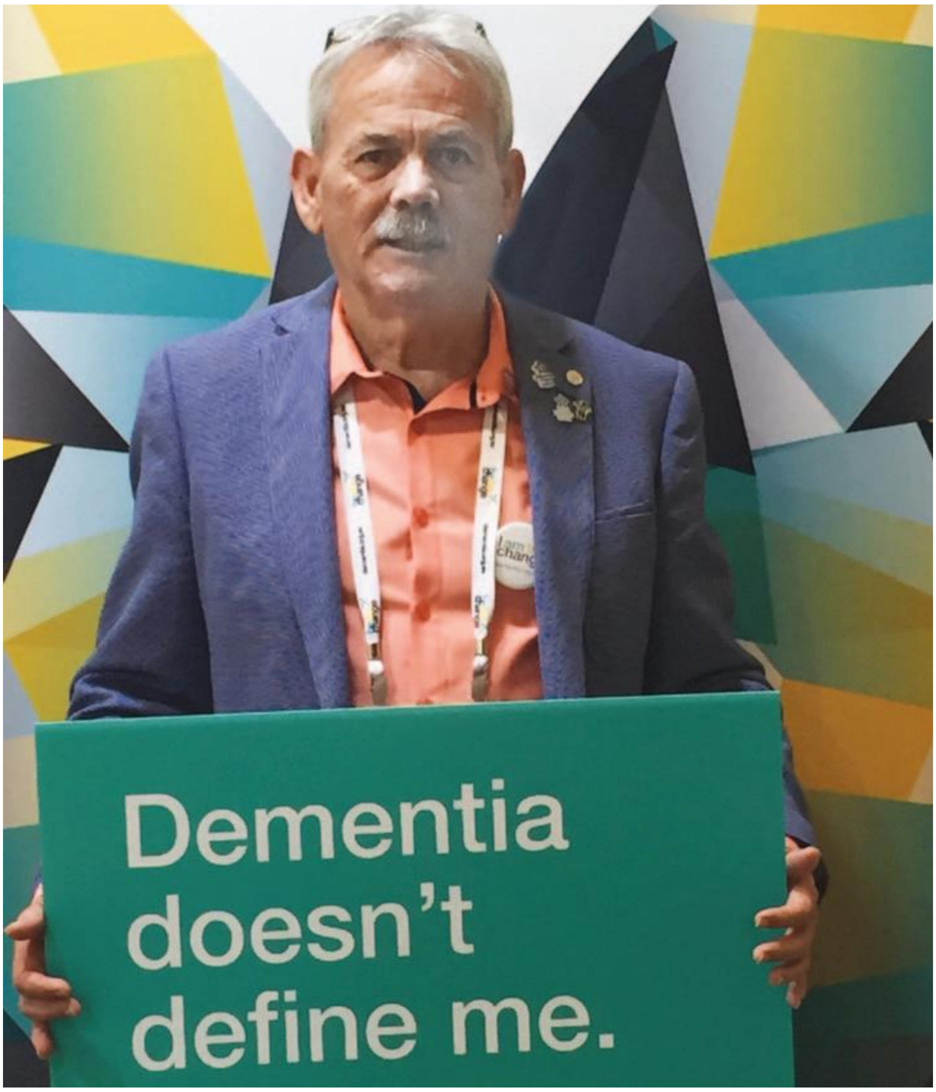
Reframing dementia to improve quality of care

Changing the way we view and treat people with dementia, coupled with a human rights approach, underpinned by a social model of disability, has the potential to transform the narrative about what authentic dementia care practices should look like, explains advocate **John Quinn**



In his dementia advocacy work in Australia and overseas, John Quinn addresses issues such as reablement, policy, reframing how people living with dementia are viewed and the role of the lived experience in research. Photos courtesy John Quinn and Glenys Petrie

I would like to ask you to visualise the following fictional scenario. Hopefully it rarely happened, even in the past, but we know from evidence presented to Australia's recent Royal Commission into Aged Care Quality and Safety, that events like this did happen. It's a scenario which evokes outrage, but fortunately through education, training and better modelling, I have to hope that it rarely happens now.

Your home is in aged care. You haven't slept well for a few nights due to undiagnosed pain in your shoulder and neck but you are now having a deep, restful afternoon sleep. A staff member holding a tray with a cup of tea and a snack walks into your room unannounced.

The staff member places the tray onto your nearby bedside table, leans over your bed, shakes you, and says, "Wake up, I have a cup of tea." You are half asleep, startled and disorientated, and despite being frail, you instinctively fling your arms in the air, accidentally making contact with the worker. That also creates more shoulder pain for you.

You are in the later stages of dementia and non-verbal, but make some incoherent noises in response to being disturbed and shaken unexpectedly. You have unintentionally struck the staff member, who immediately grabs your arms and forcefully places them to the sides of your body. You grunt and squirm as a reaction to the tight grip exerted by the staff member and the resulting pain that you are experiencing.

In response, the staff member makes a derogatory reference and then proceeds to manhandle you to prop you in an upright position against your pillow. Despite knowing that you can't feed yourself, the person leaves the room and the tray is left out of reach on a bedside table.

Upon entering the main hallway, the staff member calls out in a loud and angry voice, "The one in room 12 has just hit me. I'm sick of these people doing that." At the same time there is a loud bang and more utterances from room 12. It's discovered about 10 minutes later by another staff member, who comes to follow up a complaint, that you [the resident] are on the floor beside the bed.

We are all human and when under stress we may make poor decisions. However, in this scenario, I pose these questions:

- Are the behaviours and derogatory language used by the staff member dehumanising?

Above: John Quinn and his partner Glenys Petrie with geriatrician, author and dementia advocate Dr Allen Power (right).
Left: As members of their local Dementia Alliance, John and Glenys, pictured with Father Michael Twigg, Rector of Iona College, Brisbane, delivered an education program to students and staff on how to make their school community dementia-friendly

- Why have such behaviours and demeaning language use continued for so long towards the most dependent, loneliest and vulnerable members of our communities?
- Why has cruelty, neglect, inhumane behaviour and treatment existed within what is supposedly a caring society?
- Why have these incidents occurred despite policies and procedures and the ensuing expectations of the people living with dementia, and others in need of specific care and support, and their families?

With the life-expectancy of Australians increasing, age being a risk factor for developing dementia, and with one in three elderly citizens over the age of 80 in full-time care living with a diagnosis of dementia, the reality is that this could be you or I in the future.

In need of reform

Fortunately, this scenario is not what plays out in all care homes. However, the fact that these interactions and practices still exist is indicative of:

- a culture whose origins are a hangover from the past because only a few decades ago people with dementia were considered senile or mad and, before that era, relegated to asylums
- in a number of instances, a reflection of a workforce that is inadequately trained, poorly paid, time-poor, and task-focused, rather than adopting a person-centred positive, wellbeing approach.

These workplace issues highlight a system that has demanded comprehensive reforms.

Too often we still hear comments such as:

- dementia is ‘a thief that robs them of their loved ones’
- that the person is the ‘patient’, the ‘sufferer’, or a ‘shell of her/his former self’
- that the family caregiver is the ‘hidden victim’
- the ‘long goodbye’
- that the person is ‘no longer there’
- referring to people with dementia as 'ferals' who are 'out of control'
- ‘the burden of dementia’; and
- ‘a dementia tsunami’ (should a major global health issue be likened to a sudden catastrophic environmental event?).

As asserted by Cahill (2019) in an article in *The Irish Times*, “These words do nothing to promote the agency, dignity and humanity of the individual who, no matter how severe their cognitive difficulties, is never gone and is still a recognisable human being that must be treated with dignity and respect.” Moreover, Cahill (2019) believes that, “words are powerful and influence how we perceive and interact with people”.

Therefore, disabling language simply reinforces the public’s perceptions of those living with dementia and the stigma about dementia. Words and images can be emotive, and, consequently, can and do medicalise many behaviours which, in turn, often precipitates pharmacological prescription.

Fortunately, these commonplace depictions of dementia are being challenged through greater public awareness, often led by dementia advocates. Their personal stories have demonstrated that not all people with dementia are the same and that, with appropriate and timely support and adaptations to their daily lives, it is possible for people with dementia to continue engaging with their previous lifestyles beyond the diagnosis.

However, the focus within the aged care sector is still largely on the biomedical model due to:

- a lack of comprehensive inclusion of information about dementia in courses at tertiary institutions
- the lack of awareness about quality of care and social care principles to support the activities of daily living for the person living with dementia; and,
- the influence and profits of pharmaceutical companies. Some service providers present a major impediment to change as they are expressions of powerful, vested interests whose motives for resistance to change are motivated by the money to be had by portraying the negative aspects of the disease.

This can be seen in a number of funding areas, including the basics, where the focus is on a person’s emerging needs as opposed to support in an effort to delay those needs through the adoption of restorative and enabling principles of care. This highlights that the aged care funding model needs to also be addressed.

For example, additional funding is provided for those requiring incontinence pads. However, wouldn’t it be better to receive additional funding to delay the need for incontinence pads through a proactive approach involving allied health professionals? A similar argument may be made for mobility. Funding to maintain a person’s core strength will benefit both issues.

And, whilst talking about funding for care, dignity and respect, what about a basic support package provided at the time of diagnosis of dementia regardless of age?

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Impediments to change

Sadly, past perspectives of dementia have been the roadblock to any initiatives to look at the disease through different lenses.

One of the most significant impediments to change is the existence of a culture underpinned by ageist beliefs whereby, as people age, it is thought:

- their value to their communities is diminished
- their contributions to society aren't valued; and
- as their health deteriorates, they become more dependent on society.

These beliefs are exacerbated when dementia is involved.

As suggested by Macdonald *et al* (2019 p1ff), we need to "create a society in which vulnerability is a legitimate, well-supported life experience, and care is valued as central to all life... Instead of starting with dementia as a cruel, feared and vilified disease, let us start with a revaluing of vulnerability and care as intrinsic to all life."

Their beliefs align with many of us who advocate that challenging the stigma of dementia engenders conditions for viable rich lives for all who are living with dementia.

Reframing dementia

We need to move beyond the deficit-based, biomedical model of dementia, where knowledge about the pathology of the disease presents a narrow, clinical view of pathways of care for people with dementia. Therefore, there needs to be a paradigm shift in the way we view people with dementia. We need to reframe dementia.

The concept of reframing dementia is not new. It has been around for decades and has been informed and guided globally by the work of people living with dementia, researchers, medical professionals, activists and policy makers, through the written and spoken narrative.

By reframing dementia, it should not be assumed that all the energy and commitment that has gone into finding a cure; developing a better understanding of the disease, including preventative measures; and improving treatment and care practices, are not valued. All of these efforts provide people with dementia *hope*. However, these are not enough. People with dementia need to live as well as possible, *now*.

Concerted efforts to change the dominant dementia narrative by introducing new viewpoints have emanated from a number of fronts.

John Quinn at the Alzheimer's Disease International Conference in Budapest in 2016, where he presented on the topic Exercise Helps Me Remember My NAMES (Nutrition; Attitude, Acceptance and Art therapy; Mental activities/games, Music and Meditation; Exercise and Enjoyment; and Sleep, Support, Socialisation and Setting goals)

The new perspectives about dementia proffered by Kitwood (1997) about personhood; Bartlett and O'Connor's (2007, 2010) citizenship model; a social constructivist view (Sabat 2011, 2014, 2018); and a wellbeing stance (Power 2010, 2014, 2018) were instrumental in transcending the narrative about dementia beyond the myopic, reductionist model and embracing a bio-psychosocial viewpoint of the disease highlighting concepts of personhood, agency, social inclusion, independence, connectedness, participation, dignity, empowerment, autonomy, and maintaining capacity and wellness.

In addition, numerous researchers and organisations have added to the conversation about quality of life through, for example:

- the Alzheimer's Australia NSW (now Dementia Australia) *Living Well with Dementia* Discussion Paper (Stupar & Moore 2016)
- University of Exeter's Professor Linda Clare's IDEAL (Improving the Experience of Dementia and Enhancing Active Life) and IDEAL-2 projects (Clare *et al* 2014-2018 and 2018-2022) (www.idealproject.org.uk); and
- Professor Henry Brodaty and colleagues' ongoing COGNISANCE (Co-Designing Dementia Diagnosis and Post Diagnostic Care) project at UNSW Sydney (www.cheba.unsw.edu.au/consortia/cognisance).

They, along with other researchers have looked, or continue to look, at the key aspects of positive pathways of care which will lead to living well during the pre- and post-diagnostic period for people with dementia. Such projects will also contribute to changing the dementia narrative.

The global social movement using the dementia-friendly communities initiative as a vehicle for greater public awareness and understanding has also been instrumental in demystifying and de-stigmatising dementia. With regard to public awareness, Macdonald *et al* (2019 p9) assert, "Raising social awareness and changing dominant narratives about ageing and dementia with more empowering frameworks will be crucial in moving towards reducing ageist abuse and building capacity for equitable resource distribution."

Importantly, it could also be argued that the most pivotal moment that has contributed to a seismic shift in the way we view dementia was the acceptance of dementia as a disability under the United Nations' Convention on the Rights of Persons with Disabilities (UNCRPD) in Geneva in 2016, to which Australia is a signatory, and the human rights ascribed to this acknowledgment. This recognition has elevated the hopes of those living with dementia and those who support them.

Transforming the narrative

Notwithstanding the lived experience stories, the intersection between the contemporary perspectives about dementia previously highlighted, coupled with a human rights approach, underpinned by a social model of disability, have the potential to transform the narrative around dementia about what authentic dementia care practices should look like.

Moreover, they provide a framework or analytical tools by which we can interrogate the alignment of their inherent principles with regards to current policy, regulations and social and clinical care practices for people living with dementia. As asserted by Cahill (2019) in *The Irish Times*, this model "gives agency, power and control back to the individual whose voice is elevated. The voice of the lived experience should be front and centre in any conversations about their health and wellbeing."

Furthermore, Cahill (2019) writes that "…people with dementia have the same legal rights as others throughout all stages of their life; these legal rights are inviolable and can never be removed no matter how advanced the dementia." After all, aren't we the ones that endure the indignities, the shame, the stigma, social isolation and discrimination that almost invariably follow from a dementia diagnosis?

On a global level, a number of dementia activists have attempted to draw greater attention to the recognition of dementia as a disability as acknowledged under the UNCRPD. Unfortunately, they feel the need to highlight this issue because of the slow response by their own governments, health care professionals, some service providers and others who work in the dementia space to put in place the legislation, policies, practices and programs for people with dementia which reflect their rights under this Convention.

I believe that one of the most powerful ways we can change the narrative about dementia, thus reducing the stigma, the fear and negative mindsets, is to speak openly about dementia, like we do with other medical diagnoses. We need to respond to a dementia diagnosis just like we do when someone gets a chronic health condition such as cancer, heart disease or has a stroke. The use of the word 'dementia' should be normalised and comfortably incorporated into our everyday language as necessary.

We need to challenge people who hear a diagnosis of dementia and say, 'how tragic', and encourage them to say, 'How can I support the person and his/ her carers?'. At this point it's also important to highlight that not everyone who receives a diagnosis of dementia has the support of family, and may in fact live alone.

As mentioned at the outset, to change the way we view and treat people with dementia, and ultimately enhance their quality of life, there needs to be systemic reforms.

Assessing outcomes

From this viewpoint, how has the reframing narrative translated into better support and quality of life for people living with dementia?

Over several decades in Australia there have been a number of inquiries into the quality of care provided to the aged, particularly those in full-time residential care, of which a number live with dementia. Sadly, many of the recommendations were not adopted.

Following widespread outrage due to a number of public revelations about the continued sub-standard care provided within the aged care sector, a Royal Commission into Aged Care Quality and Safety commenced in 2019. The Commission's recommendations, released on 1 March 2021, *must* not only be mandated, but also implemented. The regulatory body *must* have some 'teeth', and punitive disincentives for non-compliance *must* be enforceable.

During the Royal Commission's hearings, new Aged Care Quality Standards (Quality Standards) were established to "focus on outcomes for consumers and reflect the level of care and services the community can expect from organisations that provide Commonwealth subsidised aged care services" (Aged Care Quality and Safety Commission 2019). These Quality Standards incorporate the benchmarks against which service providers are audited for accreditation and funding.

The Royal Commission's Interim Report, titled *Neglect*, (Commonwealth of Australia 2019), documents incidents of neglect and, in a number of cases, financial and physical abuse within the aged care sector. It also highlights that the aged care sector is grappling with how to attract, train, retain and sustain its workforce. With regard to dementia, expert witnesses cite an over-reliance on the use of physical and chemical restraints as a way of managing dementia clients' responsive behaviours.

Witnesses appearing before the Royal Commission provided statements including the following:

"My father was like a caged animal and we asked how long he was restrained at any one time. The policy is two hours and then they are unrestrained but with one-to-one care for a bit for him to be toileted before being restrained again. It's appalling to see this" (Commonwealth of Australia 2019 p116).

"Dad was off his face, drugged up to the eyeballs, incoherent and lying in a pool of urine. I have video of this, it was very, very distressing" (Commonwealth of Australia 2019 p117).

Since these testimonies, the Australian Government has introduced new, mandated guidelines to minimise the use of physical and chemical restraint in residential aged care (which are to be followed by all aged care providers).

In relation to the new Aged Care Quality Standards (Aged Care Quality and Safety Commission 2019), following the release of the draft Quality Standards in 2017 for public consultation, people with the lived experience of dementia expressed concern that the eight Quality Standards would not necessarily ensure quality dementia care is delivered. This led to a series of discussions in 2019, initiated by Dementia Australia's Consumer Engagement Team, with over 31 focus groups across Australia, with 137 people participating, including people living with dementia, their families and carers. A thematic analysis identified recommendations in the context of each draft Standard. These were published by Dementia Australia in 2019 as a communique titled *Our Solution: Quality Care for People Living with Dementia.*

I will share with you the recommendations and comments from dementia advocates relating to draft Standard 1, Consumer Dignity and Choice from the communique. You will see from reading these that people with dementia and their carers are quite clear as to what they believe dignity and respect should look like – and feel like. Respect and dignity reflect *how* things get done rather than *what* gets done. The following excerpts from the communique are re-published here with the permission of Dementia Australia:

Standard 1: key themes

- Trained, caring and empathetic staff.
- Relationship building and taking time to get to know the person.
- Patience.
- Respect.
- Maintaining identity.
- Human rights.

The communique goes on to outline the following expectations by dementia advocates with regard to organisations:

1. The workforce understands and recognises the diversity of dementia through building personal relationships with the person living with dementia, their families and carers.
2. Additional time is allocated for the workforce to care for a person living with dementia, to understand their needs, behaviours and potential triggers.
3. The workforce is trained to communicate effectively with the person living with dementia, their families and carers with respect and empathy.
4. There is a focus on active involvement with the person living with dementia, their families and carers in decision making.
5. The workforce demonstrates knowledge and practice of what is important to the person living with dementia and respects their preferences through a human rights and person-centred approach to care.
6. There is acknowledgment and inclusion of the person living with dementia as a valued member of the community through engagement, recognition and participation in activities and social gatherings.

The following statements from the communique are from people living with dementia and carers about what dignity and respect looks like and feels like to them:

"The most important thing is that the care worker has empathy and recognises that individual person not just as another person they need to shower and feed – this is Grace

[not her real name], she likes wearing lipstick and these clothes, she still has her identity and this is very important." (carer).

"Every person with dementia is different and every day is different." (carer).

"Maintain my identity – let me do the things I can do." (person living with dementia).

"It is having the time to spend with people. Getting to know who they are, their likes and dislikes. That's what matters." (carer).

Where are we at now?

In March 2019, the Australian Department of Health facilitated workshops in Hobart, Brisbane and Sydney on co-designing policy to support people to live well with dementia, as part of a project called Dementia in the Community, conducted in 2019-2020. The Dementia in the Community Policy Co-Design workshops were attended by people living with dementia, carers, allied health professionals, GPs, medical specialists, dementia educators, specialist dementia services, researchers (including for Aboriginal and Torres Strait Islander and Culturally and Linguistically Diverse people) and Primary Health Network staff.

My partner Glenys and I were involved with the Brisbane workshops. This exercise itself was empowering because we were able to place *all* issues on the table for discussion and inclusion.

As a result of these workshops, a number of policy concepts were developed, namely:

- becoming a dementia-inclusive society
- timely diagnosis and early supports to live well with dementia
- ongoing supports for people with dementia and their carers
- a health and aged care workforce that delivers exemplary dementia care.

The policy concepts resulting from the Dementia in the Community project were submitted as evidence to the Royal Commission into Aged Care Quality and Safety. The policy concept document, which is publicly available, states that the "Department of Health will continue to work collaboratively with people living with dementia and those supporting them, to shape these ideas into future policy and program recommendations over the short, medium and long term…" (Commonwealth of Australia 2020). The concepts are part of the inputs that will assist to inform the Government's response to the Royal Commission recommendations.

As a requirement for ratifying the CRPD all signatory countries agreed to develop policies, legislation and guidelines to comply with the CRPD. In Australia to date there has been little, if any advancement in this area. Hopefully the above policy work will go some way to achieving this.

Conclusion

The opportunity is there for organisations and practitioners to use the CRPD, the Department of Health's Dementia in the Community Policy Co-Design Workshop Outputs document described above, and Dementia Australia's recommendations contained in the *Our Solution: Quality Care for People Living with Dementia* communique (2019) to interrogate practice, identify inequalities, enhance care and lobby for protection and fulfilment of the rights of people with dementia.

But there *must* be transparency and accountability because at the moment we are stripped of our dignity, our sense of worth and agency because of the stigma that accompanies a diagnosis of dementia.

Recently, the level of interest by those working in the dementia space, including people living with dementia and those who are either paid or undertaking voluntary work, to challenge current practices, language-use and highlighting our rights is encouraging.

I'm optimistic that now is a crossroads of intersecting viewpoints, regulations and a demonstration of respect towards those of us who have the lived experiences.

As a person living with dementia, I would have some *hope* for the future if this was to happen. Why? Because I want to live well *now*. ■

This is an updated version of John Quinn's presentation to The Dementia Centre, HammondCare International Dementia Conference in Sydney (11-12 June 2020), titled *Reframing Dementia: A Catalyst for Change in Quality of Care*. Published with the permission of The Dementia Centre, Hammondcare.

■ John Quinn is an Australian dementia advocate and person living with younger onset dementia. He is a member of eQC (evaluating Quality Care) Patient and Carer Advisory Board, Centre for Health Services Research, University of Queensland; the consumer representative on Queensland's Statewide Dementia Clinical Network (SDCN) Steering Committee; a member of Brisbane North PHN's Dementia Strategy Expert Advisory Panel; Sydney Dementia Network Lived Experience Expert Advisory Panel (SDN-LEEP); and a committee member on StepUp for Dementia Research. John is also the national ambassador for the QUT 'Getting Home Safely' project. He's been involved in many research committees over the past four years and in 2019 was on the panel for the National Health and Medical Research Council's Boosting Dementia Research Grant application selection process. Contact John at john_quinn12@hotmail.com

References

Aged Care Quality and Safety Commission (2019) *Aged Care Quality Standards*. Canberra: Commonwealth Government. Available at: agedcarequality.gov.au.

Bartlett R, O'Connor D (2007) From Personhood To Citizenship: Broadening The Lens For Dementia Practice and Research. *Journal of Ageing Studies* 21(2) 107-118.

Bartlett R, O'Connor D (2010) Broadening the Dementia Debate: Towards Social Citizenship. Bristol, UK: The Policy Press.

Cahill S (2019) Reframing Dementia as a Disability and a Human Rights Concern. *The Irish Times*. Available at: http://bit.ly/3ctkIDO.

Clare L *et al* (2014-2018, 2018-2022) IDEAL and IDEAL-2 projects. University of Exeter. Available at: www.idealproject.org.uk.

Commonwealth of Australia (2019) Royal Commission into Aged Care Quality and Safety *Interim Report: Neglect* Vol 1. Available at: www.agedcare.royalcommission.gov.au/publications.

Commonwealth of Australia (2020) *Dementia in the Community Policy Co-Design Workshop Outputs.* Document presented to the Royal Commission into Aged Care Quality and Safety. Available at: CTH.0001.1000.5602.pdf (royalcommission.gov.au).

Dementia Australia (2019) *Our Solution: Quality Care for People Living with Dementia*. Consumer Summit Communique. Available at: https://bit.ly/3qGkIFC.

Kitwood T (1997) *Dementia Reconsidered: The Person Comes First.*
Buckingham: Open University Press.

Macdonald G, Mears G, Naderbagi A (2019) Reframing Dementia: The Social Imperative. In: Macdonald G, Mears J (Eds) *Dementia As Social Experience: Valuing Life and Care.* Abington, UK: Routledge.

Power GA (2010) *Dementia Beyond Drugs: Changing the Culture of Care.* Baltimore: Health Professionals Press.

Power GA (2014) *Dementia Beyond Disease: Enhancing Well-being*. Baltimore: Health Professionals Press.

Power GA (2018) Looking Beyond Disease. *Australian Journal of Dementia Care* 7(2) 17-19.

Sabat SR (2011) A Bio-Psycho-Social Model Enhances Young Adults' Understanding Of And Beliefs About People With Alzheimer's Disease: A Case Study. *Dementia* 11(1) 95-112.

Sabat SR (2014) *Understanding People With Alzheimer's Disease – A Bio-Psycho-Social Approach.* Paper presented at the Genio Annual Dementia Conference, Davenport Hotel, Dublin, December 2014.

Sabat SR (2018) *Alzheimer's Disease & Dementia: What Everyone Needs To Know.* New York: Oxford University Press.

Stupar M, Moore B (2016) *Living Well with Dementia, Alzheimer's Australia NSW Discussion Paper 17*, August 2016.

WHO (2016) *Draft Global Action Plan On Public Health Response to Dementia*. Report by the Director-General. EB 140/28, 29 December. Available at http://bit.ly/2x3cRf9.