

Well-being: a strengths-based approach to dementia

G Allen Power discusses why the person-centred care philosophy has failed to become a reality for so many people and suggests alternatives to traditional approaches to dementia care

The past two decades have seen the emergence of two parallel tracks of thought revolving around ageing issues. The first, usually credited to the late Tom Kitwood, is a movement to approach dementia from a more holistic viewpoint that centres on maintaining personhood throughout one's life. The second is a worldwide movement to transform care homes from sterile institutions to life-affirming communities.

Having worked extensively with both movements, I continue to straddle these parallel tracks and strive to wed the common themes of each, in order to advance the cause of both. I have learned that the two are deeply related, and that one cannot be truly successful in pursuing one of these tasks without also engaging in the other.

This, to me, explains why all of the attention devoted to the philosophy of 'person-centred care' has failed to bring about an enduring reality for so many people who live with changing cognition around the world. It is one thing to adjust our attitudes about the people we support; but unless we also change our systems of support to reflect that new way of thinking, our best intentions will never come to fruition.

The medicalisation of dementia

In the cases of both aged care and dementia, the prevailing models revolve around dominant biomedical views of ageing and of cognitive change. As a geriatrician, it would be foolish to state that such considerations do not exist. However, an overreliance on these biomedical aspects produces a narrow perspective that has led to the medicalisation of all aspects of people's lives.

One could argue that the medicalisation of dementia over the past few decades has done very little to truly improve the lives of those living with the condition. That alone should be a sufficient indictment of a narrow biomedical view; but equally important is the fact that it has also resulted in the disempowerment, dehumanisation, institutionalisation and overmedication

of millions of people around the world.

I can trace my own efforts to challenge the use of antipsychotic drugs back to 1997, the same year that Professor Kitwood published his seminal work, *Dementia reconsidered* (1997), although I would not hear of the book until several years later. That year, I gave a lecture at a local hospital entitled *Hold the Haldol: nonpharmacological approaches to dementia*. Although my ideas on the subject were rudimentary at the time, it was becoming clear to me nearly two decades ago that the drugs I was prescribing were not accomplishing what I had hoped, and that another approach was needed.

Coincidentally, that was also the year I first heard about the concept of 'culture change' in long-term care, after attending a lecture about The Eden Alternative™ philosophy. Looking back, I now see that these two events provided the seeds that grew into the work I am doing today. In essence, that work revolves around repositioning biomedical aspects of ageing and cognition within the larger context of the human experience.

For readers of this journal, the underpinnings of the person-centred care philosophy are likely well known and do not require a detailed review. In this article, I would like to discuss some ways in which the philosophy has failed to become a reality for so many people, and suggest some ideas that may be new to many readers.

Transformation of the supportive environment is critical because the dominant biomedical model has so thoroughly infiltrated every aspect of daily life that we often do not realise how much its stigmas and misconceptions have corrupted our attempts to focus on the needs of the person. There is no better example than the widely touted, yet misguided concept of 'nonpharmacological interventions'.

Why nonpharmacological interventions do not work

I struggled with this concept for many years, as evidenced by the title of my 1997 lecture. I gave many seminars on

nonpharmacological interventions and incorporated them into care plans for many people living in the homes where I practised. What I found in the vast majority of situations was that they simply did not work in the long term. And yet, just as we have continued to prescribe antipsychotic drugs, seemingly blind to their lack of efficacy, so do we continue to teach about the importance of nonpharmacological interventions, even in the face of scant evidence of benefit.

My conclusion is that "'nonpharmacological interventions' as they are most commonly applied are attempts to provide person-centred care from a biomedical mindset. As such, it is only a half-hearted paradigm shift, and so it falls short" (Power 2014, original emphasis).

How do our typical nonpharmacological interventions fall short? Let me count the ways:

First, they are often *reactive*, used in response to an expression that is determined to be distressed or undesirable (by *our* judgment). As such, these interventions may distract or calm a person in the short term, but usually do not provide any insight into deeper issues.

Second, they are often applied at intervals, like doses of pills; and just like pills they have a limited period of effectiveness and need to be reapplied. In other words, they may calm a person's distress in the moment, but usually fail to prevent that distress from recurring again and again.

Third, such interventions are often prescribed as a 'laundry list' of possible activities (a list that often includes laundry!) to be applied in a trial-and-error method until something is found to be successful. These lists are usually generated by the care partners, with little insight into or understanding of the person's expressions within a historical context.

Fourth, they are often simply superimposed upon the usual patterns of daily life and operations, ignoring the role these factors may play throughout the day in contributing to the person's unease.

During a speaking trip to Iowa in 2011, I heard the story of a gentleman who lived in an assisted living home in a rural part of the state. He was repeatedly attempting to exit the back door, and each time was redirected by his care partners, who did not feel he was safe walking outside alone. His attempts to go outside became more insistent with each redirection.

Finally, the administrator suggested that the staff not interfere the next time he opened the door, but simply watch from the doorway, to see what he might be trying to accomplish. When they did so, the gentleman walked to the fence at the back of the yard, which adjoined a cow pasture. He watched the cattle grazing for about 10 minutes, and then turned around and came back inside.

In soliciting more information about the gentleman, they learned from his family that he had been a farmer who would go out every day to “check on the cows”. This pattern was being repeated at the home, and once this longstanding practice was revealed, he was able to do so daily, with the knowledge that his identity was being preserved and his need fulfilled (Power 2014, 60-61).

The purpose of sharing this story is not simply to show how one organisation cleverly decoded a person’s actions. The real insight comes from asking ourselves what we usually do when we see someone trying to exit a door. In most cases, we redirect, distract, or attempt to engage the person in a variety of activities or ‘nonpharmacological interventions’. But what if he simply wishes to “check on the cows?” All of those attempts will fail to give him what he seeks, and he will continue to head for the door.

This also explains the tepid results seen with most research studies of nonpharmacological interventions. Many such studies show some benefit, certainly as much or more than is seen with psychotropic medication. But they rarely show the kind of robust response that one would hope to see.

Consider how such studies are usually conducted. A researcher chooses an intervention (eg an aromatherapy massage) to test. The researcher comes into a care home, randomises a number of people living with dementia and provides an intervention of her choosing, at a time and location of her choosing, and in the very same manner to each subject, so as to preserve the ‘purity’ of the intervention.

Such methodology leaves no room to discover the person’s individual identity, rhythms, or the historical context through which he expresses himself. Therefore, it should come as no surprise that such an approach is not wildly successful. After

all, an aromatherapy massage can never help a person who needs to check on the cows!

The fifth and most important drawback to our typical nonpharmacological approaches is our tendency (rooted in biomedical thinking) to view the person’s distress as the problem, rather than a symptom of a larger issue. I often describe this approach as being akin to treating pneumonia with cough syrup. The cough syrup addresses one prominent symptom of pneumonia and may calm that symptom in the short term; but the real issue remains unaddressed and will eventually worsen.

Reducing the use of antipsychotic drugs, while highly desirable, should not be our primary goal, as removing medications alone will not create the conditions for a person to thrive. But it also follows that reducing distress should not be our primary goal either. Neither of these efforts can truly succeed unless we achieve something deeper.

The goal of well-being

I have come to believe that our primary goal should be to enhance well-being. Following this line of thought reveals many startling insights about the shortcomings of our approach to supporting people who live with changing cognitive abilities.

Well-being can be defined in many ways, but for my purposes, I have chosen one model (Fox *et al* 2005) that I find to be comprehensive and readily understood.

This model focuses on seven ‘domains’ of well-being: *identity, connectedness, security, autonomy, meaning, growth and joy*.

Of course, many legitimate models of well-being have been advanced, from Kitwood and Bredin (1992), to Nolan *et al* (2006), to economist Max-Neef (1991). My purpose is not to advance one model over others but to show how the concept of well-being can provide a framework for reimagining our roles in supporting each person to live as fully as possible.

For this purpose, any model we choose should have the following characteristics: (1) it should reflect ideals that are universal across ages, cultures and nationalities; (2) it should reflect qualities that do not depend upon a certain level of physical, cognitive, or functional ability in order to be realised; and (3) when the person has difficulty in maintaining her own well-being, those who support her should be able to help her to do so to the greatest extent possible.

In creating a pathway for supportive partners to restore or maintain these aspects of well-being, I have re-sequenced the original seven domains from Fox *et al* and arranged them into a Maslow-like hierarchy (see Figure 1 below).

Note that, unlike Maslow’s hierarchy of needs (Maslow 1943), I have not placed security on the bottom tier. In this model, security refers to more than simple physical safety and shelter – it also refers to emotional security, which arises from familiarity, trust, respect and a sense of balance. These require deep knowing and

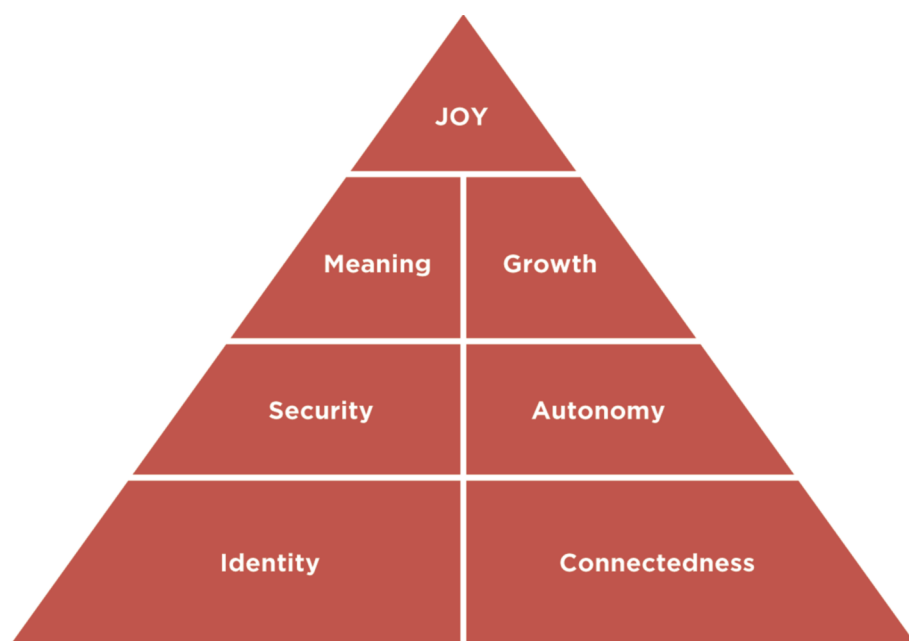


Figure 1. The well-being pyramid illustrates the hierarchy of domains to be addressed for restoring well-being. (From *Dementia beyond disease: enhancing well-being* by G Allen Power. Published by Health Professions Press. Copyright 2014, Health Professions Press, Inc. All rights reserved. Reprinted by permission).

close, consistent relationships in order to be optimised.

While well-being can flow in multiple directions, *operationalising* the support of these domains works best when the hierarchy is used as a reference. For example, rotation of staff within a care home erodes the domains of identity and connectedness for both the person and those supporting her. This in turn erodes the familiarity and trust needed to enhance one's sense of security. Therefore, the use of consistent (or what I prefer to call 'dedicated') staff assignments is the best way to operationalise security (and the higher domains), because it strengthens the foundation of the pyramid.

Combining the primary goal of well-being with a model that views dementia through the lens of the individual's experience also reveals the shortcomings of many other common care practises. Examples include: using alarms on chairs and doors; telling 'little white lies' to calm people; using stigmatising language; creating segregated, dementia-specific housing; and commonly misapplying labels such as 'hallucinations', 'delusions', and 'sundowning' (Power 2012, 2014).

However, the primary advantage of a well-being framework is that – in contrast to our pharmacological and nonpharmacological interventions, which are mostly reactive and deficit-based – it provides a proactive, strengths-based approach to supporting 'people who are of a different mind'. This framework is useful, not only for ongoing daily support, but also as a tool to understand expressions of distress.

Building ramps

The seminars I facilitate around well-being culminate in an exercise that employs a rather counterintuitive process for approaching challenges in daily support and care. Using a real-life challenge presented by a participant – one that has not been solved through a variety of well-intentioned 'interventions' – the group turns its attention to the domains of well-being and quickly discovers how seriously these have become compromised for the person in question.

It is a remarkable insight to examine a situation where 'everything conceivable has been tried' and to discover how much our care system has ignored these seven essential areas of human need!

The participants then proceed to build 'ramps' for the individual. Using a disability metaphor, a person whose legs are paralysed and who is sitting in her

Book giveaway

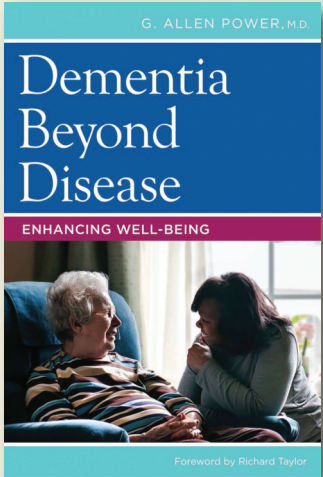
AJDC has five copies of Dr G Allen Power's book *Dementia beyond disease: enhancing well-being* to give away, courtesy of Footprint Books. To go into the draw to win, simply email publicity@footprint.com.au with your name and the answer to this question:

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wheelchair at the foot of a stairway does not need to be coerced to stand and walk up the stairs as we do; nor does she need a psychotropic medication. She needs a ramp, so that she can continue to succeed despite her different ability. The parallel process for dementia is to stop trying to 'fix the behavioural expression' and instead build 'ramps' to the various domains of well-being.

This is a much more difficult exercise than it sounds at first blush; such is our deeply ingrained tendency to focus on the distress. But focusing on distress only addresses the 'cough', not the 'pneumonia'.

It is not always quick or easy to restore well-being. But doing so provides a path to sustainable improvement, not just a temporary reprieve, because it builds on existing strengths to create an infrastructure for ongoing success. After all, once you build a wheelchair ramp, the person can use it every day, and the result is both an enhancement of her well-being and a reduction in excess disability.

One more example of an insight provided by a well-being approach is the light it sheds on limitations of the 'needs-based, dementia-compromised behaviour model' that is commonly taught. While unmet needs are often the genesis for distress, an overreliance on this model can cause one to pathologise expressions that may be part of normal life.

Examples of such expressions include curiosity, spontaneity, agency, desire to care for another, aesthetic enjoyment and various aspects of social citizenship, a concept beautifully developed by Bartlett and O'Connor (2010). The result of looking at such expressions through the

narrow lens of 'unmet needs' is simply one more form of positioning.

The beauty of a well-being approach is that it does not attempt to judge personal expressions. Rather, it sets a primary goal of creating an environment where the domains of well-being can thrive. Where unmet needs exist, doing so will help relieve the cause of distress; but where other expressions (such as those listed above) are concerned, the well-being approach provides a safe and supportive environment for the person to pursue those goals.

Lastly, although it is not the focus of this article, it should be noted that all of these principles are equally applicable to home and community-based living. The limited available evidence suggests that antipsychotic overuse is far more prevalent in the community than in residential care, and it can be presumed that other practises that erode well-being are as well.

Conclusion

In summary, the best way to provide optimal support for those who live with changing cognitive abilities is to move beyond viewing dementia purely as a disease, but rather as "a shift in the way the person experiences the world" (Power 2104). Instead of trying to change that which we cannot, the focus is on creating well-being for each person within the context of her unique life path.

By using a strengths-based approach, we can truly break free of the limitations of a narrow biomedical view and realise successes that have been unattainable with our traditional approaches. Regardless of any future advances in

medical therapy, well-being remains essential, and will never come out of a pill bottle. ■

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Dr Power's new book, *Dementia beyond disease: enhancing well-being* (Health Professions Press) was released in 2014.



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Creative support for complex needs: living with bvFTD

In the first of two articles on behavioural variant fronto-temporal dementia, **Jenny La Fontaine, Anna Buckell** and **Jan Oyebode** explain the distinguishing features of this rare type of dementia and suggest a range of ways of offering individualised support

For many people, dementia is primarily associated with Alzheimer's disease and with difficulties with memory. Indeed, many therapeutic interventions are directed at supporting people who live with Alzheimer's disease and their family members (ECDC 2011a). However, other less common forms of dementia occur, such as fronto-temporal dementia (FTD), that are not experienced in the same way and are less well understood (Shnall *et al* 2013). Many people living with FTD and their families lack support to help them manage the challenges that this form of dementia brings (Shnall *et al* 2013).

This is the first of two articles that focus on the impact and experience of behavioural variant FTD (bvFTD), a type of FTD. This article explains what bvFTD is and summarises what we know about how it is experienced by the person with the diagnosis. Strategies to support the person are also discussed. A second article will consider the experience and support needs of family members.

FTD and person-centred care

Kitwood (1997) placed considerable emphasis on the need for the experience of dementia to be considered within the context of the whole person, and the

many factors that influence how each person lives with dementia. The enriched model (Kitwood 1997) emphasises the need to recognise all of these factors including neurological changes, biography, personal experience and relationships, and the interplay between them. Each factor needs to be understood in order to support people living with dementia to retain their personhood.

Accordingly, while the form of dementia does not define the person, it is nevertheless important to understand how changes to the brain (which result in a range of changes in cognitive and emotional functioning) influence a person's ability to live their life as they would wish to, and the needs they may have. Understanding the changes brought about by FTD is important because its impact is significantly different from Alzheimer's disease. Accounts from family members and people living with bvFTD have highlighted that others often fail to



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