their own devising, the book is at times essentialistic about what expression counts as genuine, with the almost unstated assumption that whatever is genuine will find affirmative recognition and political support.

Consider the readers implied in chapters 4 and 5. The first one likes narrative coherence, and warms to people with dementia upon seeing that they can produce coherent narratives. The second has a greater taste for the experimental and is willing to entertain a less linear experience. Perhaps we should hope for the first reader to become the second. But this will not be a simple or inevitable process. We can also imagine the chapter 4 reader encountering the texts of

chapter 5 and deciding that the chaos there is not worth living with, or even the reader of chapter 5 looking at the chapter 4 texts and inferring that people with dementia are recessive, backward-looking, aesthetically unadventurous. Not all representations of dementia are equal, nor are all ways of reading about it. But this is not just a question of being—to employ a figure Zimmermann uses repeatedly—willing to hear. It is a question of much more actively performed interpretations and judgments.

The point here is not that every claim for the agency of a text requires an in-depth sociology of readership. The point is that, if the condition of success for representations of dementia is that they be unmediated, it is difficult to see how this condition will ever be met, or how the act of interpreting or writing about these representations can have any value. All visions of dementia are mediated, and the nature of the mediation is a crucial factor in how a given representation helps or harms. This fact makes Zimmermann's more autonomist gestures hard to support: "We are urged to ask, whether [caregiver accounts] can reliably picture the patient's situation and world of experience, not least since the caregiver's agenda, inevitably, differs from the patient's outlook. We need to ask this question even in the awareness that patients themselves cannot write about their experiences in the final stages of the condition" (13). The asymmetry in the first sentence, whereby caregivers have agendas but patients have outlooks, elides the fact that texts by people with dementia, like every other kind of text, are constructed works of rhetoric rather than reliable portals into interiority. There is mediation on the receiving end of the literary transaction as well. Even in this acknowledgment that late-stage dementia troubles ideas of transparent access, Zimmermann urges us to resist efforts to bespeak the late-stage patient's interests. But inasmuch as those interests are not explicitly stated for us (the point of the imagined situation is that they cannot be), are we not still ourselves acting as interpretive caregivers, as third-person writers, even if only in prohibiting further acts of writing? This book itself is a mediation, with clear preferences for some firsthand accounts over others. What else could it be?

Despite the controversialist framing, the book's body sections offer much appreciative consideration of mediations which are at once active and affirmative, from Lars-Christer Hydén's crucial work on the collaborative enactment of memory to the roles of Rachel Hadas and Annie Ernaux as "archivists" for a husband and a mother. (Here we could also mention the compelling work of John Killick, Oddgeir Synnes, and others, to help people with dementia find voice as creative writers.) In the caregiver chapters, Zimmermann recognizes that the family members who often occupy these active-supportive mediatory roles have their own, very serious concerns with regard to recognition and support, and there is some much-needed thinking on the unequal burdens placed on male and female family members (though in these sections Zimmermann's animus against caregivers who feel that they have lost the person with dementia can sometimes seem uncharitable). There is even an acknowledgment that we mediate dementia narratives in the very act of reading them: The fifth chapter roots its own possibility in an increasing comfort with postmodern narrative form among readers and publishers. But the meta-discussion of these interventions pins their benevolence to a transparency that is hard to believe in: at one point, Zimmermann demurs ascribing significance to the style in Jeanne L. Lee's *Just Love Me* on the grounds that the text is a "collaborative composition" with Lee's editor, Cliff Reid. Few of us would want a test like this for our own work.

In *Forgotten*, Marlene Goldman focuses not on who is representing dementia but on how patterns in representation align with different ways of approaching dementia in reality. The organizing axis is not literary form or genre – though Goldman is mainly concerned with the novel – but nation. Short of a claim that dementia had a significantly different status in Canadian culture than it has in France, Ireland, Australia, or Sweden, this could seem somewhat arbitrary. As it happens, though, Goldman does suggest that Canadian writers have a particularly self-conscious relationship to some of the central forms of dementia storytelling, for reasons connected to the country's settler-colonial history. There are other rewards for the national focus as well. For one, the book is able to offer a complementary showcase of the strong culture of dementia

scholarship in Canada, from social scientists including Pia Kontos and Stephen Katz to critical humanists such as Sally Chivers, Stephen Katz, Kim Sawchuck, May Chazan, and others. *Forgotten* also underscores the surprising number of Canada's most celebrated authors (at least in English, since Goldman leaves French Canadian literature as another subject) who have dealt at length with this theme, including Alice Munro, Mordecai Richler, Margaret Lawrence, and Michael Ignatieff. But the strongest justification for this national-linguistic focus is the parallels it allows Goldman to develop between literary, institutional, and societal change in a specific context. Alongside its close readings of fiction, the book attentively recounts thinking about dementia in Canadian medical and legal-carceral systems, from nineteenth century asylums to the country's new protocols for assisted dying. The result is a bountifully situated work of historicist criticism.

The central argument is that different ways of writing about dementia have traceable correlates in policy and action. The defining transition is from what Goldman calls elegy to what she calls gothic. In brief, a consolation for inevitable loss tendered in artistic form gives way to a less reconciled sense of dementia as a baffling evil that must be defeated. By linking this second attitude with a literary genre, Goldman vividly illustrates how dementia focuses the deepest anxieties of rational modernity. Just as the monks, witches, and chasms of desire allegedly banished from Enlightenment Europe had to be resurrected and triumphed over again and again on its popular stages, dementia enters our own age as a symbolic challenge to biomedical mastery in particular and to the life of reason in general. Goldman convincingly shows this anxious turn away from elegy across much of dementia's medical history. Those who have thought much about cancer will recognize the figure of the cure, singular and final, invoked in much historical Alzheimer's research, and above all in explanations of this research to the public. It is not surprising that this kind of talk should nourish apprehensions of Alzheimer's as an unlivable horror.

The literary close readings in *Forgotten*, all of which are sensitive and highly enjoyable, rarely set out to diagnose gothic. That attitude is mostly exemplified in journalism, policy language, medical discourse, and popular culture, with the

bulk of examples coming from the late nineteenth to mid twentieth centuries. The novels and short stories which Goldman then takes up, which mostly come from the later twentieth century, are said to qualify or even critique gothic modes, linking their own images of dementia with other kinds of marginalization in Canadian history. This argument does not flatten the distinctiveness of individual texts. Goldman is less comfortable with Michael Ignatieff's *Scar Tissue* than with Jane Rule's *Memory Board*. In general, however, literary fiction appears in *Forgotten* as a third way between elegy and gothic. Goldman calls this third option irony, an idea of contingency and multiplicity whose parallels range from Athenian drama to surrealism to contemporary feminist reworkings of elegy.

Passing between the extremes of elegy and gothic, the ironic mode figures dementia as neither necessarily inevitable nor necessarily intolerable. In other words, the axis of difference which Goldman uses irony to bisect is about predictability rather than about negativity: neither the inevitable nor the intolerable sound especially positive. In terms of negativity, the literary fiction cannot be a midpoint between the two previous modes, since *Forgotten* attaches great value to novelists' conceptions of life with dementia as full of chances for joy and meaning, conceptions which exceed both elegy and gothic. What irony would mean along this second axis is a subject for future thought. Goldman's readings draw out varieties of delicate ambivalence, which hold life with dementia open to both pain and possibility. But it might be worth invoking a more brutal contrast than Goldman does: as far as irony goes, totally positive views on dementia should raise the same problems as negative ones, bending the hysterical absolutes of dementia gothic into an opposite but parallel unironic certainty. If the gothic has such a rosy doppelgänger—in, for instance, those occasional presentations of dementia as rhizomatic liberation—we could call it dementia melodrama.

While we are on the subject of gothic, or of melodrama, we could wonder about the binary sometimes implied in Goldman's treatment of literary fiction on the one hand and both popular culture and biomedicine on the other. To be anti-stigma is not necessarily to be anti-gothic. In a discussion of Alice Munro,

Goldman credits several short stories with exhuming marginalized people from symbolic exile among the dead, “a form of live burial” (278). But are such rescues not a core feature of the gothic genre, with its crypts, dungeons, and abducted maidens? Is this not the same kind of symbolic release sought by the public and biomedical discourses of *the cure*? There is a crux here which goes to the core of critical humanist scholarship. We are structurally obligated to argue for nuance and reflectiveness in thought and representation (for Goldman, this is irony). Meanwhile, made a certain way, the case for ironic thinking is itself unironic.

This bind certainly does not rule out the view that literary complexity has a special role to play in helping us approach complex intersubjective problems, that, on average, works which have the polyphonic pluralism and self-awareness that professional critics tend to value may do the most for our thinking about dementia. There is certainly no reason to wish that Goldman had been more suspicious of her texts; as Robert J.C. Young points out, Freud’s diagnostically suspicious reading of gothic fiction is itself highly gothic. But to this reader, *Forgotten* is most compelling not in its *ascriptions* of beneficent irony, but in its own wonderfully fine-grained demonstrations of plurality and contingency in what dementia can mean, from text to text and age to age. Even if none of them is exactly utopian, the crucial difference between narratives about dementia shows that new understandings are always possible, that no framing of these illnesses, biomedical, popular, or literary, is beyond contestation.

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