

Title: Carer's Perception of Pain and Physical Function in Dementia**Participant information sheet****Research team**

This research is being conducted by University of Tasmania researchers Mr Henok Derso, Dr Kathleen Doherty, Dr Alice Saul, Dr Julie Campbell, and Dr Jessica Roydhouse.

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1. Invitation

You are invited to participate in a study that will help us understand the experience of carers providing information about the health of the person they are caring for.

2. What is the purpose of this study?

The purpose of this PhD project is to identify ways to improve questionnaires that informal caregivers of people with dementia and multiple sclerosis might be asked to complete about the person they are providing care to. In this specific study, we are interested in exploring the experience of informal carers when answering questions about people with dementia.

3. Why have I been invited to participate?

You are eligible to take part in this study because you are:

- Currently or formerly caring for a family member or friend with dementia
- Used to care for a family member or friend with dementia.
- You are aged 18 years or older.
- You live in Australia.
- You have been asked to provide a report to a healthcare worker about the health of your family member or friend living with dementia on their behalf.

Your participation is entirely voluntary. Your decision to participate in this study will not affect your participation in the massive open online course (MOOC), the University of Tasmania, other studies, employment, or health care.

4. What will I be asked to do?

We will ask you to answer some questions about yourself and the person you are caring for. These questions will have tick boxes or other ways to select answers. We will invite you to

reflect on how you would approach questions about the quality of life and health of the person you are caring for. These questions will have boxes where you can write your answers. All questions will be online and anonymous.

5. Are there any possible benefits from participation in this study?

The study will help us understand how to improve questionnaires for people who are asked about the quality of life and health of the people they are caring for. We do not expect there to be direct benefits for people who participate in this study. However, improvements in knowledge can potentially help support organisations, decision-makers, researchers, and possibly carers of people living with dementia.

6. Are there any possible risks from participation in this study?

Other than the time required to respond to the questions, there are minimal risks associated with this project. You may experience some discomfort when thinking about how you answer questions about the health and quality of life of the person you are caring for. You will not have to answer any questions you do not want to, and you can choose to end your participation at any time.

7. What if I change my mind during or after the study?

At any time, you may decide to withdraw from the study. However, once you have completed the study, your data cannot be removed. Because all your responses are anonymous, we have no way to identify and remove your responses once you have completed the study.

8. What will happen to the data when this study is over?

All data will be kept for five years following publication in a password-protected, secure electronic database behind institutional firewalls at the University of Tasmania. Only researchers involved in this study will have access to the data.

9. How will the results of the study be published?

The results of this study might be published as a report or article or presented at a scientific conference. You will not be identifiable in any written publications or presentations. We may include quotes from the written answers you have provided. These quotes will never include identifying information.

10. What if I have questions about this study?

If you have any queries, concerns or issues with this study, please feel free to contact the principal investigator, Dr Jessica Roydhouse, by email (jessica.roydhouse@utas.edu.au) or phone (03 6226 4794).

This study has been approved by the University of Tasmania Human Research Ethics Committee (HREC). If you have concerns or complaints about the conduct of this study, you can contact the Executive Officer of the HREC at (03) 6226 6254 or email human.ethics@utas.edu.au. The Executive Officer is the person nominated to receive complaints from research participants. You will need to quote Project ID H0030059.

11. How can I agree to be involved?

If you wish to take part in the study, please proceed to the survey [here](#) . When you complete the survey, this implies consent to data use.

If you do not wish to participate, please click [here](#) .

Thank you very much for considering our invitation to participate in this research.