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(Dementia)

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Submission

Dementia: The Reality

Inquiry into Dementia
Early diagnosis and Intervention

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Summary

This submission addresses the Terms of Reference by highlighting the human and personal costs, the significant financial impact to individuals and families, and responds to the current status of age appropriate resources and services, or lack thereof, for people diagnosed with younger onset dementia and their families and extended networks. It recommends increased and improved GP education of dementia is required to ensure earlier detection and diagnosis and referral to medical specialists; increased Practice Nurse training in detection and management of dementia; changes to Accreditation Standards in residential care to properly accommodate people with younger onset dementia; focus on psychosocial care and therapies and non pharmacological interventions; authentic brain injury rehabilitation for people with dementia particularly in the early stages; improved general health care, including education about diet and exercise specific to dementia; NeuroPhysiotherapy; Neuro plasticity [brain] training; holistic health options, including Transcendental Meditation, supplements and hypnosis; funding for improved service provision; better education of service providers and their staff; age appropriate in home services, respite and residential care for people with younger onset dementia; increased clinical research funding, new funding for research into non pharmacological interventions and for improved quality of life outcomes for people with dementia; non means tested carer allowance, and access to assisted technology.

The report addresses the implications of early versus delayed diagnosis of dementia, improving quality of life through early diagnosis, increasing opportunities for social engagement; residential, in home and respite care, awareness and education of service providers and the community, implications of the current Health Care Reform Package, and strongly recommends an information resource pack prepared collectively between Alzheimer's Australia and the Medical Associations, as a hand out to all people diagnosed at the time of dementia, and improved dementia education of nurses and medical staff in hospitals. It recommends reform in the insurance industry as it currently discriminates against people with dementia. There is a thin veil between people with dementia being treated with dignity or being treated like morons. Therefore, it is people with their own stories who have the most chance of impacting change. As a person living with dementia, and included in this report is a brief summary of my story, and a person who has nursed in the industry, I am in a unique position to critique the service provision of, and funding for, people with dementia and their families. Finally, it recommends changing the term ACAT to Disability Care Assessment Team (DCAT), to ensure people under the age of 65 years can access these services.

Positively living with dementia

This is my personal story of being diagnosed aged 49 with a younger onset fronto temporal dementia, and the non-pharmacological interventions used to promote wellness and happiness. At the time of diagnosis, I was working full time, studying at a tertiary level full time, and caring for my husband and children. With no treatment options¹, and the realisation it is a terminal illness, I accepted it as a disease with disabilities to be managed, rather than symptoms contributing to my demise. Features prominent in 2006, first examined in 2007 were impaired cognition and comprehension, mild speech difficulties and language dysfunction, episodic memory loss, mild anomia and surface dyslexia. Initially it was easy to compensation for these disabilities.

In 2008 after further MRI, SPECT and PET scans, and following further neuropsychological testing showing increased deficits in the semantic categories, increased anomia, object and auditory agnosia, increased surface dyslexia, prosody and behavioural changes, and cognition and number impairment, I was diagnosed with a fronto temporal dementia, possibly Semantic. Pharmacological interventions are still unavailable, and due to this, and my proactive response, treatment continues to be positive psychology and other non-pharmacological interventions. The advice of medical practitioners and some service providers was to give up work, give up studies and *start living for the time I had left*.

This *prescribed dis-engagement* seemed at odds with what I perceived to be *positive living*, so I ignored it, instead developing strategies to be productive setting up a regime of activities and lifestyle changes specifically focused on symptom management and meaningful engagement. Neuroplasticity exercises², Transcendental Meditation, self-hypnosis, diet, supplements, exercise, education (tertiary), brain training³, volunteering, counselling, creative writing, poetry, music therapy⁴, and laughter have ensured I've reached wellbeing through engagement, fun and meaning; in effect, focusing on Dr Martin Seligman's PERMA Principles⁵. Resilience has also been vital to remaining positive. A phenomenological⁶ approach to this illness is also a significant key to positivity.

I have become a spokesperson for Alzheimer's Australia at events such as the national Fight Dementia campaign rally in October 2011; have given talks to service provider groups as part of staff dementia education; I performed at the 2012 Adelaide Fringe, sharing my story with an even wider audience, thereby changing perceptions and destroying some of the

¹ Knibb, J. & Hodges, J., 2005, Semantic Dementia: Losing the meaning of everything, *Practical Neurology*, 5, 236-239.

² Doidge, N, 2010, *The Brain That Changes Itself*, Scribe Publications.

LIPTON, B, 2005, *The Biology of Belief: Unleashing the Power of Consciousness, Matter and Miracles*, Hay House Inc., 103, 105-106.

³ Luminosity, 2012, retrieved 1 May 2012, <<http://www.lumosity.com/app/v4/personalization>>

⁴ Forinash, M; Gonzalez, D., 1989, A phenomenological perspective of music therapy, *Music Therapy*, Vol 8(1), 35-46.

⁵ Seligman, M, 2011, *Flourish: A Visionary New Understanding of Happiness and Well-being*, Free Press.

⁶ Carel, H, *Illness*, 2008, *The Cry of the flesh*, Acumen Publishing, Stockfield, UK.

myths about dementia, which I hope will also help bring about the much needed change; I am working as a consultant with a number of service provider groups helping them to reform aged and dementia care within their organisations; I have presented at national and international conferences, including The Thinkers In Residence conference in Adelaide in February 2012, Alzheimer's Disease International in London in March 2012, and I am key note speaker at the Alzheimer's New Zealand conference in May 2012. In this capacity, I have become an advocate and lobbyist for aged and dementia care, and actively engaged in policy, and in other positive and constructive ways, such as this submission.

Treating symptoms in the early stages of dementia, as the gateway to supporting disabilities, not managing them in ways that restrict and hinder, and managing emotional changes with counselling and positive engagement, rather than treating the symptoms with drugs, have become paramount to my well being and perceived longevity.

Terms of Reference⁷

Australia's population is ageing and over the next 20 years the number of people with dementia is predicted to more than double. Early diagnosis and intervention has been shown to improve the quality of life for people with dementia, as well as for family members and carers.

The Committee will inquire into and report on the dementia early diagnosis and intervention practices in Australia, with a particular focus on how early diagnosis and intervention can:

- Improve quality of life and assist people with dementia to remain independent for as long as possible
- Increase opportunities for continued social engagement and community participation for people with dementia
- Help people with dementia and their carers to plan for their futures, including organising financial and legal affairs and preparing for longer-term or more intensive care requirements
- How best to deliver awareness and communication on dementia and dementia-related services into the community

⁷ House of Representatives Committees, 2012, *Inquiry into Dementia: Early diagnosis and Intervention: Terms of reference*, Parliament House Australia, retrieved 23 April 2012, <http://aph.gov.au/Parliamentary_Business/Committees/House_of_Representatives_Committees?url=haa/dementia/tor.htm>

Implication of early vs delayed diagnosis

Early Diagnosis

The primary purpose of early diagnosis is timely access to information, advice, and support and access to a pathway of effective treatment and care from the time of diagnosis to end of life care, and to enable interventions that may only work or be suitable in the earlier stages⁸. Early diagnosis for people with the symptoms of dementia is essential as they may still have the ability to think logically, even though their powers of reasoning may have started to be impaired. They will still be able to discuss the implications of the illness and how it will affect them and their families now and in the future, and it is the time when decisions regarding future care needs and financial and legal issues must be considered, while the person with dementia is still legally competent. Giving the diagnosis at this early stage is not that different to the diagnosis of any other chronic and terminal illnesses, in terms of the discussion process. Obviously it is important to remember the person with dementia may already be experiencing memory difficulty, and therefore time must be taken to give the information in ways it can be retained, including repetition, printed information, and having other family members present. Engaging the person with dementia is easier at an early stage because they are more likely to be less impaired cognitively and their memory loss will be less impaired.

Early diagnosis addresses three of the four Terms of Reference. It empowers the person with dementia to improve their own quality of life and assists them to remain independent for as long as possible. It offers more opportunity for increased and continued social engagement and community participation, and helps people with dementia and their carers to plan for their futures, including organising financial and legal affairs and preparing for longer-term or more intensive care requirements. The fourth term of reference may be attended to by early diagnosis as the person with dementia will be in a position to become active with advocacy and education of and about their condition within their own community. Early diagnosis also allows the best outcomes for activities such as brain training, relearning and retention⁹ training, It also seems clear that the impact of developing a shared social identity among a group of people with early-stage dementia is important in the well being and happiness of these patients¹⁰.

⁸ World Alzheimer's Report, 2011, Executive Summary, p 8

⁹ Bier, N., Macoir, J., Gagnon, L., Van, d. L., Louveaux, S., & Desrosiers, J. 2009, Known, lost, and recovered: Efficacy of formal-semantic therapy and spaced retrieval method in a case of semantic dementia. *Aphasiology*, 23(2), 210-235.

Heredia, C. G., Sage, K., Ralph, M. A. L., & Berthier, M. L. 2009, Relearning and retention of verbal labels in a case of semantic dementia. *Aphasiology*, 23(2), 192-209.

¹⁰ Bright, P., Moss, H. E., Stamatakis, E. A., & Tyler, L. K. 2008, Longitudinal studies of semantic dementia: The relationship between structural and functional changes over time, *Neuropsychology*, 46(8), 2177-2188.

Early intervention may also allow the person to stay in paid employment for longer, reducing the cost impact to families, and ultimately governments.

Key findings of the World Alzheimer's Report 2011, listed on pages 4 and 5¹¹ of the Executive Summary, clearly support early diagnosis. I have quoted this list in full, as it supports my experience, and my findings above.

- Dementia diagnosis provides access to a pathway of evidence-based treatment, care, and support across the disease course
- Perhaps as many as 28 million of the world's 36 million people with dementia have yet to receive a diagnosis, and therefore do not have access to treatment, information, and care.
- The impact of a dementia diagnosis depends greatly upon how it is made and imparted. Evidence suggests that when people with dementia and their families are well prepared and supported, initial feelings of shock, anger and grief are balanced by a sense of reassurance and empowerment
- Earlier diagnosis allows people with dementia to plan ahead while they still have the capacity to make important decisions about their future care. In addition, they and their families can receive timely practical information, advice and support. Only through receiving a diagnosis can they get access to available drug and non-drug therapies that may improve their cognition and enhance their quality of life. And, they can, if they choose, participate in research for the benefit of future generations
- Most people with early stage dementia would wish to be told of their diagnosis
- Improving the likelihood of earlier diagnosis can be enhanced through: a) medical practice-based educational programs in primary care, b) the introduction of accessible diagnostic and early stage dementia care services (for example, memory clinics), and c) promoting effective interaction between different components of the health system
- Early therapeutic interventions can be effective in improving cognitive function, treating depression, improving caregiver mood, and delaying institutionalisation. It is simply not true that there is 'no point in early diagnoses or that 'nothing can be done'. Some of these interventions may be more effective when started earlier in the disease course
- Available evidence suggests that governments should 'spend to save' – in other words, invest now to save in the future. Economic models¹² suggest that the costs associated with an earlier dementia diagnosis are more than offset by the cost savings from the benefits of anti-dementia drugs and caregiver interventions. These benefits include delayed institutionalisation and enhanced quality of life of people with dementia and their carers

¹¹ World Alzheimer's Report, 2011, Executive Summary, pp. 4-5

¹² World Alzheimer's Report 2011, *The benefits of early diagnosis and intervention*, p 61, retrieved 30 April 2012, < <http://www.alz.co.uk/research/WorldAlzheimerReport2011.pdf>>.

Delayed diagnosis

A delayed diagnosis has a number of significant and negative outcomes.

- Rate of the disease may progress more quickly as minimal healthy lifestyle interventions
- The person with dementia may no longer be legally competent to make decisions in their own interests
- Decreased willingness or ability to participate in social or other activities
- Reduced ability to accept they have dementia and come to terms with it
- Impaired ability to go through a healthy grieving process
- Impaired ability to share end of life decisions with their family
- Impaired ability to make financial decisions
- Appointing people to make decisions in their best interest possibly impaired
- There may be a conflict of interest between the person with dementia and the person who will end up having to take over your affairs
- Accepting decisions such as the loss of their driving license more difficult
- If medication is available for the type of dementia they are diagnosed with, they will have missed out on the opportunity of improved quality of life this can give them
- Drugs trials may no longer be available to them because of the stage they have entered
- Family members will lose the opportunity to share the fully diagnosis, and grieve with their loved one
- Person with dementia at risk of physical injury
- Person with dementia at risk of wandering and getting lost
- Driving may become very dangerous, therefore impact to own and others safety
- Insurance policies may be null and void if diagnosis is discovered to have been delayed, and an accident takes place
- Personal growth that could have been achieved through self awareness of the disease impaired by late diagnosis
- Advocacy, socialisation and community involvement impaired
- Increased isolation
- Increased loneliness
- Increased problems with general health
- Increased visit to the GP because of the 'masking' of dementia symptoms, with obvious cost implications to governments
- Increased levels of depression, anxiety, anger, and behaviour management requirements
- Increased costs of care¹³
- Reduced stigma and increasing awareness, as the community see people living well in their communities, in spite of dementia, rather than just seeing people at later stages with high levels of impairment

¹³ World Alzheimer's Report, 2011, Executive Summary, p 3.

Impact of a diagnosis of younger onset dementia

Younger onset dementia is simply the diagnosis of a person under the age of 65 with dementia. It varies, but the impact on a person under this age and their families is very different to someone over the age of 65.

- Usually the person is in paid employment
- They may still have school aged children
- Once they have to give up paid employment, usually recommended early, their family income halves as they become a 1-income family
- Their health costs can more than double
- Reduced self worth as their valued roles are diminished or completely negated, which can increase issues such as depression
- Their travel costs, to accommodate health care appointments and other services required, increase
- There are NO age appropriate services
- Therefore many of the Aged Accreditation Standards are being breached in the residential setting
- Childcare may be required because of the person with dementia not being able to care for their children, and their partner having to work
- Means tested carer allowance is not only unreasonable, it is not cost effective¹⁴
- The negative impact, and the physical and emotional burden on their children, husband and older parents, as care givers, becomes significant

Innes's book *Dementia Studies*¹⁵, concludes further studies need to look at the micro level of experiences of dementia patients themselves, and must move beyond current research and policies, to establish services and support for real well-being, rather than to support current policies and services provided in the care settings.

The most significant missing link for people with younger onset dementia is age specific support and services.

¹⁴ Innes, A, 2009, *Dementia studies* (London ed.) SAGE Publications Ltd, p 36.

¹⁵ Innes, A, 2009, *Dementia studies* (London ed.) SAGE Publications Ltd, pp 162-163.

Improving quality of life: non pharmacological interventions

Non-pharmacological interventions, such as holistic options, improved diet, psychological and psychosocial interventions have the potential to improve cognitive function and therefore improve the quality of life. They can also delay institutionalisation, as well as reduce carer strain and psychological illness, thereby increasing wellness, and perceived longevity. Minimal attention has been paid to the specific needs of people with dementia and their family members in the early stages of the disease. In the USA, there was a needs assessment carried out and participants expressed the need for practical information, financial and legal counselling, emotional support, and an interest in research, including clinical trials for the disease¹⁶.

Little research has yet been done on the value of NeuroPhysiotherapy, but evidence is slowly growing to support its benefits; I plan to partially fund a small study in this area being run through Flinders University School of Physiotherapy later in 2012. Evidence to support the benefits of Neuro plasticity and its ability to create new pathways in the brain is growing, and Norman Doidge cites examples¹⁷ of healing based purely on neuroplasticity training. Dr Bruce Lipton discusses Trans-cranial Magnetic Stimulation¹⁸, used to treat depression and to improve cognition. He also discusses using the brain¹⁹, and that the brain controls the behaviour of the body's cells; "the brain controls the behaviour of the body's cells". He states "the overuse of prescription drugs provides a vacation from personal responsibility"²⁰.

Dr Ross Walker [medical cardiologist] in his latest book *The Five Stages of Health*²¹ discusses how to "cut through the mixed messages we get in the media about maintaining our health. He cuts through the myths with his new book, cutting through the health hype". Happiness, peace and love are far more important to your overall health than the purely medical or physical things, and have more to do with wellness than we might think. Three of the stages discuss more than medical health²²; Stage two (2) discusses Environmental Health, stage four (4) Emotional Health and stage five (5) discusses Mind Health, highlighting non pharmacological interventions including the use of supplements, and the real value of things such as the cleansing of energies flowing through our bodies (our Chakras). He cites a

¹⁶ Batsch NL, Miller RV. An Assessment of Needs for Serving Individuals Diagnosed With Alzheimer's Disease and Related Dementias in the Early Stages. *Alzheimer's Care Today* 2009; 10(3):140-155.

¹⁷ Doidge, N, 2010, *The Brain That Changes Itself*, Griffin Press, pp 18-19, 27-44, 45-92.

¹⁸ Dr Bruce Lipton, 2005, *The Biology of Belief: Unleashing the Power of Consciousness, Matter and Miracles*, Hay House Inc. p 170.

¹⁹ Dr Bruce Lipton, 2005, *The Biology of Belief Unleashing the Power of Consciousness, Matter and Miracles*, Hay House Inc., pp 185-190.

²⁰ Dr Bruce Lipton, 2005, *The Biology of Belief Unleashing the Power of Consciousness, Matter and Miracles*, Hay House Inc., p 160.

²¹ Dr Ross Walker, 2012, *The Five Stages of Health*, Transworld Publishers (Division of Random House Australia).

²² Dr Ross Walker, 2012, *The Five Stages of Health*, Transworld Publishers (Division of Random House Australia), p 9.

study²³ showing MRI proof of a reduction of Alzheimer's disease after a 12-month course of therapy.

There is a body of clinical evidence slowly growing to support non pharmacological interventions, by respected medical doctors, Neuro physiotherapists and scientists. The South Australian government has funded Dr Martin Seligman, a prominent psychologist as one of their Thinkers In Residence this year, who not only supports the notion of wellness based on positive psychology and lifestyle options, he travels the world promoting it. Based on my own experience, I believe if the medical community and service providers of dementia and dementia care don't start to embrace these interventions soon, not only are they doing their clients a grave disservice, the lost opportunity will increase the cost impact of the dementia epidemic worldwide.

²³ Dr Ross Walker, 2012, *The Five Stages of Health*, Transworld Publishers (Division of Random House Australia), pp 60-61.

Increasing opportunities for social engagement

Early intervention is an important key to increasing opportunities for social engagement. With an early diagnosis, people with dementia are not only more likely to want to remain engaged in their current communities, but are more able to be. Obviously, a dementia friendly environment is pivotal to social engagement.

The Prime Minister of England, Mr David Cameron, issued a national challenge²⁴ on dementia at the Dementia 2012 conference, committing to boost dementia research, address quality of dementia care, increase public understanding of dementia, and make communities more dementia friendly. Alongside this, Alzheimer's UK has launched a program to promote Dementia friendly communities; villages, towns, cities and organisations working to challenge misunderstandings about dementia, seeking to improve the ability of people with dementia to remain independent for longer with choice and control over their own lives. Dementia friendly communities have the potential to transform the quality of life of hundreds of thousands of people, supporting their independence and reducing pressure on the medical and social systems. Endorsed by the World Health Organisation, Belgium²⁵ has commenced with the Healthy Cities program, and was officially accredited in March 2011 as member of the Network of European National Healthy Cities Networks in Phase V. This has been successfully implemented in 25 cities in Belgium, and the Belgium Alzheimer's Association²⁶ is helping to draft the Dementia Friendly Charter. Further to their proposed charter, education of people in the community providing services, for example, dementia education of taxi drivers and retail assistants would reduce isolation, and increase socialisation for those with dementia, making our cities and communities truly dementia friendly.

Finding funds to provide age appropriate in home services for people with younger dementia would also promote this. Outreach programs such as the Bunning's Project in South Australia that links people with dementia to Bunning's, to work as volunteers alongside paid employees keeping engaged and feeling valued; community programs and clubs that are socially enticing to individuals; a focus on harnessing the skill sets of people with dementia who are no longer in paid employment to become involved as volunteers in their communities, places like residential care settings, school tuck shops, council programs and so on. All of these activities increase the sense of feeling valued, or self worth, and ensure skill sets are not being completely lost in the early stages of dementia. They reduce depression and anxiety levels, reduce the need for paid care, and reduce the need for other social support.

²⁴ Cameron, D, 2012, Prime Ministerial challenge, <<http://alzheimers.org.uk/dementia2012>>

²⁵ http://www.euro.who.int/__data/assets/pdf_file/0008/145934/HCP_Liege_book_of_abstracts.pdf

²⁶ <http://alzheimer-europe.org/News/From-our-member-organisations/Wednesday-30-March-2011-Belgian-Alzheimer-association-helps-to-draft-the-Dementia-Friendly-Cities-Charter>

Longer term dementia care

Residential [aged] care

The *human cattle yards for aged care and dementia* are what many people with dementia call residential care facilities. They talk about, but do not deliver person centred care. It is very rare to find one with a private room. Most people there feel as if *they have been locked in prison*. Reassurance they are not in prison, and that they have been moved for their own safety and care does not serve to stop them feeling like they are in prison; the experience has been likened to the gas chambers. The activities, the day room, the dining rooms, all full of people, who all seem to be suffering from what Martin Luther King calls *a sense of nobodiness*²⁷ as they are herded together to allow facilities to work more efficiently, and to ensure the perceived *provision of better care*. Apart from the small often shared bedroom, these places are also set up for the masses, with minimal ability for individuality. The ambulance paramedics make visits for acute medical issues, as doctors don't treat residents in aged care at that level, so further medical bills with no Medicare rebate available. Many residents and their families in Australia are told they have a right to get up on their own and walk, but that it is important they realise it is unsafe for to do so! Hence many are strapped in with seatbelt style restraints, for their own safety, or drugged to achieve the same result. Physical and pharmacological restraints are illegal in other western countries, but legal in Australia. Not condoned, but legal. Even in high care they still do not have enough staff to ensure a residents safety. I have worked in aged care and seen this. I have family and friends currently in aged care and see this. I have dementia, and am fearful this will happen to me.

Professor Richard Fleming Director, NSW & ACT Dementia Training Study Centre, University of Wollongong has 30 years experience in geriatric care, including deinstitutionalising psychiatric services for older people while working for the New South Wales government. He is the leader of the Environmental Design node in the Primary Dementia Collaborative Research Centre based in UNSW. His publications include papers on environmental design, reminiscing therapy, reality orientation, assessment of the elderly and service evaluation as well as books on care planning for people with dementia, environmental design and a comparison between Australian and Japanese dementia care. He is an innovator in dementia care, and has set up a FREE Environmental Audit Tool²⁸ for residential facilities to audit their dementia units to ensure they provide the best environments possible. He has proven this reduces significantly the need for behaviour management through physical or pharmacological restraints. He spoke in Adelaide recently, and said, "Research highlights it is not architects not understanding design features appropriate to good care, but the

²⁷ King, Jr, Martin Luther, 1963, *Letter from a Birmingham jail*, letter, 16 April.

²⁸ Fleming, R, 2012, Environmental design for people with dementia: charting the gap between theory and practice in the design of new residential facilities, <http://www.dementia.unsw.edu.au/index.php?option=com_drcrc&view=drcrc&layout=project&Itemid=144&pid=142>.

managers and owners of residential sites who lack this knowledge, and they need to stand up for the evidence.”

The excerpt below by Jane Sherwin²⁹ was written about her own grandmother. She works in aged care.

“I’d like to tell you about two characters. The first had the following descriptions in her various files: arthritis, cataracts, congestive cardiac failure, periodic urinary tract infections, difficulty sleeping at times, needs a prompt to take medication, never owned a house, can’t drive and never has, hardly goes out, uses a wheelchair to lean on and push around at home, can’t get in and out of the shower over the bath, cannot shower herself, trips over her own feet, losing interest in cooking and eating, is not entirely safe with the gas stove, can’t hang out the washing, can only do light cleaning, can only stand for short periods without leaning on something. If asked what the probable lifestyle of this person would be, many professionals would advise medical procedures for the various bodily complaints, a day service for her social isolation, a respite service to give her family a break, an in-home support service for her personal care and that eventually she would need to move to a nursing home.

The second character lived through World War 2 and the Depression, raised six children, is a grandmother, great grandmother, senior citizen, is a lover of crochet, gardening, TV game shows and Canasta, voted Labor all her life, is the Patron of a large hockey club, plum pudding maker, and her grandchildren describe the delightful smell of Johnson’s baby powder around her and that she is wonderful to hug. Anyone asked to think about what would be a desirable lifestyle for this person is likely to say such things as that she would grow old in her own home, maintain her centrality in the family, maintain her roles, be surrounded by the comings and goings of family, be part of all important family rituals, be encouraged to do much for herself, be surrounded by the things that mean something to her, maintain her interests, keep healthy, maintain her connections to old friends even by phone and that she would have a reason to get out of bed each day.

Interestingly, these two identities are one person: my grandmother, known affectionately by her extended family and often by their friends as Nan.”

Respite care

Respite care for people with dementia is also set up for the masses and not funded for people under the age of 65. Activities in day rooms, with strangers make up the majority of available respite care services. Day care or residential respite care is invasive, and often frightening for people with dementia as by the time they need this type of care, they cope badly in new environments. The lack of permanent full time staff in nursing and carer organisations also increases the sense of fear, and reduces the willingness to want to go into respite care, increasing the burden of the family at home.

Age appropriate respite care services for people under the age of 65 must be a priority.

²⁹ Sherwin, J, 2010, A person centred response: keeping Nan at the centre of her life, *Social Justice*, Brisbane: Uniting Care Centre for Social Justice. (5) 1, 8, 9.

Home and Community Care (HACC) program

HACC services are instigated after an Aged Care Assessment Team (ACAT) assessment. ACAT assessments are technically only available to people over the age of 65. This leaves people with younger onset dementia with no access to services. Suitably trained staff and consistency of staff for this type of care is imperative, but hard to access.

Navigating any of the available dementia (or aged) care systems is difficult and the lengthy waiting lists and paperwork make it difficult for people who are impaired in some way and usually very vulnerable by the time they need services of any kind. This has meant there is a growing group of private consultants, charging exorbitant fees to sick and vulnerable people, to assist them with a system that should be free and accessible.

Changing the term ACAT to Disability Care Assessment Team (DCAT), to ensure people under the age of 65 years can access these services is imperative.

Younger onset dementia and Aged Care Accreditation Standards

I am a 53 years old female. There is NO age appropriate residential facility or age appropriate respite or in home service provision available for me. If I enter an aged care facility, the site will be breaking no less than ten (10) of the Australian Aged Care Accreditation Standards, because of my age. This breach of a duty of care towards people with younger onset dementia appears to have been completely overlooked by the government, aged care facilities, and importantly, the Accreditation board. The standards a residential aged care facility would contravene when residents under 65 years of age are residing permanently or in respite, include,

Standard 2: Health and Personal Care

- 2.12 Lack of appropriate continence management, and instead the necessity by neglect of the use of continence aids
- 2.15 Oral and dental care cannot be provided if the resident does not have suitable mobility to travel to a dentist as there is no dental service available on site

Standard 3: Resident Lifestyle

- 3.4 Emotional support requirements differ to the aged person
- 3.5 Independence changes – not easy to maintain friendships and participate in life of the facility due to significant age differences
- 3.6 Dignity may be impaired due relationships are only available with residents with significant age differences
- 3.7 Leisure activities set up for the elderly, not people under 65
- 3.8 Very different lifestyle, age related cultural backgrounds and values
- 3.9 Impaired choice and decision making as no matter how much control they may be able to exercise, the choices available are specific to the elderly

Standard 4: Physical environment and safe systems

- 4.4 Living environment set up and aesthetically suitable for older residents
- 4.8 Catering provision is targeted to the taste requirements of a different generation, and to residents who may be far more impaired physically

Awareness and education of service providers and the community

This is imperative to reduce the myths, stigma and isolation caused by a lack of real awareness and education in the community about dementia. It is necessary to empower nursing and carer staff to provide authentic person centred care, not just in residential care settings but in hospitals. Patients with dementia in general hospitals usually stay longer, have more behaviour management issues because the staff are not trained properly in dementia care, and the hospital environment is not conducive to quality dementia care. Dr Faizel Ibrahim, a Consultant Geriatrician working at The Queen Elizabeth Hospital in South Australia has set up the Dignity Does Matter program³⁰, based on the success of a similar program he had seen in the UK. His personal goal is to make 80 public presentations per year about changing dementia care in hospital, through education and innovation.

It is people with their own stories who can have the biggest impact on change, and so people with dementia should be encouraged to become involved in education and awareness programs, run by Alzheimer's Australia, or other service providers to help bring about change. These people have the power to create change in attitudes, and public awareness. Nursing staff in hospitals and aged care need more specialised training in dementia care; dementia education and awareness programs for taxi drivers, retail staff and other people working in the community; local council and community service providers need dementia education and awareness programs. There is no better way to understand the needs of someone with dementia, than to ask them. Senior high school students also need dementia education and awareness courses as part of their curriculum.

In a summary of a report by the World Health Organisation (WHO)³¹ it states *“Information and education campaigns for the public – including people with dementia, their caregivers and families – aimed at raising awareness, improving understanding and decreasing stigmatizing attitudes should help overcome barriers to accessing and using services.”* In the United Kingdom an extensive review of qualitative and quantitative surveys has identified several themes, as reported in the WHO report. These are: raising public awareness and understanding of dementia; reducing the stigma of dementia and challenging discriminatory behaviour; recognizing the early signs of dementia to aid early diagnosis; living well with dementia; the importance of a healthy lifestyle and reducing risk³².

Early diagnosis and intervention of people with dementia will further empower many of these people to speak up; to advocate and educate their communities, not only to educate, but to break down the barriers and myths causing stigma and isolation.

³⁰ Ibrahim, F, 2012, Dignity Does Matter, <<http://www.hospitalresearch.com.au/dignity-does-matter/>>

³¹ World Health Organisation, 2012, Report: Dementia: a public health priority, UK, p 80.

³² World Health Organisation, 2012, Report: Dementia: a public health priority, UK, p 84

Implications of the recent Health Care Reform Package

The Australian Federal Government recently introduced a large Aged Care Reform package. On the surface it sounded reasonable, but the more I read about it the more I wonder about the intent. They claim over the next 5 years the aged care sector will receive a \$3.7 billion dollar injection of funding. Only \$577 million of this will be new funding, and the rest it seems will be raised through means testing in-home care and aged care eligibility for older Australians, as well as removing \$1.6 billion in subsidies paid to residential facilities for high care service provision. It is moving closer to user pays, and whilst this reform is hoping to address the issues of nursing homes who rort the system, it seems the government's intention is also to rort hard-working, previously taxpaying older Australians. With associations like The Council of Ageing condoning the plan to allow the elderly to borrow up to \$60,000 against their homes, to pay for the increasing cost of their care, it appears the user pay system is well and truly on its way. It says there is extra funding for dementia, but I've yet to work exactly where this money will be spent. I want to have the final say about my own care and life, the type of care the aged care system simply currently does not allow or encourage. The catering to the masses goes on, and the person centred care of individuals continues to be ignored. Where is the funding to allow the increase of staff to resident ratios, adequately increased wages to retain the truly dedicated carers and nurses to provide improved person centred care, and the education reform? You have come a long way, but there is a very long way still to go.

Recommendations

- Increased and improved GP education of dementia is required to ensure earlier detection and diagnosis and referral to medical specialists
- Increased Practice Nurse training in detection and management of dementia
- Changes to Accreditation Standards in residential care to properly accommodate people with younger onset dementia
- ACAT becomes Disability Care Assessment Team (DCAT)
- Focus on psychosocial care and therapies
- Focus on non pharmacological interventions
- Authentic brain injury rehabilitation for people with dementia in the early stages
- NeuroPhysiotherapy
- Neuro plasticity [brain] training
- Improved general health care, including education about diet and exercise specific to dementia
- Holistic health options, including Transcendental Meditation, supplements and hypnosis
- Funding for improved service provision
- Better education of service providers and their staff
- Age appropriate in home services
- Age appropriate respite and residential options for people with younger onset dementia
- Increased clinical research funding,
- Funding for research into non pharmacological interventions
- Funding for improved quality of life outcomes for people with dementia
- Non means tested carer allowance
- Assisted technology
- information resource pack prepared collectively between Alzheimer's Australia and the Medical Associations, as a hand out to all people diagnosed at the time of dementia

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Submission accessibility

This submission is approved for publication in full.

I am willing to appear as a witness at a parliamentary committee public hearing.

Electronic format

Electronic version supplied in PDF format.

Signature

Signed*: *Kate Swaffer*

Dated: Wednesday 5 May 2012 (due date extended via email from original due date of 2 May 2012).

* This electronic signature is in lieu of a hand written signature, for which I stand accountable.