

**SUBMISSION/COMMENT Department of Health and Ageing**

**From: CONJOINT PROFESSOR KIM WYLIE**

Care and management of younger and older Australians living with dementia and behavioural and psychiatric symptoms of dementia (BPSD)

**Terms of Reference**

The care and management of younger and older Australians living with dementia and behavioural and psychiatric symptoms of dementia (BPSD), including:

- (a) the scope and adequacy of the different models of community, residential and acute care for Australians living with dementia and BPSD, with particular reference to:
  - (i) Commonwealth-provided support and services,
  - (ii) state- and territory-provided services, and
  - (iii) services provided by the non-government sector;
  
- (b) resourcing of those models of care; and
  
- (c) the scope for improving the provision of care and management of Australians living with dementia and BPSD, such as:
  - (i) access to appropriate respite care, and
  - (ii) reduction in the use of both physical and chemical restraints.

## Comment to Inquiry

It is not possible to comment on specific terms of reference of this inquiry, simply because its focus as suggested by the above title is meaningless and erroneous. For this reason, I can comment only on the subject of the inquiry as indicated by the title. 'Management' of people, regardless of age, who live with dementia and so-called BPSD, is a strategy discussed, encouraged and practised throughout Australia. Words and inference within the title may have been acceptable some time ago, however significant research, discourse and changing worldviews have provided evidence that now refutes the legitimacy and ethics of such terms in the care of people living with dementia (Cohen-Mansfield & Mintzer, 2005<sup>1</sup>; Kitwood, 1997<sup>2</sup>; De Bellis, 2006<sup>3</sup>).

It is deeply concerning that those people in a position within government responsible for ensuring the health and wellbeing of younger and older people with dementia in funded and non-funded care not only encourage unethical 'management' practice through the lens of legislation but also disregard contemporary research and practice. Likewise, the same applies to funding bodies who continue to support research about behavioural management despite international research which contests such a waste of limited resources.

What most bureaucrats and many health professionals fail to grasp is that the behaviour of a person living with dementia, considered in need of 'management', commonly signifies an expression by the person of ordinary human emotions and unmet needs (Cohen-Mansfield & Mintzer, 2005; Trevitt & MacKinlay, 2006<sup>4</sup>). When the person living with dementia cannot find the appropriate words to express their needs, then often they express, that is, *communicate* their needs by other means (Cohen-Mansfield & Mintzer, 2005; Chenoweth, King et al., 2009<sup>5</sup>; Kitwood, 1997). Rather than speaking of models, what is needed is education and training in communication skills - how to work out what the person needs, when they need it, why they need it and how you can answer their unmet need.

Needs and emotions which people often struggle to convey arise when for instance, the person is ill (Quality of Care and Support, 2011<sup>6</sup>), in pain (Wylie & Nebauer, 2011<sup>7</sup>), depressed (Snowdon, 2010<sup>8</sup>), hungry (Gaskill et al., 2008<sup>9</sup>) frightened and/or alone (Trevitt

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<sup>1</sup> Cohen-Mansfield, J. & Mintzer, J. E. (2005). Time for change: the role of nonpharmacological interventions in treating behavior problems in nursing home residents with dementia *Alzheimer Disease and Associated Disorders*, 19(1), 37-40.

<sup>2</sup> Kitwood, T (1997) *Dementia Reconsidered. The person comes first*. Buckingham: Open University Press.

<sup>3</sup> De Bellis, A. (2006) *Behind open doors A Construct of Nursing Practice in an Australian Residential Aged Care Facility*. Unpublished Doctoral Thesis. Flinders University, South Australia

<sup>4</sup> Trevitt, C. & MacKinlay, E. (2006). 'I am just an ordinary person. . . .' spiritual reminiscence in older people with memory loss. *Journal of Religion, Spirituality & Aging*, 18(2/3), 79.

<sup>5</sup> Chenoweth, L., King, M. T., Jeon, Y-H., Brodaty, H., Stein-Parbury, J., Norman, R., Haas, M. & Luscombe, G. (2009). Caring for aged dementia care resident study (CADRES) of person-centred care, dementia-care mapping, and usual care in dementia: a cluster-randomised trial. *Lancet Neurology*, 8, 317-325.

<sup>6</sup> Quality of Care and Support. (2011). *Report to the Productivity Commission*. Retrieved September 3, 2012 from [www.pc.gov.au/data/assets/pdf\\_file/000/14/aged-care-chapter10.pdf](http://www.pc.gov.au/data/assets/pdf_file/000/14/aged-care-chapter10.pdf)

<sup>7</sup> Wylie, K & Nebauer, M. (2011). The fragmented story of pain: A saga of economic discourse, confusion and lack of holistic assessment in the residential care of older people. *Collegian*, 18, 11-18.

<sup>8</sup> Snowdon, J. (2010). Depression in nursing homes. *International Psychogeriatrics*, 22(7), 1143-1148.

<sup>9</sup> Gaskill, D., Black, L. J., Isenring, E. A., Hassall, S., Sanders, F., & Bauer, J.D. (2008). Malnutrition prevalence and

& MacKinlay 2006). In essence, for people with dementia, loneliness, fear, pain and other shared human experiences are actions 'which might be regarded as quite logical and reasonable' ... but 'instead, interpreted as pathological' (Sabat, Johnson, Swarbrick & Keady, 2011, p. 286<sup>10</sup>). Put simply, as opposed to considering the person for example may be feeling despair related to their situation, such despair is linguistically characterised as 'agitated' behaviour, 'the dementia', BPSD and so on. Hence, the person's understandable and 'normal' feelings of despair are medicalised (and treated accordingly e.g. medication) as opposed to the person being assessed and comforted by a caring 'other'.

Without doubt, neuronal damage may contribute to a person displaying strong emotions, however so too do the lived social and physical environments in which the person is confined; their physical health, and the way in which others value, relate and communicate with the person. How can educated people talk of managing dementia? Brain cells cannot get angry or depressed nor can caregivers manage brain cells. Only people can experience these emotions and emotions cannot be managed; emotions require understanding. When did we start to believe that we have the right to manage a person who happens to have dementia (Barnett, 2000)<sup>11</sup>?

It is my and many others' experience that the lexicon of behavioural management of dementia, particularly the dominant positioning of BPSD has nurtured the growth of a custodial environment in many Australian residential facilities. One of the most common spoken and written terms in custodial facilities of this type is 'challenging behaviour'. This has led to care of the unique and sensitive older person being replaced with custodial containment of their 'diseased body and damaged brain'. It is time to transform the lexicon of caring for people with dementia from promoting a model of management of deviance to one of person-centred care. It is time to frame the phrase challenging behaviour as it should be: an act of meaningful communication on the part of the person with dementia; usually communication of an unmet need. We must teach those who provide care that so-called behavioural and psychological symptoms are not always related to dementia but often to the way people with dementia are cared for and about or not cared for at all.

There is an urgent need to consider the term challenging behaviour in a different light – as a behavioural communication response cycle – using this linguistic turn the cycle can provide a simple way of understanding behaviour as a form of communication of an unmet need or a response to something or someone (Powell, 2000<sup>12</sup>). A response cycle of this nature is based on the premise that everything older people and people living with dementia do and say or don't do and say has a reason – that is - 'behaviour' is an act of *meaningful* communication. If the meaningful communication is ignored or inappropriately addressed, the person responds accordingly (Cohen-Mansfield. & Parpura-Gill, 2008)<sup>13</sup>.

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nutrition issues in residential aged care facilities. *Australasian Journal on Ageing*, 27(4), 189-194.

<sup>10</sup> Sabat, S. R., Johnson, A., Swarbrick, C. & Keady, J. (2011). The 'demented other' or simply 'a person'? Extending the philosophical discourse of Naue and Kroll through the situated self. *Nursing Philosophy*, 12(4), 282-292.

<sup>11</sup> Barnett, E. (2000) *Including the person with dementia. Designing and delivering care. 'I need to be me'*. London: Jessica Kingsley Publishers Ltd.

<sup>12</sup> Powell, J. (2000) *Care to Communicate. Helping the older person with dementia*. London: Hawker Publications.

<sup>13</sup> Cohen-Mansfield, J. & Parpura-Gill, A. (2008) Practice style in the nursing home: dimensions for assessment

The role of the caregiver is to find out what lies beneath the person's behaviour (what is this person saying to me?): is it boredom, hunger, thirst, sore legs - the possibilities often are determined by how well the caregiver knows the person - their biography, their family, health problems – usual way of being-in-the-world, often simple issues such as how long has the person been sitting in the same chair? Are they experiencing pain? Is this person angry because nobody has spoken to them for hours? The same cycle applies to caregivers and all others involved in the organisation. Human beings behave in a certain manner according to what, how and why they wish to communicate to and with another (Powell, 2000).

Meaningful verbal and non-verbal communication is dependent upon person-centred language, knowledge and practice (Brooker, 2007)<sup>14</sup>. Perhaps changing the title of the inquiry may be the first step and help elicit more meaningful responses from healthcare professionals and others concerned with caring for younger and older people living with dementia. For instance:

**How can we improve our communication skills with younger and older Australians living with dementia in order to meet their unmet needs and enhance their well-being?**

Yours sincerely

Dr Kim Wylie

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and quality improvement. *International Journal of Geriatric Psychiatry*, 23, 376-386.

<sup>14</sup> Brooker, D. (2007) *Person-centred dementia care. Making services better*. London: Jessica Kingsley Publishers.