Choice to stay at home and end of life care for people with dementia and their caregivers in the community

PARTICIPANT INFORMATION STATEMENT

(1) What is this study about?

You are invited to take part in a research study that explores the issues and challenges of providing end of life care for people with dementia. We are seeking to better understand the perspectives of family carers (including relatives, friends, neighbours or significant others) concerning the care of their relative or friend with dementia during the final stages of their life. To date, little attention has been given, to the needs and wishes of individuals with dementia in relation to their end of life care, or to the perspectives of family members who are providing the day-to-day care. A need exists therefore, to better understand the processes involved in providing end of life care for people with dementia living at home in order to develop appropriate models of end of life care for this population group, address the knowledge gap and promote access to appropriate care services and resources.

You have been invited to participate in this study because you have experienced the death of a family member with dementia in the previous two years. The person may either have lived at home with your care and support and died at home or they may have been transferred to a hospital/nursing home/hospice for end of life care and consequently died in that facility.

This Participant Information Statement tells you about the research study. Knowing what is involved will help you decide if you want to take part in the research. Please read this sheet carefully and ask questions about anything that you don’t understand or want to know more about. Participation in this research study is voluntary. So it’s up to you whether you wish to take part or not.

By giving your consent to take part in this study you are telling us that you:

✔ Understand what you have read
✔ Agree to take part in the research study as outlined below
✔ Agree to the use of your personal information as described.

You will be given a copy of this Participant Information Statement to keep.

(2) Who is running the study?
Funded by the Collaborative Research Network (CRN), the study is being carried out by the following researchers:

- Professor Yun-Hee Jeon, Sydney Nursing School, University of Sydney
- Associate Professor Heather McKenzie, Sydney Nursing School, University of Sydney
- Associate Professor James Gillespie, School of Public Health, University of Sydney
- Dr Alexandra Young, Sydney Nursing School, University of Sydney
- Professor Iain Graham, School for Health and Human Science, Southern Cross University
- Ms Alaina Evanson, School for Health and Human Science, Southern Cross University.

(3) What will the study involve for me?

Participating in this study involves completing an anonymous online survey. You will be asked questions in relation to your experiences of caring for your relative or friend with dementia during the final stages of their life. If your relative or friend with dementia was living at home or was transferred to a hospital, nursing home or hospice at the end of their life, we are keen to understand your thoughts and experiences of the process.

(4) How much of my time will the study take?

We anticipate that completion of the survey will take approximately 30 minutes.

(5) Who can take part in the study?

You are invited to take part in this study if you have cared for a relative or friend with dementia who died in the previous two years (since Jan 2013). You are invited to participate if you have had a relative with dementia who died at home, was transferred to a hospital, nursing home or hospice at the end of their life.

(6) Do I have to be in the study? Can I withdraw from the study once I've started?

Being in this study is completely voluntary and you do not have to take part. Your decision whether to participate will not affect your current or future relationship with the researchers or anyone else at the University of Sydney or any consumer organisation you may belong to (e.g., Alzheimer’s Australia and Carer’s Australia).

Submitting your completed questionnaire is an indication of your consent to participate in the study. You can withdraw your responses any time before you have submitted the questionnaire (pressing the submit button). Once you have submitted the questionnaire, your responses cannot be withdrawn because they are anonymous and therefore we will not be able to tell which completed questionnaire is yours.

(7) Are there any risks or costs associated with being in the study?

After answering the questionnaire you may wish to speak to someone about the issues raised. At the end of the questionnaire you will be provided with a list of resources and services you could consult, should you wish to talk further about your experiences.

(8) Are there any benefits associated with being in the study?

We cannot guarantee or promise that you will receive any direct benefits from being in the study. The results of the study will however, contribute to a better understanding of the experiences of families and friends providing support to people with dementia living at home in the community. The study has the potential to influence policy directions and services in relation to caring for people with dementia at the end of their lives.
(9) **What will happen to information about me that is collected during the study?**

By providing your consent, you are agreeing to us collecting personal information about you for the purposes of this research study. Your information will only be used for the purposes outlined in this Participant Information Statement. Your information will be stored securely and your identity/information will be kept strictly confidential, except as required by law. Study findings may be published, but you will not be individually identifiable in these publications.

(10) **Can I tell other people about the study?**

Yes, you are welcome to tell other people about the study.

(11) **What if I would like further information about the study?**

When you have read this information, Professor Yun-Hee Jeon will be available to discuss it with you further and answer any questions you may have. If you would like to know more at any stage during the study, please feel free to contact Professor Yun-Hee Jeon via email yun-hee.jeon@sydney.edu.au or telephone (02) 9351 0674, Associate Professor Heather McKenzie via email h.mckenzie@sydney.edu.au or telephone 02 9351 0546 or Dr Alexandra Young via email alexandra.young@sydney.edu.au or telephone 9114 4084.

(12) **Will I be told the results of the study?**

You have a right to receive feedback about the overall results of this study. Feedback from the online questionnaire will be in the form of a one page lay summary which will be available from the Chief Investigators upon your request. We also plan to make this short summary of the study publicly available through a number of relevant organisation websites including Alzheimer’s Australia and Carers Australia. You will receive this feedback after the study is finished.

(13) **What if I have a complaint or any concerns about the study?**

Research involving humans in Australia is reviewed by an independent group of people called a Human Research Ethics Committee (HREC). The ethical aspects of this study have been approved by the HREC of the University of Sydney [2015/144] As part of this process, we have agreed to carry out the study according to the National Statement on Ethical Conduct in Human Research (2007). This statement has been developed to protect people who agree to take part in research studies.

If you are concerned about the way this study is being conducted or you wish to make a complaint to someone independent from the study, please contact the university using the details outlined below. Please quote the study title and protocol number.

The Manager, Ethics Administration, University of Sydney:

- **Telephone:** +61 2 8627 8176
- **Email:** ro.humanethics@sydney.edu.au
- **Fax:** +61 2 8627 8177 (Facsimile)

If you consent to participate in the study, please click https://surveys.sydney.edu.au/surveys/?s=KbG8MkxU7o