





# Creating hope by improving the way clinicians deliver a dementia diagnosis



### What is the focus of the research?

Developing best-practice guidelines for clinicians to communicate a dementia diagnosis in a way that educates and supports people and their families.



#### Why is it important?

Dementia is a terminal condition that erases memories and causes profound heartache for the person and their loved ones.

People who receive a diagnosis of dementia may see it as a threat to their identity. Many become fearful of losing themselves and the impact that will have on their family.

The time of diagnosis can feed this fear and helplessness, or it can empower people, their families and carers to take control and equip themselves to navigate what's ahead.

This makes communicating the diagnosis a complex and challenging task for clinicians.

Essential features of this communication process include demonstrating compassion; offering opportunities for questions; finding ways of giving hope; having awareness of family and carer dynamics; and providing written information to increase understanding of dementia.

Unfortunately, this doesn't always happen and there are no evidence-based, best-practice guidelines for clinicians to follow when delivering a diagnosis. Research shows that the wide variation in methods can lead to poor treatment decisions and severely impact the mental health of everyone involved.



Clinicians have the opportunity to educate and empower people with a compassionate, person-centred diagnosis. 

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- Dr Bridget Regan

In this project, Dr Regan will review the extent to which doctors, neuropsychologists and allied health professionals in memory clinics follow their own guidelines around diagnosis communication and determine their effectiveness.

In conjunction with people living with dementia and their carers, Dr Regan and her team will design and pilot an intervention program that aims to improve communication and provide training in diagnosis delivery for clinicians.

The results of this project will contribute to the development of Australian best-practice guidelines for communicating a dementia diagnosis that supports and educates people, their families and clinicians.



#### How will this happen?

**Stage 1:** recruit 45 clinicians and 100 people living with dementia and their primary carers from three memory clinics. Ask all participants to provide feedback about their experience of receiving or giving a diagnosis.

**Stage 2:** conduct a workshop at each memory clinic that a) educates clinicians on key aspects of best-practice guidelines, and b) provides feedback on diagnosis delivery from patients and carers.

**Stage 3:** a further 100 people with dementia and carers to provide feedback on their experience of diagnosis communication in the period after the clinicians have received the workshop. Clinicians to rate the impact of the workshop on their practice.



## What will this mean for people with dementia?

- Receiving a diagnosis that is compassionate and tailored to their individual needs.
- Advice on where to access dementia education information.



## What will this mean for clinicians?

- Official guidelines on how to deliver a person-centred diagnosis.
- The confidence to communicate a diagnosis that offers hope to people and their families.
- Training and education on the nuances of delivering a diagnosis that supports and educates people.



#### Who's undertaking the research?

Dr Bridget Regan, La Trobe University

Dr Regan is a clinical and research neuropsychologist who focuses on maximising cognitive function, wellbeing and quality of life for people with mild cognitive impairment and dementia.

She has a PhD in cognitive rehabilitation in mild cognitive impairment from La Trobe University and a Doctor of Psychology in clinical neuropsychology

from Melbourne University.

For over 20 years, Dr Regan has worked in public health across a range of settings, including medicolegal, head injury rehabilitation, neurology, aged mental health, and schools. She is the director of Neuroinsight, a clinical neuropsychology practice in Melbourne; senior clinical neuropsychologist at the Eastern Health Cognitive, Dementia and Memory Service; and a senior research fellow at La Trobe University. Dr Regan also has a strong research background with a track record of grants and publications.

The title of Dr Regan's project is *Improving the communication of dementia diagnoses – a pilot study.*