



Research Directions

Office of Research Services

Dealing with Dementia

Professor Esther Chang from the Nursing Family Health, Outcomes, Resilience, Capacity Building Evidence (N-FORCE) research group, is leading a research team to evaluate a family information booklet for family carers of people with dementia. Funding is being provided by the Commonwealth Government Department of Health & Ageing.



'Dementia is a growing health issue with perhaps one in four people aged over 65 years having a diagnosis of dementia by 2020' said Professor Chang. 'Family members play a crucial role in caring for people living with dementia, however, their need for information and support is often not well addressed and they can suffer from depression. By providing education to the carers about the progressive nature of dementia, the incidence of depressive symptoms experienced by carers can be reduced. Investigation has shown that family members can be relieved for example when they know that the person is dying rather than experiencing new symptoms and what steps they can take to assist with this stage of palliative care.'

To address this need for information, a booklet has been developed by the three partner organisations in consultation with dementia and aged care experts, providing information on what to expect as the dementia progresses. For example, it addresses end of life issues, palliative care options and where to obtain ongoing support. 'The booklet is the first of its kind, so evaluation is imperative to understand, for example, if carers are finding the information too confronting and what is the most appropriate time for certain information to be given' said Professor Chang.

Family members and carers will be given the booklet to use for a month and then they will be asked to fill out an evaluation form. The evaluation data from these 100 families and carers will be collated to assess the booklet's acceptability and suitability. This information will be used to finalise the booklet prior to making it broadly available.

The completed booklet will be published on the World Wide Web giving vital support to innumerable families, carers and service providers locally, nationally and internationally.

Project Title: *Evaluation of a family information booklet for family carers of people with dementia*

Other team members: *Professor John Daly, Ms Amanda Johnson and A/Prof. Trish Davidson, working in partnership with Sydney West Area Health Service Primary Care and Community Health Network and Blue Mountains Division of General Practice.*

Funding has been set at: \$36,422.
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Contact Details

e.chang@uws.edu.au

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