

Plain Language Statement

Department of Psychiatry
Faculty of Medicine, Dentistry and Health Sciences
This project has full ethics approval from the University of Melbourne (ID #28451)



Project: Young-onset dementia: pathways to care, gaps, barriers and positives (survey)

Project Supervisor: Associate Professor Samantha Loi
Tel: +61 3 9342 8750 Email: samantha.loi@unimelb.edu.au

Additional Researchers:

Dr Monica Cations	Email: monica.cations@flinders.edu.au
Dr Clare Beard	Email: clare.beard@flinders.edu.au
Dr Priscilla Tjokrowijoto	Email: priscilla.tjokrowijoto@mh.org.au
A/Prof Jade Cartwright	Email: jade.cartwright@utas.edu.au
A/Prof Adrienne Withall	Email: a.withall@unsw.edu.au
Dr Nathan D'Cunha	Email: nathan.d'cunha@canberra.edu.au
Ms Naomi Moylan	Email: naomi.moylan@brightwatergroup.com
Mrs Debbie Stange	Email: debbie.stange@wesleycollege.edu.au

Introduction

Thank you for your interest in participating in this research project. The following few pages will provide you with further information about the project, so that you can decide if you would like to take part in this research.

Please take the time to read this information carefully. You may ask questions about anything you don't understand or want to know more about.

Your participation is voluntary. If you don't wish to take part, you don't have to. If you begin participating, you can also stop at any time.

What is this research about?

Young-onset dementia (YOD) is a type of dementia that starts before the age of 65, affecting around 5-10% of all dementia cases. In Australia, about 28,000 people are estimated to have YOD. While less common than dementia in older adults, those with YOD often face delays in diagnosis and struggle to access appropriate support services. Managing the cognitive, behavioural, and functional changes that come with YOD requires high-quality, evidence-based services, which are currently fragmented and unequal in Australia.

People with YOD, often diagnosed in middle age, also deal with the psychosocial impact of dementia, including challenges related to employment, driving, finances, and changes

in relationships and identity. Post-diagnosis concerns include accommodation options, leisure activities, family dynamics, and advance care planning. Managing YOD effectively requires a holistic family approach.

Navigating the journey from pre-diagnosis to post-diagnostic care for YOD is challenging, with different services and supports available in each State and Territory in Australia. There's a lack of clear guidelines and accessible knowledge regarding the services needed at different stages of YOD, and many existing services are designed for older adults, not being age-appropriate for those with YOD.

Accessing the range of services for YOD is complicated, with care falling at the intersection of health, disability, and aged sectors. People with YOD often experience long waits for diagnosis and support, are offered services that aren't suitable for their age, and may fall through the gaps in these services. The project aims to identify these gaps and barriers, advocating for flexible, individualised, affordable services that provide meaningful engagement for individuals with YOD.

What will I be asked to do?

Should you agree to participate, this part of the research will involve completion of a questionnaire that will take you 20-30 minutes to complete. You will be able to take a break and return to the questionnaire if you like. This questionnaire will ask you about your experiences along pathways of care for young-onset dementia – from the perspectives of a person with young-onset dementia, a family/friend caregiver, a clinician who works with people with young-onset dementia, or a healthcare provider.

You can also leave your name and contact details if you would like to participate in a focus group so that you can provide further information about your experiences with young-onset dementia. Please note that these identifying contact details will be removed from the questionnaire results so that we will not be able to identify your responses.

What are the possible benefits?

We cannot guarantee or promise that you will receive direct benefits from this research. However, results from this study will improve our understanding of pathways to care for people living with young-onset dementia, and inform what can be done to facilitate timely diagnosis and management of functional changes, support the psychosocial impacts of YOD, and remove barriers to accessing appropriate services. Ultimately, the findings may contribute to shaping policies and guidelines that enhance the overall quality of life of individuals with young-onset dementia and their families. Additionally, upon completing the survey, you will have the opportunity to enter a draw to win one of five \$100 gift vouchers.

What are the possible risks?

Some participants may experience inconvenience or distress when answering questions about their experience. Please let the researcher know if you are experiencing distress as a result of your participation in the project, and they will be able to arrange appropriate counselling or support services. You can also ask to discontinue the questions or withdraw from the project at any time.

If you wish to contact services that are not affiliated with anyone from the research team, the organisations listed below are available to you in case you experience distress. You may also wish to contact your general practitioner for support.

Lifeline: 13 11 14

BeyondBlue: 1300 22 4636

Dementia Helpline: 1800 100 500

Do I have to take part?

No. Participation is completely voluntary. You may want to complete just the questionnaire or be involved in just the focus groups, or you may want to do both. You are able to withdraw at any time. If you decide to leave the project, the researchers will keep the information about you that has been collected so far, in de-identified format.

Will I hear about the results of this project?

The results of the project will be disseminated via websites, social media and public presentations. They will also be published in scholarly journals. If you would like to receive a summary of these findings, please contact the researchers.

What will happen to information about me?

Any information obtained in this research will remain confidential. It will only be disclosed with your permission, if failure to disclose suggests imminent risk to you or others, or as required by law. To maintain confidentiality, a unique identification number (ID) will be assigned, which will be used to label all forms and recordings. Contact details obtained from the survey will be kept separate from the study data. Raw data including focus group recordings will be accessible to only the researchers of this project. Your data will be kept for five years as per the University of Melbourne's regulations, then all electronic data will be permanently deleted. It will only be used for this project and data will be de-identified and kept in a database.

The researchers plan to present the results of this research at conferences and in peer-reviewed publications; however, any data presented will be in de-identified format. This means that any presentation or publication will report information in such a way that you cannot be identified.

Is there any potential conflict of interest?

Some of the researchers listed may also provide treatment to potential participants of the research project. Whether or not the potential participants decide to participate is entirely voluntary and will not affect the treatment they are receiving from the clinician

researchers. This potential conflict will be managed by the de-identification and anonymity of the questionnaires and removal of contact details if present. Researchers who do not provide treatment to potential participants will be responsible for contacting those who have left their contact details on the questionnaires to review interest in participating in focus groups. For focus groups, it will be ensured that if there are any participants whom the researchers also provide treatment for (whether it is the person with young-onset dementia and/or their family/friend caregiver), this researcher will not be present.

Who is funding this project?

The project is funded by the Department of Social Services (\$258000).

Where can I get further information?

If you would like more information about the project, please contact the researchers: Associate Professor Samantha Loi, Drs Clare Beard and Priscilla Tjokrowijoto.

Who can I contact if I have any concerns about the project?

This project has human research ethics approval from The University of Melbourne (ID #28541). If you have any concerns or complaints about the conduct of this research project, which you do not wish to discuss with the research team, you should contact the Research Integrity Administrator, Office of Research Ethics and Integrity, University of Melbourne, VIC 3010. Tel: +61 3 8344 1376 or Email: research-integrity@unimelb.edu.au. All complaints will be treated confidentially. In any correspondence please provide the name of the research team and/or the name or ethics ID #28541 of the research project.