

NZ Association of Gerontology & Age Concern NZ Conference

Wellington 7-9 October, 2009

Justice and Ethics

Authors: Grace O'Sullivan (PhD candidate) & Dr Clare Hocking

Exploring the concept of occupational justice for people with dementia

My presentation is based on the findings of an action research project undertaken to explore ways of assisting people who live with dementia to engage in daily activities. 22 people participated in this study and of those, 11 had dementia. While the initial intent was to look for practical ways to assist people with dementia, the findings point to systemic issues relating to societal attitudes towards dementia and the people who live with it.

As you know, dementia is not a disease; dementia is the term used to describe the symptoms of diseases in the brain that cause a decline in people's ability to function. Alzheimer's disease is the most common type of dementia although there are many other causes. Currently, there is said to be over 24 million people living with dementia worldwide. Here in New Zealand, the recent Economic Impact of Dementia Report (Access Economics, 2008) estimated that nearly 50,000 people are living with dementia. What's more, with our rapidly ageing society that figure is predicted to increase to nearer 75,000 in less than 20 years. Clearly, Alzheimer's and similar disorders are diseases of our times.

In the past, it was understood that people with dementia lose their personality, and their ability to do things. For example, the 4th edition of Mosby's Medical Dictionary (Anderson, Anderson, & Glanz, 1994) defined dementia as "a progressive, organic mental disorder characterized by chronic personality disintegration, confusion, disorientation, stupor, deterioration of intellectual capacity and function, and impairment of control of memory, judgment and impulses" with most types being identified as "not amenable to treatment" (p. 450). As a result of definitions like this people with dementia have been treated as if they know nothing and can do nothing, their future an impending decline into

institutionalized care. Accordingly, community based services have focused on supporting the carers (Mace & Rabins, 1991; MacRae, 2007).

Those ideas have not apparently shifted, despite accumulating evidence that people with dementia can create meaningful lives (Bryden, 2005; Friedell, 2003; MacRae, 2007; Nygård, L. 2004; Nygård, & Öhman, 2002; Sabat, 2001; Snowden, 2001; Zeisal, 2005). The message I want to share today is that a diagnosis of Alzheimer's or similar type disease need not be considered an inevitable slow death with an undignified end. If understanding of what it means to live with dementia can be improved, then there is reasonable hope for transformation of the disease process from a dreadful one-way street to a manageable, and treatable, chronic disorder that allows for ongoing quality of life. In light of this, the notion of occupational justice is important. The concept of occupational justice underpins the belief that recognizing, and providing for, the occupational needs of people, and communities, is a step towards healthy living in a fair and just society (World Federation of Occupational Therapists, 2006).

The principle behind occupational justice is bound up in concepts of health and includes the belief that the right to engage in occupations is a matter of social justice (Wilcock & Townsend, 2000). When people are excluded from engaging in "the daily round of work, play, rest, self care, and care of others" (Wilcock & Townsend, p. 84) whether by regulations, funding policies, fear or stigma they are deprived of social connections, and opportunities to experience competence and success, all of which add meaning to life. Occupational justice is not served by prevailing attitudes towards people with dementia, which frame them as lacking ability and no longer themselves. Neither is it served by health and support services that monitor the decline of people with dementia rather than advising them about maintaining their health and capacity. Indeed, evidence shows that health services diminish physical and cognitive capacity of people with dementia through inappropriate use of antipsychotic medications (Ballard et al., 2005; Fossey et al., 2006; Salmon, 2006), while support services mainly focus on supporting the carers.

In relation to occupation, justice is about enabling alternatives. It is about having policies that will add depth and meaning to life by encouraging active participation in wide ranging occupations for people of all ages, without discrimination. To expand on this notion, when

people are engaged in a meaningful occupation, in doing something they enjoy, their mind is focused on what they are doing; and brain cells are firing because they are active and involved. From this perspective, occupation is central to functioning, health and well-being. There is also a very important social aspect. Research has shown that being part of a group, be it a gardening club, a football team or a walking group gives people a sense of identity and fulfillment.

In this respect people with dementia are no different to others however, there is one key difference between them and others in society - when it comes to opportunities to engage in occupations people with dementia are deprived. Although the connection between occupation and health is unmistakable, opportunities to engage in occupations are influenced by social perceptions. In most instances, other people are so preoccupied with the significance of dementia they seem to have forgotten that people respond and react to the way they are treated. Therefore a critical component of the action in this research was uncovering aspects of social injustice which disadvantages people with dementia.

It is over 20 years since the World Health Organization (1986) advocated that: "*Health promotion action aims at reducing differences in current health status and ensuring equal opportunities and resources to enable all people to achieve their fullest health potential*". For people with dementia difference makes a difference but not in any simplistic, basic, or fixed way. Factors such as: age, attitudes, family support, gender, social connections and opportunities, not to mention culture all influence the ways in which difference is manifest. Not all of these issues can be addressed in this presentation but the important point is - understanding difference is an opportunity to learn, to expand our knowledge, and to emancipate people with dementia (Kögler, 1999).

Difference is the foundation upon which the findings of the research are based. To convey the essence of the findings I want to share a few stories. When diagnosed with Alzheimer's disease at age 81, Harry was not unduly perturbed. He knew his health had deteriorated but he wasn't worried by it. He lived at home with his wife Betty and had a caregiver to help him shower three times a week. Before retiring, Harry led an extremely busy lifestyle. He was a very social person with lots of friends. Nowadays he is content to live life quietly. He said:

I sort of know that I am having a problem at times ... I realize that I am in a stage of my life where I need a bit of help ... slowed down a bit yes, but there must be a lot of people have the same problem. I just love sitting here looking out ... it's nice to know that I can look out the window and think hey! I am still here. ... I am quite happy and I am very lucky with my wife and all my friends... When there's nothing else to do, I come and sit in this seat and look out the window. I recognize where I am and what I am doing. Oh yes, I have had quite a career going back. My memories, well I've got the war and I survived that, yes I survived alive. Yes, it goes through my tired brain.

In fact, Harry spent a good portion of the day just sitting looking out of the window. He was fortunate inasmuch as he did not have a sense of barriers to participation in his daily choice of activities because he was supported in occupations he found satisfying in a familiar environment. If Betty had to go out she would take him with her. She said he was happy to sit in the car and watch the passing parade while waiting for her to complete her errands. His children and grand children visited regularly and took him out occasionally. The fact that Harry did very little for himself did not bother him, in fact he seemed unaware of it. He said: *"I shouldn't be bored ... it's nice to be an old bugger sitting here listening and talking. It's nice to be able to do that."*

Alternatively, Ron who was diagnosed with Alzheimer's at age 54, was also cared for by his wife Ann. Unlike Harry, he was frustrated. His primary occupation, a walk with a caregiver who took him out for forty five minutes on two afternoons during the week. He also attended a community group facilitated by his local branch of the Alzheimer's Association once a month. Otherwise, Ron spent most days on his own while Ann was at work. In talking about Ron's predicament Ann said:

When I see the guys down at Alzheimer's and they are all looking for that companionship that they used to have at work. They're looking for something, being able to do something useful. The general day-to-day stuff you know getting Ron dressed is not a problem. For most people what becomes a problem is when you come home from work, you know, Ron has been sitting there all day and so okay let's go out and do something. So it would be great if that group of guys could have something, something to do, they need an occupation.

Ann was very resourceful in finding strategies to help Ron, but lack of support eventually took its toll. On being reassessed after a particularly bad weekend during which Ron flooded the garage when trying to do something to help, Ann was advised he needed full

time care. Once admitted to residential care it became apparent that Ron was different because he was a comparatively young and healthy looking man in a facility providing care for older people. For Ron, the change was devastating. The turn around in his well-being was such that the speed of his physical and cognitive decline took everyone by surprise. Why this happened is not fully understood but there are a number of contributing factors which have to be considered. Ron was moved between three facilities within 3 months. He was given a 'cocktail' of medications to 'manage' the symptoms. His physical health deteriorated rapidly and 4 months after being taken into care Ann said he had more or less withdrawn from all aspects of life. He could only walk *"twice around the garden."*

Systemic barriers contributed to this outcome inasmuch as there is no appropriate support for couples like Ron and Ann. In addition, the frequency of the Alzheimer group was insufficient to support Ron's well-being and there were no other age appropriate options for engagement in occupations suitable to a man with dementia in his 50s.

In contrast, Harry was eventually taken into residential care due to Betty's failing health. The difference between Ann and Betty's views of having Alzheimer's disease is significant. Betty stated: *"I think Alzheimer's is a very gentle disease, there's no pain and it allows a gradual end to life."* On the contrary, Ann said: *I feel such grief, loss, guilt, and anger at what is happening. This is such a cruel disease, watching the person you love deteriorate and knowing there is little you can do to protect him any longer."* In hindsight Ann said *"I wish I had ignored all the advice given by the so-called health professionals."* This outcome could have been very different if services were in place to support Ron in his own home. Opportunities to engage in occupations would have helped him retain abilities. To justify that statement I move onto Dutch and Moses and the notion of 'Ways of being' in the world with dementia. This second theme is informed by the work of Hans-Georg Gadamer the German philosopher best known for his work in the humanities.

Dutch was diagnosed with Alzheimer's disease, aged 67, and both he and his partner Moses who was also 67, were devastated. Nonetheless, once the shock subsided they agreed to live life to the best of their ability and in so doing strove to maintain a relatively normal lifestyle. Moses facilitated this by having expectations of Dutch and treating him as a valuable human being whose sense of self is important, and whose ability to act

meaningfully intact. They established a weekly routine, whereby they participated in various activities every day except Friday because Moses said:

Friday is housework morning – always. He's still so capable of doing so many things which I find quite amazing. Because he's done them all his life you know. It's like this house, it looks like a museum and I say to him if you're going to have all these things on the walls, you're going to have to do the dusting and the cleaning. He still does it. I mean he might miss the odd corner or something.

To which Dutch responded: *And he will find it, he goes around with glasses.*

Rather than allow Dutch to become a helpless, and confused person lacking a sense of being in the world Moses encouraged him to offset the debilitating symptoms of dementia. For instance, they play board games such as Mahjong and Rummikub three mornings a week at local community centres, they are also members of a Classical Music Club, a Couples Club, the Fruit Season Garden Club and they *"thoroughly enjoy"* the Auckland Music Club every third Tuesday of the month. They regularly go out walking. Until recently they travelled overseas at least once a year but then they had to cancel a trip because Dutch was daunted by the thought. He said *"I especially hate the hustle and bustle of airports."* So they went for a sea cruise instead. Moses' rationale was that at least on a boat Dutch would not get lost.

In the time since diagnosis, Dutch experienced a gradual decline in his ability to do things and if a problem arises Moses looks for practical ways to overcome it. For instance, Dutch began to stumble while navigating the stairs in their home, so Moses lined the edge of each step with a white strip to make it clearly visible. This was a simple but effective solution to a visual perceptual problem. Six years after diagnosis Dutch was still enjoying life. Yes, his abilities declined and yes, some activities fell by the wayside but so many people doubted Dutch's diagnosis that he was reassessed. The diagnosis was confirmed. By actively overcoming barriers or identifying alternative environments with fewer barriers, Moses facilitated participation in everyday occupations through an enabling attitude and navigation of their social environment.

Other people's expectation of what it means to have dementia brings me to the final theme: Prejudice and power. This theme, which is informed by the work of French philosopher Michel Foucault, is grounded in the widely accepted beliefs that shape

attitudes in the everyday world. These attitudes, which are socially constructed, determine ways of thinking about dementia and give rise to the stigma associated with dementia. Ultimately, this stigma imprisons people with ideas of who they are and what they can do. People with dementia are set apart for reasons such as: prejudice, ignorance, a perceived lack of intellectual capacity, in a society without strategies to support them.

In advocating for meaningful occupation it is important to understand how social policies can affect people with dementia. Many of the issues associated with dementia are unique and so the models of care used with other client groups are inadequate. At this point in time there is no rehabilitation programme for people with dementia to help them retain functional ability because to date it has been assumed that little can be done to prevent decline. On the contrary, some abilities remain intact for an indeterminate time, but how those abilities are acknowledged, and supported by others in society is critical (Sabat, 2001). Evidence showing people with dementia can benefit from active participation in activities is constantly increasing. Therapeutic interventions tailored to the person's assessed needs, strengths and limitations promote and maintain cognitive skills, mobility and independence in wider activities of daily living. Understanding this means grasping both the negative ways in which the disease has affected the person, while seeing positive aspects. What we 'see' will affect how the person is treated and therefore, how they behave.

Recent studies on maintaining cognitive ability identify three important factors; physical exercise, mental challenges and social activities (Cotman, cited in Roan, 2006). Science has found that when brain cells are not appropriately stimulated, they self-destruct. This process is known to be an important factor in Alzheimer's, stroke, and motor neuron disease (Coulson, Fox, McKenna, & Stathi, 2008). Since no two human brains are exactly alike, no one challenge will adequately satisfy all people but these days the range of available, stimulating activities is infinite. For some, physical activity is gratifying; for others, finding and processing information is rewarding; for still more others, working with creative ideas is enjoyable. Regardless of the activity, it is the challenge to the brain cells that is important (Jakobson Ramin, 2007).

I am not blind to the downside of living with dementia. There is no doubt that it is a physically and emotionally stressful challenge - for all concerned. The key point is that people with dementia can maintain abilities and enjoy more years of life satisfaction if they are given opportunities to participate in activities on a daily basis. There is a tendency to see only the risks in encouraging people with dementia to do things but the balance of risk needs to be carefully weighed to include the dignity of risk. Doing things gives people purpose and meaning in life which in turn helps them to maintain a sense of self respect, dignity and quality of life.

At this point in time there is no vaccine or cure for Alzheimer's or similar type disease yet people have a right to expect health services which consider their well-being. If available medications worked as well as engagement in meaningful occupations they would cost a fortune. The point I am trying to make is: participation in a satisfying round of daily activities is an effective approach. A human life is too important to be allowed to waste, the time for action is long overdue. New Zealand lags behind other western countries in this respect. We need community development interventions, we need to challenge stigmatising attitudes, we need to work with community partners to educate and prepare people who offer services in the community - gyms, social groups, clubs - to be able to recognise and respond to the needs of people with dementia. Enabling people with dementia to remain in their own home and to engage in a range of daily activities will mitigate the impact of dementia, thereby delaying the need for institutionalization. Accomplishing this requires a radical overhaul of societal and medical attitudes towards dementia. It requires a refocusing of support services to engage people with dementia in everyday activities, support them as they navigate societal attitudes, and bring them into partnership in designing services that address their needs. To bring about the required change we need courage as defined by Plato: *"It needs the best of what the best among us can give and the help of everybody."*

References

- Access Economics Pty Limited. (2008). *Economic impact of dementia in New Zealand*. Melbourne: Author.
- Anderson, K. N., Anderson, L. E. & Glanz, W. D. (Eds.). *Mosby's medical, nursing, and allied health dictionary* (4th ed.). (1994). Chicago: Mosby.
- Ballard, C., Margallo-Lana, M., Juszczak, E., Douglas, S., Swann, A., & Thomas, A. et al. (2005). Quetiapine and rivastigmine and cognitive decline in Alzheimer's disease: Randomised double blind placebo controlled trial. *British Medical Journal*. Retrieved May 22, 2008 from http://www.ncbi.nlm.nih.gov/pubmed/15722369?ordinalpos=73&itool=EntrezSystem2.PEntrez.Pubmed.Pubmed_ResultsPanel.Pubmed_DefaultReportPanel.Pubmed_RVDocSum
- Bryden, C. (2005). *Dancing with dementia*. London: Jessica Kingsley.
- Coulson, J. C., Fox, K. R., McKenna, J., & Stathi, A. (2008, September). *The OPAL qualitative sub-study: Getting out and about: The role of physical activity and neighbourhood in older people's lives*. Paper presented at the Annual Conference of the British Society of Gerontology Symposium. Bristol, UK.
- Fossey, J., Ballard, C., Juszczak, E., James, I., Alder, N., Jacoby, R., & Howard, R. (2006). Effect of enhanced psychosocial care on antipsychotic use in nursing home residents with severe dementia: Cluster randomized trial. *British Medical Journal*. Retrieved May 23, 2008 from [http://www.ncbi.nlm.nih.gov/pubmed/16543297?ordinalpos=56&itool=EntrezSystem2.PEntrez.Pubmed.Pubmed_ResultsPanel.Pubmed_DefaultReportPanel.Pubmed_RVDocSum&log\\$=freejpmc](http://www.ncbi.nlm.nih.gov/pubmed/16543297?ordinalpos=56&itool=EntrezSystem2.PEntrez.Pubmed.Pubmed_ResultsPanel.Pubmed_DefaultReportPanel.Pubmed_RVDocSum&log$=freejpmc)
- Friedell, M. (2003). *Dementia survival – A new vision*. Retrieved 31 October, 2007 from <http://members.aol.com/MorrisFF/Vision.html>
- Jakobson Ramin, C. (2007). *Carved in sand: When attention fails and memory fades in midlife*. New York: HarperCollins.
- Kögler, H. H. (1999). *The power of dialogue: Critical hermeneutics after Gadamer and Foucault*. Massachusetts: Massachusetts Institute of Technology.
- Mace, N. L., & Rabins, P. V. (1991). *The 36-hour day: A family guide to caring for person's with Alzheimer's disease, related dementing illnesses, and memory loss in later life*. (Rev. ed.). Baltimore: John Hopkins University Press.

- MacRae, H. (2007). Making the best you can of it': Living with early-stage Alzheimer's disease. *Sociology of Health & Illness*, 30(3), 396-4121.
- Nygård, L. (2004). Responses of persons with dementia to the challenges of daily activities. A synthesis of findings from empirical studies. *The American Journal of Occupational Therapy*, 58(4), 435-445.
- Nygård, L., & Öhman, A. (2002). Managing change in everyday occupations: The experience of persons with Alzheimer's disease. *OTJR: Occupation, Participation, and Health*, 22(2), 70-81.
- Roan, S. (2006, January 19). To sharpen the brain, first hone the body. *The Vail Daily*, pp.C1.
- Sabat, S. (2001). *The experience of Alzheimer's disease: Life through a tangled veil*. Oxford, UK: Blackwell.
- Salmon, N. (2006). Cognitive stimulation therapy versus acetyl cholinesterase inhibitors for mild to moderate dementia: A latter day David and Goliath. *British Journal of Occupational Therapy*, 69(11), 528-530.
- Snowdon, D. (2001). *Aging with grace: What the nun study teaches us about leading longer, healthier, and more meaningful lives*. New York: Bantam Books.
- Wilcock, A. & Townsend, E. (2000). Occupational terminology interactive dialogue: Occupational justice. *Journal of Occupational Science*, 7(2), p. 84-86.
- World Federation of Occupational Therapists. (2006). *Position statement on human rights*. Perth, W. Australia: Author.
- World Health Organization. (1986). *Ottawa charter for health promotion*. Ottawa, Canada: Author.
- Zeisal, J. (2005, May). *Respect and personhood are not optional*. Paper presented at the Alzheimer Australia National Conference, Sydney, NSW.