



Equipping family members to manage behaviour changes in loved ones with younger-onset dementia



What is the focus of the research?

Exploring a family-directed education program to help carers manage behaviour changes associated with younger-onset dementia and delay the need for residential care.



Why is it important?

Changed behaviours such as aggression and sexual or social inappropriateness are common symptoms of younger-onset dementia, which includes early-onset Alzheimer's disease and frontotemporal dementia. In severe cases, behaviours become a threat to personal safety. In addition, there is a relationship between the severity of behaviour changes and progressive cognitive decline. Changed behaviours can be unpredictable and lead to crisis events for the person with dementia and their loved ones, who are rarely properly equipped to respond appropriately and effectively.

The lack of support and inability for carers to cope is why many people are placed into

residential care far too early. It is also a heavy economic burden, with healthcare costs estimated to exceed \$125,000 per person per year – twice that of late-onset dementia. With the ageing population in Australia, we can only expect this to increase.

Medication is the most common intervention for behaviour changes, but it is not always effective and can cause negative side-effects, such as nausea and insomnia. Positive behaviour support (PBS) is considered the most appropriate approach when responding to behaviour changes. Preliminary findings show that a PBS education program designed for a group of family carers increases their confidence when applying strategies to manage behavioural-variant frontotemporal dementia. Dr Cheung will broaden these findings and explore the effectiveness of a family-directed PBS education program for other younger-onset dementia variants. The program will be run in-person and online. Dr Cheung and her team will evaluate online participation and explore the potential to increase the program's reach across Australia via telehealth delivery.



How will this happen?

Stage 1: recruit family members of people with younger-onset dementia who display changed behaviours to take part in the program.

Stage 2: participants will attend two-hourly education sessions over five weeks. They will complete outcome measures about the behaviours, carer experience, behaviour support strategy success, and the program itself.

Stage 3: participants can choose to provide more in-depth feedback via short interviews. Feedback and outcome measure data will be used to create facilitator guidelines and inform future iterations of the education program and related resources.



What will this mean for family carers?

- A better understanding of about behaviour changes in younger-onset dementia.
- Increased capacity to support those changed behaviours.
- An evidence-based non-pharmacological intervention.
- Formalised support for carers.



The challenges of residential care

Dementia is considered younger onset if a person is diagnosed before the age of 65. Most people still have active home lives, young families and careers. While they would prefer to remain at home, the challenges associated with changed behaviours, such as premature retirement and loss of income, plus a lack of family carer support, often means they require residential care.

Most disability facilities are not equipped to support complex neurodegenerative conditions. The only option for many younger people is to enter residential aged-care facilities, where the average age is 84. Many people describe these facilities as isolating environments that cannot provide the necessary stimulation and meaningful activities. This impacts their mental health, wellbeing, feelings of self-worth and independence.



Who's undertaking the research?

Dr Sau Chi Cheung, University of Sydney

Dr Cheung is a clinical neuropsychologist and post-doctoral researcher at the University of Sydney's FRONTIER Frontotemporal Dementia Research Group. She has worked extensively as a clinical neuropsychologist and joined FRONTIER to further her research interests in dementia. Within this, she is passionate about improving the diagnosis, monitoring and

management of younger-onset dementias.

Dr Cheung has a strong interest in improving how we understand quality of life and the grief experience of people with early onset dementia and their carers.

The title of Dr Cheung's project is *Supporting changed behaviours: positive behaviour support in younger-onset dementia*.