

**Voluntary Assisted Dying (VAD) and Dementia in Australia: An Exploratory Study****Research team**

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**What is the purpose of the research?**

This research aims to:

- further the evidence base on voluntary assisted dying (VAD) for people living with dementia;
- ascertain stakeholders' views about VAD and dementia; and
- identify and evaluate possible laws that could allow people living with dementia to access VAD.

**Are you looking for people like me?**

You are eligible to take part in this research if you:

- have been diagnosed with a form of dementia; or
- you are currently an unpaid carer for a person living with dementia (or previously have been); and
- cohabit with them or care for them for approximately four hours per week (or previously have done so).

**What will you ask me to do?**

Your participation will involve taking part in a joint interview (comprising a person living with dementia and their loved one) lasting approximately 30 minutes via Zoom.

In the case that you are a carer of a person living with dementia, who can no longer make decisions for themselves and communicate (or is now deceased), you will be required to participate in the interview individually.

During the interview, we will seek to understand your views about permitting VAD for people living with dementia, and your thoughts on a potential law that would allow this to occur safely. This interview will be recorded, and a transcript will be generated. We will invite you to review your transcript and offer you the opportunity to edit the transcript should you wish to do so.

If you are unfamiliar with Zoom, one of the researchers can provide you with information about how to use the platform and set aside time to provide you a tutorial if need be.

**Are there any risks for me in taking part?**

There are some risks of participating in this research project. You could potentially experience distress or discomfort due to the subject matter. If you do experience distress or discomfort during the interview you will be free to skip any questions, pause the interview or end the interview without any explanation. There are also several support services detailed in the participant information statement that we will provide you with, which you are free to contact if this occurs.

To protect potential participants, we will only interview participants if they are able to make informed decisions and communicate with us. We understand that in the case of dementia a person's ability to communicate may change over the course of the study. In the case of joint interviews, if the researchers detect this or the person's carer indicates this is the case, the person will no longer be able to participate in the study.

If you agree to participate, you can withdraw from participation in the research project or withdraw your data at any time prior to analysis without comment or penalty.

***Are there any benefits for me in taking part?***

This research may benefit you by giving you an opportunity to reflect on your experiences of living with dementia (or supporting someone living with dementia) and express your views about whether people living with dementia should have access to VAD. We will also seek your views on what you think are some of the key features and considerations of a potential law which would permit this to occur safely. We will use your views, along with others, to inform recommendations about a possible legislative framework which will provide a basis for future Australian law reform deliberations. Decisions about any future reform stemming from such recommendations, however, ultimately rest with others.

***Will I be compensated for my time?***

No, but we would very much appreciate your participation in this research.

***Who is funding this research?***

The research project is funded by the Clem Jones Foundation. The Clem Jones Foundation funds this project as part of its mission to support evidence-based law and policy deliberations about end-of-life care, including VAD. The Foundation does not have any involvement in the research beyond providing the funding. The funder does not have any input into the research design, or access to the data obtained during the research project, or a role in analysis and interpretation of the data or publication decisions.

***I am interested – what should I do next?***

If you are interested in participating in this study, please contact:

**Casey Haining**

**casey.haining@qut.edu.au**

You will be provided with further information to ensure that your decision and consent to participate is fully informed.

***Thank You!***

**QUT Ethics Approval Number: 9354**