

CARE RECIPIENT INFORMATION SHEET

TITLE: LIFELONG CARERS: The Lived Experience Witnessed Through a Documentary

RESEARCHER AND INVESTIGATOR:

Dalanglin Dkhar
PhD Candidate
Faculty of Arts & Education
School of Social Work and Arts, Charles Sturt University

PROJECT SUPERVISORS:

Professor Eleanor Gates-Stuart (Principal)
Dr. Monica Short (Co-Supervisor)

INVITATION

You are invited to participate in a research study on carers.

The study is being conducted by Dalanglin Dkhar from the School of Social Work and Arts at Charles Sturt University.

Before you decide whether you wish to be involved in this study, it is important for you to understand why the research is being done and what it will involve. Please take the time to read the following information carefully and discuss it with others if you wish.

1. What is the purpose of this study?

Although there is a large amount of research on the carers in Australia, there is a substantial gap in truly understanding the worth of the carer in Australia presently as that data does not reach our communities.

This proposed study will fill that gap by generating new knowledge and presenting and sharing the carer's lived experience through a documentary film where we can see and hear from a carer directly. This will provide valuable opportunity to understand how a carer lives. The film will help to reach a wider audience that will include community groups, health sectors, educational settings and the carers own family and friends, thereby generating new awareness and recognition of the carer in our communities.

2. Why has my carer been invited to participate in this study?

Your carer has been identified as a prospective participant for this study.

If you, as the care recipient would not like to give consent to be part of the story of your carer in their caring journey, that will be respected and will follow as a reason for your carer to not participate in the research study.

3. What does this study involve?

If you agree , as care recipient you will-

- Allow your carer to share the story of their caring journey
- Allow access to photographs of you and your carer
- Be invited along with your carer, to give feedback on the film at the rough cut and final cut stage of the film's edit

4. Are there risks and benefits to my information being included in this study?

There are no risks for my information being included in this study.

Benefits that can arise from my information being included in this research study are-

- Each care recipient will have editing rights to the film by giving feedback on the documentary twice during its editing at the rough cut and fine cut stage.
- Each care recipient can screen the documentary anywhere they would like.

5. How is this study being paid for?

It will most probably form a combination of-

- personal costs by the researcher
- scholarship

6. Will this study (or travelling to) cost me anything, and will I be paid?

As a care recipient, you will need to travel with your carer to watch the rough cut and fine cut of the film and your travel needs for these visits will be reimbursed if you are travelling from outside of the ACT.

7. What if I don't want my information included in this study?

Everyone's involvement in this research is entirely voluntarily. Whether or not you decide to have your information included, is your decision and will not disadvantage you. You can withdraw your information from the project at any time *before the filming of the interview* of your carer without giving a reason. You also have the option of withdrawing any data, which identifies you.

8. What if I want to withdraw my information later?

You may withdraw your information from the project at any time *before the filming of the interview* without giving a reason and have the option of withdrawing any data, which identifies you at any time until the research is finalised.

10. How will my confidentiality be protected?

All information collected by the researcher which identifies you will be stored securely and only accessed by the researcher and for the film footage, the editor.

Data will be retained for at least 5 years at Charles Sturt University after the project is completed. If data are identifiable, any information which might identify participants will not be disclosed without your prior consent.

11. What will happen to the information that I give you?

There will be no collection of any information or data from you as care recipient.

The information gathered from your carer will be analysed and become data that will be reported or presented in the following ways-

- as a documentary film for public consumption (tv, online)
- in a thesis to be submitted as part of the Researcher's doctoral degree

- as data for a paper in scientific journals

12. What should I do if I want to discuss this study further before I decide?

If you would like further information, please contact the researcher Dalanglin Dkhar at 0426 872 830 or dalangdk@yahoo.com.

13. Who should I contact if I have concerns about the conduct of this study?

Charles Sturt University's Human Research Ethics Committee has approved this project.

If you have any complaints or reservations about the ethical conduct of this project, you may contact the HREC Secretary on (02) 6933 4213 or ethics@csu.edu.au. Any issues you raise will be treated in confidence and investigated fully, and you will be informed of the outcome.

Thank you for considering this invitation.
This information sheet is for you to keep.