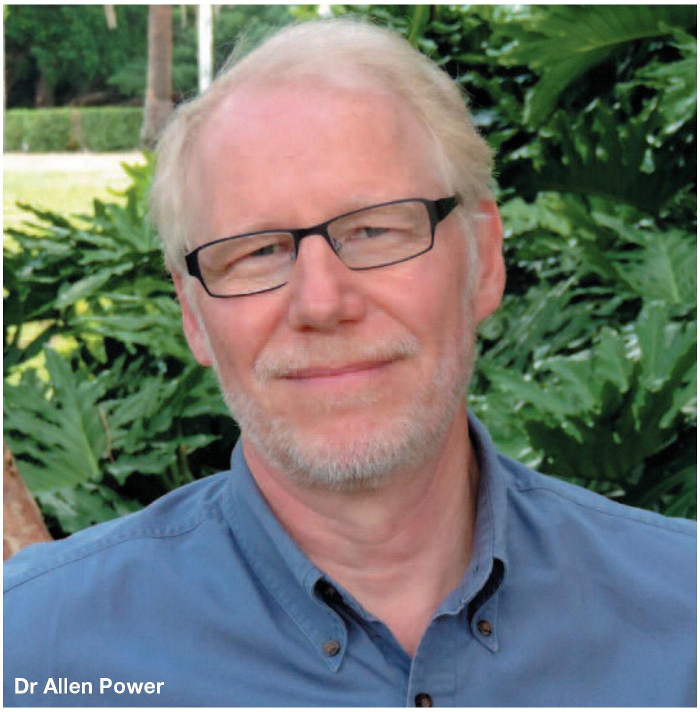
Looking beyond disease

Dr Allen Power is a physician, Schlegel Chair in Ageing and Dementia Innovation at the Schlegel-University of Waterloo Research Institute for Ageing (Ontario, Canada), Eden Alternative* mentor, advocate for people with dementia and author of two books, *Dementia Beyond Drugs* and *Dementia Beyond Disease*, that have contributed to an understanding of the lived experience of dementia. **Jason Burton** interviewed Allen during his recent visit to Australia to present a series of lectures and workshops for Alzheimer's WA's Dementia Friendly Communities Project


Dr Allen Power

***Jason:* How did you begin your career in aged care?**

Allen: It was originally done as more of a 'lifestyle move', after seven years in a busy general practice having a young family I felt I wasn't spending enough time with. A local aged care community with over 500 residents and a full-time medical staff was looking for a partner and it looked like I would have more control over my personal life. It was only after the move that I became enthralled by geriatrics, and I also gained a new sense of purpose when introduced to the culture change movement (initially via The Eden Alternative*).

***Jason:* It seems a significant change in direction going from a medical profession to challenging this medical model paradigm of dementia and focusing more on the holistic lived experience of dementia. What created that shift for you?**

Allen: Looking back, I have been uncomfortable with the use of antipsychotic drugs in people living with dementia for over two decades; I actually gave a Grand Rounds lecture at Rochester General Hospital on the topic in 1997. I never used the drugs nearly as often as other doctors – I've always had fewer than 10% of my residents taking them and was down to about 5% at the time I started to write my book [*Dementia Beyond Drugs*].

The main impetus was rising conflict with co-workers and colleagues who felt I should medicate people more often rather than challenging the care team to meet and brainstorm other solutions. At that point, I knew the drugs were bad news but didn't have a fully formed way of explaining why that was so or what to do differently (this was well before most people worldwide were talking about it).

My attempt to answer those concerns started as a paper I submitted to *JAGS* [*Journal of the American Geriatrics Society*] (which the editors liked, but ultimately rejected as it was not 'evidence-based'), and so it eventually became my first book, *Dementia Beyond Drugs: Changing The Culture of Care*. In challenging our traditional approach, I had to examine my own profession and look critically at the 'science' behind antipsychotic use, which I found to be terribly flawed. I also saw how the biomedical view of dementia was insufficient to understand and respond to the changing experiences and needs of the individual. So I knew I had to tear it all down and start with a very holistic, non-stigmatised view and work from there.

***Jason:* In your first book, *Dementia Beyond Drugs* (2010), you really challenged the use of medication as a response to distress being communicated by the person with dementia. How was this received by the aged care and medical sector?**

Allen: I got some nice reviews when the book came out and a few medical professionals thought it to be a significant contribution. Early on, however, most of my interest came from care providers, individuals living with dementia and their family members.

Most physicians found it interesting, but ultimately thought that it could not answer much of the distress that they saw – and continue to see – as 'symptoms of dementia'. The level of medical support has increased somewhat over the years, but the majority of doctors still buy into the BPSD (Behavioural and Psychological Symptoms of Dementia) paradigm that prevents any great progress with drug reduction. ➤

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* The Eden Alternative (http://www.edenalt.org/) is an international non-profit organisation dedicated to changing the culture of care from institutional models to person-directed, and creating quality of life for elders and their care partners through education, consultation and outreach.

***Jason:* Why do you think this BPSD model as a paradigm of understanding the lived experience of dementia remains so prominent?**

Allen: People are busy and working very hard to support sometimes many individuals at once; it takes a great deal of time and creativity to understand people's distress, especially if you have never been taught the proper tools, such as those that come from a well-being focused approach. The BPSD view is a slippery slope because when you don't find a quick answer, it's easy to default to the dominant theory that what you are seeing is due to brain disease and simply medicate it.

That's the biggest danger of BPSD, because its proponents give the usual 'boilerplate comment' to 'try non-pharmacological approaches first', but it gives you an out with meds after a token effort in that direction. I believe it is the biggest barrier to the reduction of inappropriate drugs.

The BPSD framework does not explain the hundreds of US care homes that use 0-2% antipsychotics (and many others around the world). It pathologises many actions that would be normal for any of us in the same situation, and it ignores relational and environmental contexts in all living environments. Also, it doesn't make sense from a neurochemical standpoint, compared with the chemistry of schizophrenia, for which these drugs were developed.

My contention is that deficits caused by dementia (such as memory impairment, communication barriers, and lowered stress threshold) are e*nablers* of distress, but rarely the *root cause* – that lies in challenges to people's well-being, which is why the approach I teach can significantly reduce or eliminate the need for such drugs.

It is also noteworthy that the framework was created in the late 1990s in meetings that were sponsored by Janssen Pharmaceuticals, and their drug risperidone is the only antipsychotic approved in Australia, the UK, and other countries, as long as you document a BPSD to justify its use. (Meanwhile, Janssen paid a $US2.2 billion criminal penalty in the US in 2014 for illegally marketing it to people with dementia, where it is *not* approved for use. The US certainly hasn't done everything well in this field, but one thing they absolutely got right was never approving any antipsychotics for use in dementia.)

And what about 'delusions' and 'hallucinations'? A 2017 study by Cohen-Mansfield *et al* showed what I have been saying for years – that the vast majority of these expressions are mislabelled, and are actually misinterpretations by people who are trying to fill in memory or information deficits to create a plausible explanation or world view. That is not something that is amenable to antipsychotics or any other drug (neither are the visions seen with dementia with Lewy bodies (DLB), which are not a dopamine problem, but rather due to damage to the visual cortex of the brain).

***Jason:* You are a strong advocate for the Domains of Well-being model. Why do you think this is such an important way of thinking about the needs of people living with dementia?**

Allen: The original framework of seven domains was created in 2005 by a group of 10 culture change specialists on an Eden Alternative grant, in order to show the universal human needs that are often unmet and unmeasured in aged care. I was part of a follow-up group that developed well-being assessment tools for use with the framework.

What I did in my own work was to re-order the original seven domains (which have since been trademarked as The Eden Alternative Domains of Well-Being), and in my second book, *Dementia Beyond Disease: Enhancing Well-being*, I applied the framework to the experiences of people living with dementia and developed proactive, strength-based approaches using the enhancement of well-being as our ultimate target.

It is sobering to think of how these aspects of well-being (which I have ordered as: identity, connectedness, security, autonomy, meaning, growth, and joy) are universal human needs that cross all ages, cultures, religions, and ethnicities, and the presence of any underlying illness; and yet, no professional training helps us to recognise them or teaches us how to restore them for people living with dementia.

This gave me the insight that if erosion of these domains of well-being was the root cause of most distress, it should not be surprising that we have not solved it for so many individuals, since we have never been taught to see this before.

By medicalising dementia, we have ignored a huge swath of life and essential human needs and replaced it with dangerous pills.

***Jason:* You have offered an alternative definition of dementia to the traditional medical diagnosis. What is this and how can it help change our perceptions and the way we support a person?**

Allen: When I knew I had to start back at square one and redefine dementia without all the medicalisation and stigma, I was not sure how to proceed until I met some of the early advocates who were speaking out, such as Christine Bryden and the late Richard Taylor. I realised that this perspective was what we were missing. So I began to define dementia simply as "a shift in the way a person experiences the world around her/him". Once I did that, a whole new world of insights opened up for me. There are two areas in particular I would like to highlight: first, this is a rather subversive definition, but also one which has great pragmatic use. You see, the brain is so complex, and there are so many different causes of dementia, that our attempts to teach care from a biomedical view leave both professional and family care partners' heads spinning with overwhelming complexity.

But this definition, in effect, says, 'Forget about all the various pathologies and 'stages', and focus on understanding the person's changing experience. This requires, first and foremost, deep knowing of the person – it therefore subverts the dominant expertise of the medical profession and elevates those who are closest to the person and know them best. Subversive, maybe – but this is where the true answers lie, once the right mindset and tools are taught.

Second, we can see that we need to find accommodations for that person's changing experience, and this led me early on to begin to look at dementia through the lens of disability, and to talk about finding 'cognitive ramps', just as we use wheelchair ramps for those with physical disabilities. As a result, I have been able to leverage the new focus on disability rights for people living with dementia in developing my approach.

***Jason:* You have very much expanded these ideas in your second book, *Dementia Beyond Disease*. How do you see examples of this approach starting to become more prominent?**

Allen: This approach has resonated well with many organisations and individuals around the world. For a clinical example, my colleague Angie Norman, a nurse practitioner from University of Arkansas Medical Sciences, approached a residential care organisation in June 2016 and asked to work with the four communities they felt were struggling most with antipsychotic use. She went into those four communities and taught the well-being approach; in just six months' time three out of four had a relative reduction in their antipsychotic use of over 60%. (The fourth community, which improved only 11% did not have the full support and guidance of its leadership, which shows the critical component of formal leaders in advancing such an initiative.)

As of 2018, all communities continue to improve, with one now at over 80% reduction from a year and a half ago. Now the state of Arkansas is asking Angie to replicate the approach in other homes across the state.

***Jason:* In your experience, as a regular and long-term visitor to Australia, where do you see our dementia care services, and what will come next?**

Allen: There are many great things I can say about care and support for people living with dementia in Australia. Your national policies and financing are more balanced in these areas than ours in the US.

Your embrace of consumer directed care has helped to spearhead many advances. You have moved forward with inclusive community initiatives, with Kiama in NSW being a standout that has been recognised by the World Health Organisation (WHO).

Dementia Alliance International has a major foothold and leadership presence in Australia. The Alzheimer's WA volunteer project that connects newly diagnosed individuals with volunteer opportunities in their community is one I always point to as a powerful antidote to the 'tragedy narrative' around dementia.

Arcare Aged Care has set a world standard with their Dedicated Staffing Initiative. Dementia Australia's language guidelines are quoted and used internationally. The Australian Aged Care Quality Agency's Better Practice conferences (of which I was honoured to be a part in 2017) are a brilliant showcasing of best practices around Australia; there is nothing like it put on by our own government agencies in the US.

The only big negative you have is that you should never have approved risperidone for use in dementia. You are currently trying to walk that one back, but it's a struggle to do so. You need a more formalised national initiative for reducing antipsychotics, such as we have.

But in spite of our progress in residential care homes, you can do far better than we are in the US by understanding that antipsychotic use is a *society-wide* issue that happens as much or more in the community than it does in residential care. Good luck! ■

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Jason Burton

Dr Allen Power's article *Well-being: A Strengths-Based Approach To Dementia (AJDC* April/May 2015), is available to read on the *AJDC* website at http://journalofdementiacare.com/well-being-a-strengths-based-approach-to-dementia/

Reference

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New Australian guideline to reduce medication use

Australian healthcare professionals now have clear guidance on when and how to deprescribe cholinesterase inhibitors and/or memantine to people with dementia

The new guideline, approved by the National Health and Medical Research Council (NHMRC), was developed jointly by the Cognitive Decline Partnership Centre (CDPC) (University of Sydney) and the Bruyère Research Institute in Ottawa, Canada and published in February. It applies only to individuals already taking one of these medications (donepezil, rivastigmine, galantamine and / or memantine).

The guidance has been endorsed by a number of key organisations, including the Australian and New Zealand Society of Geriatric Medicine (ANZSGM) and The Royal Australian and New Zealand College of Psychiatrists (RANZCP).

According to the guideline, approximately 20,000 people in Australia start using a cholinesterase inhibitor every year, and up to a third of these prescriptions are "initiated or continued inappropriately".

While deprescribing these medications has the potential to improve quality of life for people with dementia, there is also some potential for harm from deprescribing.

The guideline is now in place to help healthcare professionals to navigate these decisions with the person with dementia and their family / carers. It emphasises the need to consider the individual as well as their values, preferences and goals of care. The guideline contains seven recommendations, including guidance on monitoring and follow-up.

The CDPC says that use of the guideline will not only reduce the burden of taking unnecessary medication and medication-induced harm, but will also release money that could be better spent on non-pharmacological treatment.

"Clinical guidelines can help general practitioners and other healthcare professionals to make informed decisions," explained guideline developer and NHMRC-ARC dementia research development fellow, Dr Emily Reeve.

"The availability of these de-prescribing guidelines will provide a resource to help them, in conjunction with people with dementia and their family, decide when it is suitable for these medications to be withdrawn." ■

Evidence-based Clinical Practice Guideline for Deprescribing Cholinesterase Inhibitors and Memantine is available to download from the CDPC website. The development of the guideline is part of a project funded through the CDPC to help determine how to better manage medicines in people with dementia in the future.

Catherine Ross, AJDC Contributing Editor