

## **PARTICIPANT INFORMATION SHEET**

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

### **RESEARCHER AND INVESTIGATOR:**

Dalanglin Dkhar  
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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 participate 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 have I been invited to participate in this study?**

As a carer for your loved one, you have been identified as a prospective participant for this study. We are seeking carers who have been in the caring role since the diagnosis of the person you care for, and who continue in this role indefinitely. Your name was selected from the database of Carers ACT based on the profile of your caring duties.

If the person you care for does not give consent to exposure in the filming process or through any form of data (photographs) that will be respected and will follow as a reason for the carer to be unable to participate in the research study.

### 3. What does this study involve?

If you agree to participate, you will be -

- Be willing to be interviewed on film for a product for public consumption
- Articulate and expressive
- Consenting for your face and voice to be used for the purpose of the film
- Allowing to be filmed at a safe venue for all involved which is nominated by you and which accommodates your caring needs.
- Allow access to your daily living experiences by recording yourself on the phone (minimum twice weekly)
- Allow access to photographs of your choice that tell of your caring journey
- Asked to verify the transcripts of all the interviews recorded as true
- Asked 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 me in taking part in this study?

Risks that can arise from being a participant in this research study are-

As a researcher, I understand that the interviews will delve into disclosure of information of a more personal nature and can be a cause of discomfort or distress for you as the participant. As a carer myself, I am highly aware of the challenges and responsibilities of being a carer and will exert my utmost consideration in minimising risks for the participants in the way I conduct the research process- from giving you a guide to the questions I will ask, to filming at a time and day of your choice.

If there is any risk of discomfort or distress during your participation in the study, I will be able to refer you to carer specialized counselling and support offered specifically by my industry partner Carers ACT for all the participants in this study. Carers ACT have offered to support the participants of this study, if the need arises, with Carer Specialized counselling.

If you cannot participate in the study, your relationship with the organization Carers ACT will not be affected in anyway.

Benefits that can arise from being a participant in this research study are-

- There will be an honorarium of \$300 each to thank the participants that will be paid upfront.
- Each participant with their 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 participant and their 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 taking part in this study (or travelling to) cost me anything, and will I be paid?

As a participant, you will not need to travel for the filming as the location will be at your place of choice.

You and your care recipient are invited 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. **Fuel cost**

will be reimbursed at 78c/km. If overnight accommodation is necessary, you will be provided with a room in a centrally located accessible accommodation.

7. What if I do not want to take part in this study?

Participation in this research is entirely voluntarily. Whether or not you decide to participate, is your decision and will not disadvantage you. If you do decide to participate, (which by connection to you, means your care recipient also gives consent) you and your care recipient may also withdraw 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.

8. What if I participate and want to withdraw later?

You or your care recipient may withdraw 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.

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?

All your interviews after they are filmed, will be transcribed and will be sent back to you to check for verification.

The information 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](mailto: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](mailto: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.