

Dementia

How to live with Dementia as a common experience of ageing

Written by Gaynor Macdonald

Dr Gaynor Macdonald in the Department of Anthropology is bringing her focus on personhood and change to the understandings of personhood in the context of Alzheimer's. She has teamed up with Associate Professor Jane Mears at Western Sydney, a well-known expert in the care of the aged and elder abuse, to examine the ways in which cognitive decline is represented. They are inviting an interdisciplinary discussion about the ways to understand, represent and respond to dementia in the human social experience.

Our value as persons as well as the quality of our social relationships are influenced by philosophical and social ideas, as well as economic and medical ones. The privileging of cognition in thinking about human value means that forms of dementia challenge that value: cognitive decline is stigmatised as a loss or deficit of personhood. Bringing a cultural and social lens that can both augment but also critique medical models of ageing in the context of cognitive decline is essential to countering this negativity. Many of us will experience it ourselves – a third of us who live beyond 80 years of age – so tackling the stigmas and fears, and improving the quality of information as well as care, is an important social investment.

The particular concerns they are targeting include:

- The medicalisation of those experiencing cognitive decline as well as their family carers;
- How neoliberal thinking exacerbates stigma through narrow understandings of the 'normal' person and a focus on the economic value of persons, to the detriment of all other perfectly normal human experiences of not being 'normal' or 'economically valuable';

- The philosophical legacies of the mind-body split and individualism on medical modelling and research;
- Notwithstanding efforts to include the notion of 'person-centred' into aged care, the 'person' is not well understood and the training of carers is far from adequate, whether family or professional.
- Carer depression is so high as to be a major social issue; policy is moving too slowly. Financial and social supports remain negligible, and ageism is alive and well.

The concern in this project is not about 'how to understand dementia as an illness', nor about how to cure it. Rather, the issue is how to live with dementia as a common experience of ageing, how to learn to communicate with people with dementia, how to challenge the mind-body split that permeates biomedical models and privileges cognition in the human experience; how to reconceptualise 'care' and ensure that it is not medicalised but seen as a total social responsibility; and how to better support those directly involved. Central is the notion of 'the caring society'. Dr Macdonald and Prof Mears aim to stimulate a big picture examination of these issues (ontological, philosophical, anthropological, social, medical) by bringing together an interdisciplinary group of people committed to changing the negativity surrounding dementia, better supporting caregivers, and working towards a more caring society.