

Putting reablement into practice

As a person living with Alzheimer's disease, **John Quinn** is challenging the belief that a diagnosis means 'end of life'. Here he explains how, with adaptations and timely interventions, it is possible to live life well with dementia

In 2010, at the age of 59, I was diagnosed with Alzheimer's disease, believed to be of the familial type. This is a genetic form of dementia and is relatively rare. My mother, two aunts and an uncle had also been diagnosed with dementia in their late 50s and early 60s.

Although my diagnosis was initially a relief as I could finally put a 'label' to what changes were occurring with my ability to perform everyday activities, particularly driving and my role of a school principal, I quickly descended into a state of being characterised by hopelessness, despair and a sense of feeling alone. Sadly, these feelings are commonly experienced by many on diagnosis, and are, amongst other things, a reflection of the stigma, the mindsets and stereotypes about what a person with dementia looks like.

Fortunately, the trajectory of my condition has not progressed at the rate initially envisaged by my neurologist. I attribute the slow progression of my dementia to a number of things, particularly the psycho-social choices I incorporate into my life to live well with dementia.

My personal story, as well as that of many other dementia advocates, is challenging the well-established, entrenched belief that a diagnosis of dementia means 'end of life'. This view of dementia as a story of tragedy, being robbed of life and suddenly losing all capacities and skills has reinforced this mindset. However, there are many faces of dementia and with adaptations and timely, person-centred, evidence-based interventions, it is possible to live well with the condition.

In my advocacy role I constantly promote the benefits of reablement for people with dementia – in particular, to maintain their functionality, their independence and quality of life. Therefore, opportunities for reablement should be provided immediately upon diagnosis.

To provide some context for the evolution of reablement as a health and social care practice it is important to explore its emergence within the dementia space.

Historically, the model of care for



John Quinn, with his partner Glenys Petrie (far right), at an Alzheimer's Australia (now Dementia Australia) fundraising event in Brisbane in 2014, where John first met its then National President Ita Buttrose (centre). Ita's positive and encouraging words had a profound effect on John's attitude to his diagnosis. Photos courtesy John Quinn and Glenys Petrie

someone diagnosed with dementia was viewed through a bio-medical, deficit-based lens where the post-diagnostic care pathway was focused ostensibly on the pathology of the disease with the expectation that the gradual decline in a person's cognitive and physiological functions would lead inevitably to a position of complete dependence and ultimately to death. The treatment consisted predominantly of drug prescription, if there was one available.

The new perspectives on dementia proffered by Kitwood (1997) about personhood; a social constructionist 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, embracing a bio-psycho-social viewpoint of the disease, highlighting concepts of personhood, agency, social inclusion, independence, connectedness, participation, dignity, empowerment, autonomy, and maintaining capacity and wellness.

Articles about the benefits of rehabilitation as an intervention in early-stage Alzheimer's disease by Clare & Woods (2004) and Marshall (2005 pp13-19) were among the first to provide new insights into the potential for improvements in quality of life and self-esteem for people with dementia. Recently, Mishra & Barratt (2016) highlighted the evidence for the potential

for a reablement model to maintain and/or improve the functional capacity of older people with dementia. In addition, Poulos (2017) provided evidence that rehabilitation has an important contribution to make in the management of functional decline in people living with dementia and canvassed what clinicians have to offer in the area of rehabilitation.

At the first Ministerial Conference on Global Action against Dementia, held in Geneva in March 2015, Kate Swaffer, CEO of Dementia Alliance International (DAI), when sharing her own personal experiences of living with dementia, enunciated, amongst other things, the need for more ethical, integrated care pathways, including rehabilitation services, for people with dementia on diagnosis.

In April 2016 I attended the Alzheimer's Australia's Consumer Summit in Canberra. From the perspective of someone living with young onset dementia (YOD), I was invited to give an appraisal of the document, *Clinical Practice Guidelines and Principles of Care for People with Dementia* (Guideline Adaptation Committee 2016). Notwithstanding the fact that I believed that the document seemed to be focused heavily on older persons with dementia, I highlighted that there was only a brief reference to rehabilitation/reablement in the guidelines. Furthermore, I emphasised that why is it that if someone



Glenys Petrie and John Quinn enjoy dinner at the Eiffel Tower in Paris prior to walking the Camino de Santiago in Spain in 2015

has a stroke, reconstruction surgery or some other major injuries from an accident that rehabilitation is offered immediately, but not routinely considered upon a dementia diagnosis.

The intersection between a reframing of dementia, its acceptance in 2016 as a disability by the United Nations Convention on the Rights of Persons with Disabilities (Dementia Alliance International 2017) and the ensuing human rights ascribed to this acknowledgment have been the catalysts for the paradigm shift in the way we should be viewing dementia, particularly in relation to models of social and clinical care.

With regards to human rights Clare (2017) specifically refers to Article 26(1) of the Convention on the Rights of Persons with Disabilities (CRPD) where it outlines the right of people with disability to be able to attain and maintain maximum independence, with the assistance of comprehensive rehabilitation services, and that rehabilitation for people with dementia is called cognitive rehabilitation.

Within everyday discourse, the words 'rehabilitation', 'reablement' and at times, 'wellness' are often used interchangeably. For the benefit of a clear definition of reablement I will cite and use the definition provided in the booklet, *Supporting Independence And Function In People Living With Dementia' An Information Booklet Of Reablement Programs For People Impacted By Dementia* (Gresham *et al* 2019):

"'Reablement' refers to maintaining or improving a person's function and may

ultimately lead to improved quality of life. The goals of reablement are set by each individual. A person's goal might be to engage in everyday activities, be physically mobile and / or be able to do things they love and value for as long as possible" (Gresham *et al* 2019 p7).

Reablement strategies

My adoption of reablement intervention strategies didn't commence immediately post-diagnosis. In fact, I was in a dark place two years prior to and four years post diagnosis. Apart from a routine of running three times a week, there were few, if any, positive lifestyle choices I was observing on a daily basis. Hence, I spent most of my day sitting in a chair, looking at four walls and disengaged with life. Fortunately, there was an important turning point in my attitude about my diagnosis. In June 2014, I attended an Alzheimer's Australia (now Dementia Australia) fundraising event. Ita Buttrose, then National President of Alzheimer's Australia, was present. Ita spent a great deal of time talking with me about my interests and finding out who I was as a person. The positive and encouraging language from her and others that night had a profound effect on my attitude to my diagnosis.

In hindsight, that event was just the impetus for me to start researching and reading about dementia. I read books by Christine Bryden (2015), Martin Seligman (1992), Norman Doidge (2008; 2015) and Eckhard Tolle (2004), just to name a few. I started to show an interest in research about positive lifestyle considerations that would impact on me on a day-to-day

basis and, thereby, hopefully slow down the progression of my condition.

NAMES

There are certain capacities and skills that you don't lose immediately on a diagnosis of dementia. Therefore, I used the skills I had developed as an educator to devise an acronym to reflect the outcomes of my research findings.

Over time I have adapted it slightly, only because it helps me to keep on track and I'm still learning what I personally need. I'm learning what I need because dementia does not stand still. I call it NAMES:

N: Nutrition, including hydration.

A: Attitude and Acceptance; Arts therapy.

M: Mental activities, Music and Meditation.

E: Exercise and Enjoyment.

S: Social engagement, Support, Sleep and Setting goals.

Nutrition

My partner Glenys has fine-tuned my diet over the years, and we eat very well. There have been some positive research findings about brain health and the adoption of a Mediterranean or MIND diets. I also try to drink more water.

Attitude

As I mentioned earlier, I was lucky to have attended that fundraising event. It really was the turning point in my realisation that *I can start to live again*. Glenys says, *"that's when I got John back!"* I wouldn't pretend to know how to advise others about addressing their attitude. However, you need to be surrounded by people who encourage you and build your self-esteem through language, and also encourage you to maintain your independence.

Acceptance

On an individual level, for the person to accept the diagnosis and, in my personal case, I eventually realised that I was *not just another statistic*. For others, they need to listen to the person living with dementia if asked for help, and also to listen to our primary caregivers and families who, after all, are often strong advocates for our needs. We need to acknowledge them more, and support them too.

Arts therapy

I participate in the A Dementia Art Program for Today (ADAPT) art program at our Municipal Hall. I also attend the Art and Dementia sessions run by the Queensland Art Gallery / Gallery

of Modern Art (QAGOMA). It is now being taken seriously as a tool for boosting health.

Mental activities

I write, including regularly having my 'Letters to the Editor' published in Brisbane's *The Courier Mail* newspaper. Glenys is encouraging me to do Brain Gym (www.braingym.org.au). I do crosswords with my non-dominant hand. I'm also learning Spanish, as the research seems to suggest that learning a second language is effective in maintaining cognitive ability. All these activities are difficult for me but I persevere.

Music

In recent years, research has been published about the benefits of either playing or listening to music. Findings show a profound effect on language and overall, on engagement and interaction. In my personal case I have an individualised playlist which assists with agitation, confusion and the multi-sensory issues that I experience when travelling, particularly in the car and being in places with too much sensory stimulation. Some trials in the use of individual playlists with people with dementia have demonstrated their ability to revive verbal skills, albeit, temporarily.

Meditation

I'm still learning how to do this well. There's research about its benefits. All I know is that I always feel better after 10 minutes of meditation.

Exercise

It doesn't have to be half marathons or cycling through other countries. It might be a gentle exercise DVD, tai chi, aqua aerobics, tennis, dancing etc. I walk, run, swim and cycle on a fairly regular basis. Glenys has organised for me to attend a physiotherapist-supervised Pilates session each week, to strengthen my core muscles. I always thought that I was fit but I can feel the improvement since starting these classes. Hopefully this will help with falls prevention in the future. In recent years, there have been a number of research projects about the benefits of exercise.

As well as elsewhere, encouraging research is currently being undertaken at the University of Queensland's Queensland Brain Institute, with older mice of the age equivalent to an 85-year-old human in an 'enriched environment'. The results show neurogenesis at its best (<https://qbi.uq.edu.au/blog/2017/11/can-you-grow-new-brain-cells>); and Australian researchers at the University

of Sydney have for the first time shown that weight training can protect the parts of the brain vulnerable to Alzheimer's disease. The study demonstrated that six months of strength training slowed, and even halted, the degeneration in the hippocampus and its sub-regions 12 months after the exercise (Broadhouse *et al* 2020). My physiotherapist incorporates strength and resistance exercises in my Pilates sessions.

Another research project, known as the FINGER study, which was conducted collaboratively between Finland and Sweden from 2009-2011 and involved more than 1260 participants, showed that an intervention program of diet, exercise and cognitive training in people aged between 60 and 77 years of age was beneficial to cognition (Ngandu *et al* 2015). These concepts appear to align with much of what I'm doing every day. Recently, there have been indications that a similar intervention program may be conducted within Australia.

Enjoyment

Who doesn't like doing the things that they enjoy? Or being in the company of those we enjoy being with? Or enjoyed a comedy? More often than not, it leads to laughter and we all feel better when we laugh. Have you tried Laughter Yoga? Why not get involved in an art or dance class? Apart from the socialisation that comes from engaging in these activities

there is some evidence that participation may be beneficial to cognitive maintenance.

Social activity

I have always been a sociable person so that's an advantage for me now. As mentioned earlier, I did go through a period when I withdrew socially, and for almost my entire day I sat in a chair simply looking at four walls without exhibiting any emotion. This lasted from the time that I was forced to leave work until my diagnosis, and then up until that evening when I met Ita – six long years, four of which were post diagnosis.

With time and support I started to engage more, but I must emphasise that being in all social contexts, including just having a coffee with friends, a casual conversation on the street and, dare I add, presenting in any type of forum, *absolutely* exhausts me. It takes a lot of cognitive effort to socialise or present, and whilst I love it there's a layering effect, and it takes me days to recover.

I also:

- Volunteer.
- Attend our monthly YOD 'Remember Me' Support Group.
- Socialise with the wider international dementia community of friends who we catch up with regularly, at various conferences, chat with on Skype or Zoom chat rooms, and even holiday with.



As part of his reablement strategy, John incorporates exercise into his daily routine

- Have become more prominent in my own local community through media exposure and fundraising.

Support

I wouldn't be able to do most of what I can do without the support I receive from others. My biggest supporter is my partner, Glenys. She has been behind me all the way. She has encouraged my every effort to 'live well with dementia'. She organises most things, but in consultation with me. I also receive a great deal of support from the rest of my family, fellow Spanish students and the local businesses and people in my community.

Sleep

Current research appears to link poor sleeping patterns to dementia. At the moment we are trying to find the right balance of exercise, socialising, travel etc, and rest. The downside is that everything exhausts me. No-one sees that I need to rest every day, sometimes as early as 9am. Most days I sleep and still get about 10 hours each night.

Setting goals

I find that it is important for me to set some goals. It not only provides me with some forward planning on a daily basis, but it also helps me set some challenges for the future. Goals can be short-, medium- or long-term, and yes, although I have dementia I still set myself some long-term goals. Who knows what is ahead of us, or when.

In 2018 I trekked the Three Capes in Tasmania to raise funds for a PhD candidate in dementia research at the Queensland Brain Institute and to raise awareness about dementia. In 2020, I have set myself a goal to do a walk on Kangaroo Island.

Whilst my NAMES was specifically devised in light of what non-pharmacological interventions I could incorporate into my life to live well with dementia, its benefits are applicable to any medical condition. In my case, adherence to it constitutes my 'tools of reablement'.

Evidence, resources

A number of research projects focused on reablement care practices have highlighted their efficacy.

The Interdisciplinary Home-based Reablement Program (I-HARP) combines a range of proven health care strategies to help older people with dementia to remain healthy and independent in their homes (Jeon *et al* 2019).

I participated on three of the NHMRC's Cognitive Decline Partnership Centre's



John during a holiday in Central Australia

research committees that focused on reablement:

- The Care of Older Persons in their Environment (COPE) Project;
- The Reablement in Dementia project.
- The Agents of Change project (exercise therapy).

These programs involve clinicians such as OTs, physiotherapists, speech language pathologists, exercise physiologists, nurses and care workers. As well as providing skills for carers to manage their partner's evolving symptoms they are designed to assist the person with dementia to maintain activities of daily living; maintain their physicality; to preserve their confidence and independence; and to perhaps slow down their cognitive decline.

The Queensland Statewide Dementia Clinical Network has put together a post-diagnosis *Dementia Enablement Guide*, with versions for consumers and GPs, which provides a comprehensive overview of medical and allied health services that may be accessed post-diagnosis. These are available on the Queensland Health website at <http://bit.ly/2PDsZKJ>.

Conclusion

Kate Swaffer's testimonial on the back cover of Steven Sabat's book *Alzheimer's Disease and Dementia; What Everyone Needs to Know* (2018) includes the following statement: "There is a gross and systemic underestimation of the capacity of people with dementia, even in the later stages of the disease."

This belief is shared by many who work in the area of dementia, and should be reflected in any post-diagnostic clinical and social care programs.

It is imperative that medical practitioners, particularly GPs, who make decisions about post-diagnostic care plans embrace the benefits of reablement; recommend evidence-based

lifestyle preferences; and refer to appropriate allied health professionals.

There is a benefit-cost factor to the adoption of a reablement model of post-diagnostic care as it has the potential to delay the admission from community to residential care, thus resulting in a reduction in health care costs. ■

John will be speaking at The Dementia Centre's International Dementia Conference in Sydney (11-12 June 2020) on the topic 'Reframing dementia: a catalyst for change in quality of care'. Details: www.dementiaconference.com

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