Opening My Heart: Writing and Autoethnography as Healer

KATE SWAFFER
ADELAIDE UNIVERSITY

Opening My Heart: Writing, Autoethnography and Dementia

> *I never forgot that it was because I was "standing on the shoulders of giants" that I could see the terrain ahead.* (Singer 14)

The examination of my writing about the lived/living experience (LE) of acquiring disabilities due to a diagnosis of a rare young onset dementia aged 49 through autoethnography, quite surprisingly took my breath away. Autoethnography offered me permission to use the most intimate expression of personal experiences, musings, thoughts and personal opinions as a way of unravelling my truth into tangible data. Essentially it "invites others to become involved with a life, engage with [its] contingencies, embedded-ness in shared being" (Bochner 225). My personal blog and many public interviews and presentations have done this for almost two decades. Prior to the diagnosis of dementia, I worked as a nurse in dementia care, and then in operating theatres for over 20 years. From there, I moved into hospitality as a chef for 10 years, and then back to health care, as a regional sales manager in a health care company. They were not writing based careers, despite my lifelong desire to become a writer and a researcher. It took a diagnosis of dementia for me to take writing seriously, moving it from a devastating diagnosis and experience, to one that's become a gift.

Writing a daily blog, *Creating Life with Words: Inspiration, Love and Truth* obviously required me to write, and was unavoidably public. Becoming an accidental activist, author and speaker were direct outcomes from writing. Furthermore, these all led to me becoming a researcher. My blog is a form of creative non-fiction or life writing, even a mode of autoethnography. The readers who commented effectively became my proxy narrative therapists, part of a technique that provides the person with alternative views to their stress or situation (Béres). Without the positive responses, and perhaps more importantly, the negative responses to my blogs, I doubt I would have found the courage to publish my first book on living with dementia (Swaffer, *Love Life Loss* vol. 2), or my poetry books (Swaffer, *Love Life Loss* vol. 1 and 2).

This essay begins with the latest data on prevalence of dementia and contrasts the biomedical approach to dementia to a cognitive disabilities approach. The latter, which considers the rights of people living with dementia (PLWD) through the Convention on the Rights of Persons with Disabilities (CRPD), highlights that PLWD have the same rights as all others with disabilities. The essay then briefly examines the advocacy and discourse of dementia charities, and considers if they are causing harm and increasing, not reducing, some of the issues faced by PLWD. It introduces audism, which emerges from Deaf scholarship. The similarity between PLWD's experiences and audism is a new concept in the field of dementia. Likewise the similarity between audism and the harmful attitudes towards, and experiences of, PLWD are profound.

Dementia, disability and advocacy

The World Health Organisation (WHO) defines dementia in two ways ("Dementia"). The first is a biomedical, deficits based, pathologising framework: "Dementia is a term for several diseases that affect memory, thinking, and the ability to perform daily activities." Secondly, the WHO reports that dementia is “a major cause of disability and dependence globally.” This negative focus highlights the importance of informing PLWD that the symptoms of dementia are acquired disabilities, which means that they have equal access to disability rights and disability support. Like all others living with disabilities, they have equal access to the Convention on the Rights of Persons with Disabilities (CRPD). Identifying as a person with disabilities caused by dementia was initially difficult emotionally, “not another negative D-word” (Swaffer, *Creating Life*). However, this switch in the way I viewed dementia quickly became empowering, as my university provided me with disability support to continue to keep living my life. It pushed me to ask the question, “If my university can support me to live with dementia, why does the health care sector only advise PLWD to prepare to die?”

I’m still searching for the answer, as the research and clinical community seem averse to embedding dementia as a disability into their research or clinical practice.

Dementia is not merely a disease of cognitive decline; it amplifies societal perceptions and challenges traditional conceptions of disability. As a cognitive disability, dementia encompasses impairments in memory, reasoning, and the ability to perform daily tasks, fundamentally altering the lives of patients and their families. The cognitive disabilities experienced by PLWD do not exist in isolation but interact with societal structures and relationships, revealing a complex interplay between cognitive disabilities and societal responses (Blake 1).

The diagnostic process itself provides an additional layer of complexity. According to Molvik et al. (2024), the experience of being diagnosed can be both a relief and a burden. On one hand, a dementia diagnosis can explain cognitive and functional changes, reducing confusion and stigma. On the other hand, it introduces concerns about an uncertain future, potentially exacerbating anxiety and stress (Molvik et al. 1–2).

In 2021, the WHO estimated there were more than 57,000 million people diagnosed with dementia and projected almost 10 million new diagnoses per year (“Dementia”). Chen et al. report that Alzheimer’s disease and other dementias (ADODs) threaten the wellbeing of older adults and their communities. It also reports that the projected prevalence of dementia is expected to rise to 153 million by 2050. They suggest that global efforts are needed to reduce the problem faced by governments and society, particularly as experienced by informal Care Partners and Family Members (CPFM) who provide unpaid support to a PLWD.

While dementia prevalence is important for governments and other cohorts including researchers and health care professionals (HCPs), for PLWD, it is irrelevant. While we are denied adequate health and social care, including access to rehabilitation (Layton et al.; Cations et al.), and denied the knowledge that dementia symptoms are acquired disabilities, it seems harmful to only dwell on prevalence. The LE dementia or care is equally important. Furthermore, denying PLWD the knowledge that dementia is a disability denies them access to the CRPD, and other human rights conventions, which then translates into the denial of disability assessment and support.

The impact of being denied this knowledge on PLWD is reduced mobility, poorer quality of life, and living with unsupported disabilities, leading to increased dependence and isolation. It is like asking someone without legs to climb up a set of stairs. A lack of disability support including rehabilitation potentially also leads to PLWD experiencing earlier progression of dementia symptoms than is necessary.

The 2019 Alzheimer’s Disease International (ADI) World Alzheimer’s Report, *Attitudes to Dementia*, reported that almost 80% of the general public were concerned about developing dementia, and 1 in 4 people believed there was nothing they could do to prevent dementia. 35% of CPFM said that they have hidden the diagnosis of dementia of a family member, and over 50% said their health suffered as a result of their caring responsibilities. Almost 62% of healthcare providers worldwide thought dementia was part of normal ageing, and 40% of the general public said they believed doctors and nurses ignore people with dementia.

The 2024 ADI World Alzheimer's Report, *Global Changes in Attitudes to Dementia*, examined the results of an international survey consisting of more than 40,000 responses from over 166 countries and territories. A follow-up to the 2019 report, it explored how perceptions of dementia have, or have not, changed in five years. Results of that survey report that attitudes and stigma are worse than they were five years ago. This highlights that advocacy and research are not working; they are not creating the change needed to enable PLWD to maintain their independence, mobility and wellbeing for longer than currently projected.

The narrative used to discuss the importance of dementia prevalence is founded on "helping PLWD" and finding a cure. The issue is that the current advocacy and public discourse used is paternalistic, stigmatising, and a form of benevolent othering. In particular, focusing so much on procuring funding is disrespectful and harmful. The language describing dementia as a "tidal wave" or "tsunami," and the negative discourse of suffering, raises money for the charities and researchers, ensuring ongoing employment for millions of people without dementia.

Dementia and audism

Humphries (*Communicating*) introduced the term "audism" to define the prejudice and discrimination faced by Deaf individuals. Audism is an attitude based on pathological thinking, resulting in a negative stigma towards someone who cannot hear (Gallaudet University Library). Similarly to the stigma, discrimination and othering experienced by PLWD, audism judges, labels, and limits individuals on the basis of whether a person hears and speaks. In the case of PLWD, it happens simply because of their diagnosis and the underlying assumptions of incapacity. As O'Connell suggests, there are other issues related to audism, as it impacts the employment of Deaf people ("Opportunity Blocked"). I suggest this applies to PLWD, who others assume are no longer employable. Also, those in paid employment often lose their paid employment if they declare their diagnosis. Humphries also suggests audism is blocking employment opportunities for people in the Deaf community, a topic deserving of further exploration related to PLWD. The concept of audism has the potential to offer fresh insights, framing the biases faced by PLWD in light of societal attitudes towards cognitive impairment and disability.

We can find an example of audist-style dementia stigma and discrimination when we examine the current dementia friendly initiatives (DFIs), which, despite their many claims, continue to be discriminatory and stigmatising, and are a form of benevolent othering, and do not employ PLWD. If Australia were to attempt to develop an Aboriginal Friendly Community, but only employed white Australians we would understand this to be exclusionary, stigmatising and discriminatory—and so are the DFIs. Globally, to my knowledge, not one PLWD is employed in a DFI. Clearly, the inequities for PLWD in these initiatives deserve further examination.

Stigma, othering and paternalism are highlighted in an article in *Charity Today*, where the CEO of Alzheimer's Disease International states, "Without support for the Global action plan, we would lose a precious tool to advocate on behalf of the weakest amongst us." Referring to people with disabilities in this way is disrespectful, and an example of the stigma that exists inside the organisations purporting to advocate for PLWD. That these negative and paternalistic narratives and attitudes exist within the organisations and individuals who claim to advocate for PLWD is reprehensible, especially when they have language guidelines against this negative, demeaning rhetoric.

As an activist, it feels important to know whose shoulders I am standing on, whose activism I should learn from, and that there are many PLWD who are not "the weakest amongst us" (Bryden, "Continuing"; Scottish Dementia Working Group). Learning that others such as Christine Bryden and the late Dr Richard Taylor were organising and imagining more self-determined and autonomous, and less stigmatising and paternalistic ways forward—some for decades (Bryden, *Dancing*)—provides the sense of hope and belonging needed to continue to be an activist. After feelings of isolation following my own efforts to name what is wrong with the dementia system, and to campaign for something better for those harmed by it, it was a relief to find others and to know we are part of a long lineage of resistance. But this shared resistance has more work to do. The dementia charities, policies and systems are not just hard to work with; they appear designed to fail and exclude us. And they are counting on us to stay quiet about it and silently put up with neglect and abuse. It was once difficult to accept that my own activism has mostly been futile, and it is clear that truth telling is not enough. Sharing our stories may initially be therapeutic, but we have been coerced into believing it will help create much needed change at a systemic level. When we discover that nothing has changed, to continue this is re-traumatising.

Truth telling through writing and blogging

> *As I write about living with the symptoms of dementia, there is a strong element of self-reflection, and a deep desire to gain an understanding of this new world of dementia, not only for my own emotional survival but also to enhance my ability to retain insight for as long as possible.* (Swaffer, *Love Life Loss* vol. 1)

My own truth-telling, done primarily through speaking out and writing, has helped me reflect on the past, present and future, and continues to provide me with the courage to openly discuss and critically examine the issues affecting PLWD. The ongoing systemic violations of rights experienced once a person is diagnosed with dementia remain unchanged. The Australian Royal Commission into Aged Care Quality and Safety, whose interim report was titled *Neglect* (2019), confirmed the ongoing violations of the most basic of human rights, and other harm and neglect which continue to be experienced by PLWD and CPFM. These were well documented in the Final Report, *Care, Dignity and Respect*, which called for fundamental reform of the aged care system (2021).

Truth telling has supported me to build bridges and campaign to improve future outcomes for others diagnosed with dementia. In a process of self-discovery and then research, I came to understand my blogs are a form of autoethnographic journalling. For many years, I documented experiences, responses, and ideas around topics including death, loss, grief, exhaustion, disappointment, stigma, shame, discrimination, and so many other negative and positive experiences that I have experienced since my diagnosis.

Like Pelias I am reaching out for a "telling essence" (163) because I want connections in order to explore my progress. My blog posts are a way of exploring my living experience of dementia and my presence inside the critical illness domain—as well as the acquired disability domain. Moving beyond dementia as a terminal, biomedical illness to one of acquired disability was critical for me in changing the way I live with it, instead of only waiting to die from it. It led to my expectation of disability support and rehabilitation. Autoethnography is one way to explore the feelings of sadness and devastation, as well as highlighting the many positive experiences. It has allowed me to help myself, and ultimately to help many others with dementia. My focus moved from documenting and understanding the experience, to wanting to help others with dementia live beyond the Prescribed Disengagement® (PD) and to demand a post diagnostic pathway that includes rehabilitation, and disability supports (Swaffer, "Prescribed Disengagement"). This term emerged when I realised the only advice I'd been provided with was, *"Give up work, give up study, get my end of life affairs in order, and get* *acquainted with aged care to get used to it"* (Swaffer, *Love Life Loss* vol. 2 ch.16). Simply put, it is a prescription to give up on living. The emotional angst and perceived suffering of a dementia diagnosis was transformed into an experience of understanding, questioning, and ultimately to living with it more positively. Telling a story that explores the stigma and the discrimination and stirs feelings in others has been powerfully enabling and enlightening. I even hoped it would be another LE story with the potential to lead to significant change in the health care sector, and wider community.

Autoethnography

But what is autoethnography and why use it for truth telling? Bochner ("Suffering Happiness") and Ellis (*Ethnographic I*) write of it as a study of awareness of the self within a culture, involving a research method that uses personal experience to examine one's own experiences. It focuses on living experience by keeping conversation going, clearing the way to a shared understanding of living. I discovered that autoethnographic research of such intimate writing explores my experience and also describes the culture I connect, work and live with (Ellis, *Ethnographic I* 37).

Autoethnographic texts can emerge from the researcher's bodily standpoint as they recognise and interpret the residue that culture inscribes upon her from interaction with others. This corporeal textual orientation rejects the notion that "lived experience can only be represented indirectly through quotations from field notes, observations and interviews" (Denzin, "Many Faces" 20). In autoethnographic research the investigator is the epistemological and ontological nexus upon which the research process turns. Autoethnographers contend that self-reflexive critique of one's position as a researcher inspires readers to reflect critically upon their own life experience, their construction of self, and their interaction with others within socio-historical contexts (Ellis and Bochner, "Analyzing"; Goodall; Spry).

Autoethnography is one medium that enables me to communicate my "why"—the reasons for campaigning for myself and others—for improved post diagnostic support. It has empowered me to share my feelings about what drives me, what keeps me campaigning against the persistent Prescribed Disengagement® (Swaffer, *Creating Life* 2025) and therefore, prescribed suffering, and perhaps even the inexorable and ever-increasing fog experienced. Autoethnography however is a complex concept. To pinpoint a common meaning is not easy, because each autoethnographer uses an individual and special way to offer a unique social presence. For instance, Alford's narrative tells of her hospital admission where undignified treatment made her feel like "only a piece of meat" (596), whereas my experience was to feel non-human.

While searching for a guiding theory and methodology about my experience of journalling about dementia, I first wanted to understand the ethnographic approach which is, in a sense, the history and predecessor to autoethnography. This methodology amounts to being aware of the novelistic way it operates as it unpacks uncertainties and doubts that I will inevitably meet. It also addresses issues in depth to gain deeper insight into my existential response to a voluntary, yet "professional" activity, and requires considerable empathic strength. As an insider I achieve better understanding of my experiences because it is more comforting to "dialogically connect the ethical, respectful self to nature and [the] worldly environment [I work and live in]" (Denzin, "Interpretive Ethnography" 510).

In autoethnography I write the research (graphy) about myself (auto) in relation to culture (ethno) (Ellis, *Ethnographic I*). This privileges "a deep understanding of self, culture and the interaction between the two" (Gearity and Mertz). Selecting autoethnography was prompted by the attraction to a method that investigates the "lived" experience in a style of ethnography; a methodology that designates the researcher as being the subject/object of the study. It felt/feels like I have adopted the role of "others," but only when I began appreciating the value of genuine connection in this encounter (Pelias 163).

Autoethnography utilises narrative storytelling methods that encourage reflexivity with the "audience," whose reaction then creates the data. The autoethnographic researcher, by first exploring personal experience, creates a space where relationships are analysed and refocussed to connect with those outside the space. It is a methodology that first and foremost relies on researching and writing the self, yet there is no limit put on the way one uses that concept. As a blogger of the realities of living with a diagnosis of dementia, autoethnography became the next step to assessing my words.

The relationship of an ethnographer to the settings they observe

Even anthropologists and social scientists question the role of the researcher in ethnographic studies and ask why ethnographers need to stand outside the culture they investigate. Crawford argues that "taking the ethnographic turn, living and writing the ethnographic life, is essentially a self-report of personal experience . . . the ethnographer is unavoidably in the ethnography one way or another, however subtly or obviously" (158). While searching for data, researchers inevitably become part of the culture they are involved with. When the researcher "puts a foot" inside another's domain even tentatively, they become a member of that culture. Shaffir supports this when he says that there is a degree of self-presentation in ethnographic methodology and, as an example, acknowledges that he was drawn to Judaism when he researched that community ("Doing Ethnography").

Anthropological ethnographer Ruth Behar sees blurring of ethnographic research genres and discusses the "creative non-fiction [and] fluid field of hybrid texts [or] stories based on the testimony of lived experience" (476). Another study using creative nonfiction expressions of nursing uses ethnography of reflexive fieldwork demonstrating how embodied use of the senses "led into areas that otherwise would have remained unexplored" (Edvardson and Street 24). Nurses not only rely on readouts from instruments to diagnose a problem with the patients they care for but also use all their physical senses to supplement findings.

Holly Priddis, in "Autoethnography and Severe Perineal Trauma: An Unexpected Journey from Disembodiment to Embodiment," writes:

> Autoethnography arises from a combination of an autobiographical approach and ethnographic methodology, which focusses specifically on reflexivity and self-consciousness. When incorporated into a research project, the experiences of the autoethnographer are considered vital to the data in understanding the marginalised group of which they are a part. (21, 22)

Ellis ("Crossing") describes autoethnography as not only a way of knowing about the world, but one that is "has become a way of being in the world, one that requires living consciously, emotionally, and reflexively." Also, that as autoethnographers we must "observe ourselves observing, that we interrogate what we think and believe" and "further explore the harrowing personal toll, and soul searching, that eventuated along the way for this researcher as a consequence of using an auto-ethnographic approach." This might suggest it has nothing to do with my life, my experience, or my research, but it does highlight the personal cost (negative and positive) of autoethnography that I chose to undertake and experience in the most personal of ways.

Amanda Coffey in *The Ethnographic Self* foreshadowed as inevitable that the personal will combine with the "cultural" in future ethnographic research activities because "we are a part of what we study and [are] affected by cultural contexts shaped by our fieldwork" (37). Deborah Reed-Danahay (*Auto/Ethnography*) supports autoethnographic research, but Rosanna

Hertz ("Ethics") foreshadows ethical issues with the presence in autoethnography when the writer's personality is deployed. Meanwhile, Charmaz and Mitchell challenge the concept of a "silent authorship" and maintain that openly using the author's presence and voice gives the research substance and style: "Evocative forms of writing are not merely desirable; they are essential" (195). This standpoint opens the door to being honest and unrestricted while "involving readers' imaginative participation" when describing personal experience, (Charmaz and Mitchell 195).

This reminds me of Ellis and Bochner's (2006) reaction to Leon Anderson who maintained that autoethnography is primarily analytical ("Analytic Autoethnography"). Reading his comments coincided with Ellis watching the graphic horror of levees breaking up in hurricane-ravaged New Orleans. She was about to start writing a commentary on Anderson's views but was unable to go on. Seeing people drown stopped her writing. Ellis's distress at the massive horror momentarily halted her line of thought. This later returned, with the pain and discomfort of this process being perceived by Anderson as seriously scientific ("Analytic Autoethnography"). Ellis maintains that autoethnography is meant to be evocative, and that it is the best way to paint a word picture of emotional involvement in human experience that readers will identify with in their own lives. Ellis wanted to stay with "the world of experience, feel it, taste it, sense it, live in it" ("Analytic Autoethnography" 431). Ellis uses her heart, and not only her head, which the analytical approach dictates.

Emotional engagement with the reader

Similarly, I prefer being open and evocative. It feels as if I can only be truly reflective by using my emotional self when responding to the pain and distress of myself and the others who I have campaigned for. Coming into the world of another is a privilege. Being invited to become involved on a similar plane with the "other" to become intrigued or involved by it, is to become engrossed by the way it is told. Every story needs to be clear, easily understood and explicit. In autoethnography I am the storyteller. It is my story, and others will enter into my world and feel my very existence, my pain, my perspective and my joy.

The benefit of autoethnographic research lies in the ability to create engagement and representation. The introspective and narrative character of autoethnography informs the fundamental nature of my intended research (Ellis, *Ethnographic I*). As a theory and methodology, it encourages me to be in the present and in the past simultaneously. In practical terms this means I examine and interpret phenomena and feelings at any given time. At each step I consider what happened before and its relevance to the present with my hope and goals for its implications for the future. As such I understand that autoethnography is a conversation with myself and a dialogue with the reader (Gadamer). This directs me as the researcher to a place where storying describes life perceptions and interpretations of my world. In practical terms this means that I examine my lived experience and refuse to be objective. In this way I work in hope of understanding myself as a person before and after dementia, and what that means.

A personal roller-coaster of dementia

My personal story of dementia is written and will remain the autobiographical hub to which I return from time to time. I am aware of the process of "self interviewing" through the analysis of my blog as the initial step to understanding. It relies on my living experience as I relate to the world that houses it (van Manen). And I engage in ongoing reflectivity because that is how I identify the conscious act that commutes between my ongoing life worlds (Ellis, *Ethnographic I*). To understand the concept of consciousness in these terms, I acknowledge a multiplicity of human involvement. The body may house a wealth of individual role models over a lifetime; we are the product of a collage of experience, a proverbial rollercoaster of life, loss and love. One, at the same time, could be a parent, a child, a spouse, a teacher, a nurse, an academic, a friend or just an interested observer. These complex personalities interact and may emerge as one in the reality of living (Ellis and Bochner, "Autoethnography").

Sometimes these many personalities require different genres. Lisa Tillman (2005) used poetry to describe a community of gay men processing their response to the United States Presidential elections in 2004, and Perry ("Dialogical Intersection") in a dialogue with her academic mentor shared the pain of her father's death. I have used poetry extensively to document my experiences of dementia, but writing poetry has only emerged since dementia, and appears to be attributable to the type of dementia I am diagnosed with and the results of neuroplastic changes in my brain. As Vitturi et al. discuss ("Maurice Ravel's Dementia"), the classical composer Ravel was diagnosed with the same dementia, and his music changed dramatically due to changes in his brain. Dr Anne Adams, a Canadian scientist who died of a rare brain disease also simultaneously developed a new form of creativity that she did not have previously (Aldous; Doctorow). On reading these stories I identify the possibility of an unguided process towards my narrative.

My interest in campaigning for others with dementia was my driving force. Pelias aptly says that theory and methodology of autoethnography "lets you use yourself to get to the culture, a culture that for [you] is familiar and [you feel] an essential part of it" (372), and after my initial research through an autoethnographic lens I am reminded that as a retired member of the culture of nursing I can speak with some authority about caring and supporting others with dementia. I know the belief system, personal values, spirituality and nurturing of nursing. As the autoethnographer I stand "naked" before the reader. There is an unashamed honesty in sharing myself openly—an honesty that is foreign to my family, to my heritage, and to my upbringing, but one I am committed to. Ever the operating theatre nurse, to me, truth is like surgery. It hurts, but it heals. To lie is like a painkiller. It provides almost instant relief, but it usually has negative side effects. Despite my own experience of some others disliking my honesty, it is part of who I am.

Dementia, music and grief

Grief can be exhausting and excruciating, and when left unattended and unaddressed, and in the case of a diagnosis of dementia, unacknowledged and unsupported, it becomes disabling. It can lead to issues such as prolonged anxiety, apathy, and depression, when untreated. Angela Matthews, who explores the use of autoethnography as a therapeutic method for processing grief after the loss of a child in "Writing Through Grief: Using Autoethnography to Help Process Grief after the Death of a Loved One," writes:

> Five key features separate autoethnography from traditional ethnography: visibility of self, engagement, strong reflexivity, vulnerability, and open-endedness (Anderson and Glass-Coffin, 2013). Using these features helped give my writing, my brain, and my days a direction and purpose it lacked while I petrified in the worst stages of my grief. So I let them guide me as I worked a little each day to transform my journal entries into autoethnographic field notes.

Music and journalling to manage trauma, grief, and loss have been an important part of my life (Swaffer, *Creating Life* 2022). I too began journalling via my blog about the impact of a diagnosis of dementia, in particular about the lack of support and the many violations of my rights. Similarly to Matthews, it transformed by sensibility from despair and grief to living more positively with dementia. My love of music included a deep knowledge of classical composers and compositions until one day it was difficult to retrieve. For example, I was suddenly unable to tell the difference between Mozart and Mahler. This loss of being able to access my knowledge of music and composers caused me to experience unexpected feelings of another deep loss and grief. Whilst there are many benefits of music for people living with a diagnosis of a dementia, to my knowledge there has been little written about the impact of the loss of musical knowledge, and how music therapy may cause trauma, not relief.

Music is universal, a part of every culture, but it is not positive to refer to it as therapy in care. I once played the piano well, and although I can no longer play it and cannot remember what the name of most music is, nor the composers, I've finally relearned the enjoyment of music. But only through doing grief and loss work have I been able to happily listen to music again. Initially the loss of my ability to access my knowledge of classical music made it too painful to listen to any classical music at all, until finding an app called Shazam. This has provided practical support and helped me deal with the grief and loss as it provides a way to easily discover what I am listening to. For people with, and without, dementia, music provides a way to express themselves, even when words fail, and creates opportunities for shared joy and connection.

Oliver Sacks explains in *Musicophilia: Tales of Music and the Brain*:

> Familiar music acts as a sort of Proustian mnemonic, eliciting emotions and associations that had been long forgotten, giving patients access once again to moods and memories, thoughts and worlds that had seemingly been completely lost. Faces assume expression as the old music is recognized, and its emotional power felt. One or two people, perhaps, start to sing along, others join them, and soon the entire group—many of them virtually speechless before—is singing together, as much as they are able. (163)

In 2015, I wrote about the grief of losing my memory of music and composers, "the canvas of my musical knowledge is becoming blank." Dementia organisations, researchers and others insist that music therapy is positive for all PLWD. Music is not always therapeutic; it can be traumatising and remind us of loss:

> Being away from my regular routines, and relaxing more, highlights a number of significant changes in my abilities, increases in my deficits, and whilst I constantly challenge myself to focus on what I can still do, it is hard to ignore the changes, hard not to miss the disappearing abilities, or the vast amounts of knowledge that have simply gone into hiding!!
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> This is painful for me. . . . The canvas of my musical knowledge is becoming blank. . . . I am deeply saddened by the loss of my memory of music. . . . Right now, it just makes me want to cry a lot. (Swaffer, "Prescribed Disengagement")

The therapeutic aspects of music in dementia care may have unexpected negative consequences for some PLWD, thus we need to better examine whether these practices actually support emotional healing or exacerbate despair and grief.

Conclusion

Following an overview of dementia as a condition causing cognitive and societal disability, through the methodological lens of autoethnography, this paper underlines the significance of lived narratives, illuminating how dementia shifts the understanding of identity and autonomy for both PLWD and their family members. It delves briefly into the role of dementia charities, assessing their advocacy efforts in combating stigma and raising awareness. Despite their important work, this paper critiques these organisations for perpetuating harmful narratives and failing to address the nuances of lived experience, which often lead to increased stigma and myths. In this context, the introduction of the concept of audism offers fresh insights, framing the biases faced by individuals with dementia in light of societal attitudes towards cognitive impairment and disability.

I have come to understand intuitively what makes campaigning for myself and other PLWD so compelling. "Sensitivity" for seeing myself in the "other" (Nordvedt 1998) best describes what makes travelling with pain a true communion with those others with dementia. As the autoethnographer I am a human being with a variety of experiences and emotions, both of which will always come through in my writing (Afonso and Taylor; Ellis, "Being Real"). Autoethnographic writing does not only tell "stories about [myself] garnished with detail" (Chang 149) but also engages in an interpretive manner with others' experience to inform and share. Good writing needs to contain a whole range of emotions, even on the subject of ordinary everyday life. In writing about sadness, for instance, there needs to be some joy in order to make the sadness more fully meaningful (Bochner 226).

With or without a diagnosis if dementia, your life and your experiences matter. My life and my experiences matter. Examining them through autoethnography has opened my heart in ways I could never have imagined, and the process of self-scrutiny using autoethnography has been illuminating, healing, and meaningful. It has also raised many topics and questions for future writings and research. The notion that others know what the experiences of living with a diagnosis of dementia is like, can no longer be justified. For example, whether PLWD experience complicated, ongoing loss and grief, how devastating and disabling not receiving disability support is, or what it feels like to experience othering, stigma, and discriminations can no longer be scrutinised by people without dementia alone. This work must first be led by people with the LE of dementia.

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