

# The reliability and meaning of a dementia diagnosis

In this response to the ‘dementia doubters’ who claim public dementia advocates may, in fact, not have dementia, **Kate Swaffer** discusses the legitimacy of a diagnosis and the myth that dementia is a pathway that leads only to deficits and death

**A**lthough a multifaceted human being, retired nurse, current author, academic, and co-founder, Chair and CEO of Dementia Alliance International (DAI), I am mostly referred to only as a dementia advocate. Depleting the fullness of my lived experience and ever-changing identity, many refer to me as a victim\* or sufferer\* of dementia. Unfortunately, my diagnosis and that of others is doubted because I remain high functioning, albeit with disability support. This article discusses the impact of receiving a diagnosis, Prescribed Disengagement®, the ‘dementia doubters’, improving care and the embedded stigma and myths surrounding dementia.

## Diagnosis

Historically, receiving a diagnosis of dementia was difficult at almost any age and, as a nurse in the 1970s, I learnt there were only two ‘types’; senile dementia or presenile dementia. There were no more definitive diagnoses. Today, whenever a person is told they have dementia, they have usually been through a large suite of tests, often spanning many years, before their physician tells them (and their family) they have a dementia of this or that type. Patients usually believe their physicians, and today very few physicians will see a patient without a family member or advocate present, when testing for, and when giving a diagnosis of dementia.

However, we know reliability of a diagnosis shows great fluctuation (Van



The author, Kate Swaffer (right), with Mdm Hui-Mei Su (Amy), a member of Dementia Alliance International and Taiwan's first self advocate. Amy, an artist, was diagnosed with younger onset dementia in 2012, at the age of 62. Photo courtesy Taiwan Alzheimer's Disease Association

Dyk *et al* 2015; Takayama *et al* 2016), and in some studies at autopsy a significant number of people who presented with symptoms of, and were diagnosed with, dementia showed no evidence of it in their brains, and there are many with no symptoms whose brains showed strong evidence of it at autopsy. As a result most physicians do not tell people they have dementia without being very confident of the diagnosis. In recent years, many people with dementia have been ‘downgraded’ from dementia to Mild Cognitive Impairment (MCI), and are advised this is because they have not ‘deteriorated as expected’. Many members of Dementia Alliance International (DAI) report this, and report that sometime later they have been advised their original diagnosis of dementia is again valid.

This is stressful, often leading people to feel as if they are frauds, rather than questioning the embedded misperception among physicians and others that people diagnosed progress along some predictable, relatively brief temporal trajectory. People find this especially difficult if they have disclosed their initial diagnosis, and although it is currently confounding for everyone, it

contributes significantly to the dementia doubters. Being publicly accused of faking dementia or doubting a diagnosis could be seen as unethical.

Globally, there has been a push in the academic and clinical community for a more timely diagnosis for all people with dementia, and in the UK in 2014 there was a financial incentive for general practitioners to diagnose dementia which, naturally, resulted in many false positives. The National Health Service in the UK states (2018): “*Living well with dementia*: ...People with dementia shouldn’t simply stop doing what they enjoy in life; instead, they should try to remain as independent as possible and continue to enjoy their usual activities.”

Alzheimer’s Disease International (ADI) and Bupa developed a Global Charter (2013), *I can live well with dementia*, yet there is little to no support to do so; worse, if we dare to, people doubt our diagnosis. Surviving and living well with cancer or another terminal illness is seen as positive. Living well with dementia, on the contrary, too frequently means the widespread doubting of our diagnosis. It seems that we are with dementia where we were with cancer in the mid-1970s; still prisoners of the stigma and ignorance.

The misguided under-estimations of our potential and the increase in false positives resulting from increased efforts to make early diagnosis continue to create oppressive and humiliating barriers to the full engagement in society of those who are correctly diagnosed. Perhaps the worst myth affecting us is that people diagnosed with younger onset dementia (YOD) will exhibit the same trajectory of increased dysfunction as do those diagnosed in their later years, or indeed, anyone diagnosed at a later stage of dementia. These myths are endemic and malignant.

## Prescribed Disengagement®

Consistently, people diagnosed with dementia are, if suitable for their ‘type’ of

**Footnote:** \* The words sufferer and victim are words I don’t normally use. They are used in this article to make a point about the negative effect of the tragic discourse of dementia, leading to misperceptions we cannot live well. It’s recommended not using these and other disabling and disrespectful terms. Dementia language guidelines are available from Dementia Australia: go to [www.dementia.org.au/resources/dementia-language-guidelines](http://www.dementia.org.au/resources/dementia-language-guidelines) and DEEP [www.dementiavoices.org.uk/2014/10/dementia-words-matter/](http://www.dementiavoices.org.uk/2014/10/dementia-words-matter/)

dementia, prescribed one of the few drugs that may slow the progression. They are then mostly told there is nothing else 'we' can do, and to get their end of life affairs in order, to become acquainted with aged care, and give up our pre-diagnosis life. I have termed this Prescribed Disengagement® (Swaffer 2015; Swaffer 2016 pp157-163).

In a systematic review of the way physicians communicate a diagnosis of dementia, Low *et al* (2018) found little evidence in the literature of patients experiencing Prescribed Disengagement. However, anecdotal and other evidence suggests otherwise. For example, in a fundraising ride around Australia in 2017 Greg Kelly, who was diagnosed with dementia aged 59, said in an interview for WIN News Central Queensland: "The specialist just simply said, 'go away and get your affairs in order'" (WIN 2017). In a qualitative study Reed *et al* (2017) found there was surprisingly little discussion of the impact of dementia on personal functioning or abilities. Instead, participants mostly focused on poor interactions with physicians during and after the diagnosis process, as well as on the malignant stigma of dementia and the immediate change in the way they were treated by others in their everyday life following diagnosis.

## Rehabilitation

The WHO (2017a) states "Dementia is one of the major causes of disability and dependency among older people worldwide." One must therefore question why the health care sector does not offer proactive disability assessment and support, including cognitive and physical rehabilitation, similar to what I would have been provided had I had a stroke at the age of 49, not dementia. Speech pathology to aid swallowing difficulties, near the end of life, is too late for a person with Primary Progressive Aphasia (PPA). As far back as 2005, Marshall demonstrates that rehabilitation does have positive outcomes for people with dementia in terms of quality of life and self-esteem.

There is an increasing acceptance of rehabilitation for dementia, although misconceptions abound. Families and health care professionals, including physicians, often don't support rehabilitation for dementia because they believe the person with dementia is only "going to get worse" (Hopper 2003), thereby subconsciously ignoring the value of improving quality of life. A few years ago, I advocated for the inclusion of rehabilitation in the Clinical Practice Guidelines for Dementia in Australia;

The stories of many other advocates who speak publicly indicate the dementia doubters are global. Even those who don't speak publicly as advocates are often told by family or friends that they 'don't look like they have dementia'

curiously, it was not included, in spite of my providing evidence for inclusion. Ironically, many who advocated against this are now teaching it. Poulos (2017) provides evidence that rehabilitation has an important contribution to make in the management of functional decline in people living with dementia.

The dementia community of health care professionals have been slow to follow the evidence. Associate Professor James McLoughlin, an academic neurophysiotherapist at Flinders University, in part-time clinical practice, now lectures about and provides rehabilitation for people with dementia. In a DAI Webinar, he not only talked about its impact and value to people with dementia, but how difficult it is to get health care professionals to accept it as best practice (McLoughlin & DAI 2016).

Since 2009 I've been actively advocating for rehabilitation and proactive disability support for people with dementia at the time of diagnosis. Now the WHO *Global Plan of Action on the Public Health Response to Dementia 2017-2025* (WHO 2017b) (Global Dementia Action Plan) has been adopted, human rights must be included in dementia services, support and national dementia plans, which means, therefore, rehabilitation and disability support.

There are many other factors that may lead to slowing the progression of dementia. Doidge (2010, 2015) provides strong evidence of the power of neuroplasticity and rewiring our brains. I believe advocacy, which involves a great deal of mental effort, has contributed positively to my own (and others')

slower than expected progression, alongside my continued tertiary studies and research. Seligman (2013) suggests resilience and flourishing are major factors in being positive about life, even with a terminal illness, and Walker (2012) provides numerous examples of holistic health options supporting terminal and chronic health conditions, which improve outcomes and quality of life. Lipton (2005) has shown that we can change our cells through the power of belief.

Bredesen (2014, Bredesen *et al* 2016, 2017) provides a growing body of evidence for slowing the progression of dementia, including reversing it, with his research into people with MCI or early Alzheimer's disease (AD). This, and other holistic and lifestyle approaches to dementia not only support the pathway many advocates have self-prescribed, it is the closest thing to hope currently available. Kostoff *et al* (2018) adds to this new way of managing dementia providing non-pharmacological treatment protocols for slowing the progression of, or reversing early AD and MCI. Interestingly, I presented at the ADI 2012 conference in London on my own successful non-pharmacological interventions for dementia, which at that time was not well received.

## Not being believed

A friend and colleague Brian Le Blanc who lives in the US writes a regular blog, speaks publicly, and has published twice on this topic. After being accused by family and friends of faking dementia, he wrote in his first blog on the subject, *So...you think I'm faking my Alzheimer's disease, do you?* (Le Blanc 2017):

"Oh wait, I get it . . . I'm supposed to be curled up in a bed, not able to talk intelligently, not able to feed myself or go to the bathroom by myself, and not remember my wife and children. God forbid, should I be able to use a laptop to write blog posts that will hopefully bring awareness and education to people who don't understand the ins and outs of Living with Alzheimer's Disease that they only saw in their elderly parents and grandparents!"

Not being believed creates significant distress in those diagnosed and their families (Swaffer 2016 pp75-82). Bryden says about being 'undiagnosed' and not believed: "As if the initial diagnosis was not shocking enough, this is even more traumatic!" (2018).

An initial diagnosis for many people often occurs after many years of searching for a reason to explain their cognitive changes. When a diagnosis of

dementia is finally given, many choose to get a second, third and even a fourth one. It is not only a difficult diagnosis to make, it is a very distressing diagnosis to receive, one that our families and close friends receive as well, as without them or some type of external support, as the dementia progresses, we may not be able to live independently. In my case, every time the tests are repeated I am still hopeful it is not dementia and instead some other treatable condition is found to explain the cognitive decline I am experiencing.

The stories of many other advocates who speak publicly indicate the dementia doubters are global. Even those who don't speak publicly as advocates are often told by family or friends that they "don't look like they have dementia". A master class webinar hosted by DAI, "*But you don't look like you have dementia*" (DAI 2017), powerfully shares the stories of many who have faced this.

Adding to this discussion, at my last appointment with my neurologist I mentioned an article published last year in *The Lancet Psychiatry*, by Professor Robert Howard (2017), *Doubts about dementia diagnoses*. Howard shares his uncertainty about the diagnoses of many "dementia advocates", saying: "Although none of these individuals has been my patient, observing their performance at meetings or through their writing has led me to develop serious doubt about the diagnoses that they carry" (Howard 2017 p580).

My neurologist, who has been seeing me since 2004, immediately looked up the article and started reading it. He

seemed sincerely 'concerned' that a colleague would publicly question any physician's ability to diagnose. We both ultimately laughed, and he reminded me that over the past 10 years, I have been retested a number of times, had a second opinion from specialists at an interstate memory clinic and, although he could only confirm my diagnosis 100% at autopsy, he sincerely believes to the best of his medical knowledge that I have the semantic variant of Primary Progressive Aphasia (svPPA).

In a response to Howard's article in the same journal, titled *No doubts about dementia advocacy*, William Hu (2017) suggested:

"Dementia advocacy is a form of John Henryism (named after the American folklore figure who died victorious after showing his superior prowess over a machine), and the advocates' health can be made worse by the persistent curiosity of dementia professionals into their abilities, and that "cognitive assessment in public settings is not valid or accurate" (p830).

Unlike our close friends or family, dementia professionals and members of the public do not see the effort it may have taken a person with dementia to get dressed that day or the support required from others, nor the time and effort put in daily to continue to live a productive and meaningful life. I've referred to it as the 'Olympics of my life' (Swaffer 2013; 2016).

### The dementia doubters

So what of the dementia doubters who claim public dementia advocates may in fact not have dementia? Their views may

be based on reductionist attitudes, and the misperception that we are all the same, without considering many are being diagnosed much earlier than older people, who often do not seek a diagnosis until a crisis, due to the still very pervasive stigma being experienced (Gove *et al* 2016; O'Connor *et al* 2018), if at all. The conclusion Gove and colleagues reached around stigma in their

own profession was that: "Measures to involve GPs in tackling stigma should include training and opportunities to explore how they perceive dementia, as well as support to address structural discrimination" (p391).

This view of dementia suggests we are all the same regardless of our age or stage at diagnosis and should present that way; it is based on the medicalised deficits-based approach, and end-stage view of dementia. Even the way a person reacts to their diagnosis of dementia will be shaped by external and individual factors, such as their personality and personal history, emotional intelligence and resilience. Indeed, Howard does admit that dementia advocates "...are not a bit like the people with dementia that I have diagnosed and treated".

Thus, Howard and others may be falling prey to a sampling problem and incorrectly generalising from small samples to a larger population who have been diagnosed but who do not act as expected. Additionally, those diagnosed with younger onset dementia are unwilling to accept Prescribed Disengagement and instead, are willing try everything, including lifestyle changes. Advocacy in itself assists in reducing isolation, and the evidence consistently indicates isolation is not only a risk factor for dementia; it can speed up the progression (Poey *et al* 2017). The Alzheimer's Society in the UK is also now saying that "taking regular gentle exercise, eating a healthy diet and doing cognitive exercises can help someone with dementia manage their symptoms more effectively" (BBC News 2018).

### A significant shift

There has been a significant shift in the way some academics and clinicians view people with dementia in the last two decades. Sabat (2018 pp124-125) views dementia more subjectively than those who see it only through the medicalisation of the condition, and the medical model of care; he reviews the need for resilience, and sees stigma in a new way, helping redefine the roles that are key in changing practice and attitudes, and therefore reducing stigma. Advocacy increases resilience, also a factor for managing living more positively, with dementia or for managing any other critical period of a person's life, as found by Williamson & Paslawski (2016) and Seligman (2013).

The late Tom Kitwood (1997) is attributed as saying: "If you have met one person with dementia, you have met one person with dementia." We all react



Kate Swaffer, representing Dementia Alliance International, presenting at the 11th Session of the Convention Of State Parties (COSP) on the Rights of Persons with Disabilities (CRPD) in New York in June this year



and respond differently to the world, and to life, and these words therefore apply to every human being, experiencing any medical condition, as well as every reaction to a life event, illness or crisis. Howard and other dementia doubters seem not to take this uniqueness of all patients into account. Ironically, he and others with similar views are part of a system that is advocating for earlier diagnosis, but their attitudes and practices seem out-dated, and are potentially harmful to the very people being diagnosed earlier.

Dementia being managed as a chronic progressive disease, with lifestyle changes, is the way forward. Even if this approach is not a cure, it will enhance wellbeing and quality of life, may slow the progression, and will reduce the risk of other comorbidities and improve quality of life.

Being invited to tell our personal stories has increased the presence of people living with dementia at conferences and events, and invitations onto advisory or expert working groups. Most professionals suggest this is helpful, as it ensures outcomes are based on our genuine needs, not what others perceive them to be, and many say it has enhanced education. Ironically, it has also increased the number of dementia doubters, and the inexplicable occurrence of a 'public dementia diagnosis' whereby people feel they can diagnose, or doubt a person's diagnosis, after reading their book or blog, or listening to them present at a conference.

## Conclusion

Before dementia, people have good and bad days; life with dementia is no different. It is possible to live a positive and productive life, some of the time, even with dementia, if supported well. I suggest, with a lot more proactive disability support from the day of diagnosis, and moving away from the out-dated dysfunctional and medicalised attitudes about dementia, many more will be living positively with dementia, for much longer, either confounding the experts even further, or teaching them it is possible.

With or without dementia, we are all born with a death sentence. There is no need for a diagnosis of dementia to be seen as the catalyst to give up living, and meekly go home and wait for that to happen. ■

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