RESEARCH TEAM
Principal Researcher: Dr Elaine Fielding, Research Fellow
Associate Researcher: Dr Maria O’Reilly, Research Fellow
Professor Elizabeth Beattie
Dementia Collaborative Research Centre (DCRC), School of Nursing, Faculty of Health
Queensland University of Technology (QUT)

DESCRIPTION

This project is being undertaken by the Dementia Collaborative Research Centre: Carers and Consumers (DCRC:CC), QUT.

The purpose of this project is to develop a better understanding of the period when people with dementia transition into permanent residential care, from the family carers’ point of view.

You are invited to participate in this project because you are a family carer of a person with dementia who has recently been admitted into permanent residential care or who is on the waiting list for admission.

PARTICIPATION

Your participation will involve responding to a questionnaire, either via telephone interview or online survey, at the beginning and again in one month’s time. The first questionnaire will take up to 25 minutes to complete online or up to 40 minutes by phone. The second questionnaire will be shorter and will take up to 15 minutes online and up to 25 minutes by phone.

We will ask you some questions about your experiences of the transition of your family member into residential care, both before and after placement. We will also ask you some questions about yourself, how you are feeling and how difficult or stressful you have found the transition.

If you participate by phone, you will be asked whether you agree for our conversation to be tape recorded so we can accurately record your answers. Tapes will be kept only as long as necessary to transcribe their contents into a computer file.

Your participation in this project is entirely voluntary. If you do agree to participate, you can withdraw from the project at any time without comment or penalty. Any identifiable information already obtained from you will be destroyed. However, once the second questionnaire has been submitted all data will become non-identifiable, therefore it will not be possible to withdraw that data. Your decision to participate, or not participate, will in no way impact upon your current or future relationship with QUT or the aged care facility where your relative is on the waiting list or has been admitted for care. While completing the survey you do not have to respond to any question(s) that you are uncomfortable answering.

EXPECTED BENEFITS

This project may provide no direct benefit to you, but it is expected to benefit the wider community of carers of people with dementia by helping improve the transition into residential care in the future.

RISKS

You may experience mental fatigue whilst completing the questionnaire or interview. Some of the questions asked might also contribute to emotional distress. You are encouraged to take breaks when completing the survey if you are tiring, and you may stop the survey at any time.

QUT provides for limited free psychology, family therapy or counselling services for research participants of QUT projects who may experience discomfort or distress as a result of their participation in the research. Should you wish to access this service please contact the Clinic Receptionist of the QUT Psychology and Counselling Clinic on 07 3138 0999. Please indicate to the receptionist that you are a research participant.
You may also contact the **National Carer Counselling Program** on **1800 242 636**, or the **National Dementia Helpline** on **1800 100 500** for private and confidential counselling and information about caring for someone with dementia.

**PRIVACY AND CONFIDENTIALITY**

All comments and responses are anonymous and will be treated confidentially. The names of individual persons will not be connected to the data. However, on the first questionnaire, you will be asked to provide contact details (email or phone number) for the follow up survey. These will be destroyed at the conclusion of the study and all your responses de-identified with only a code identifying each person participating in the study. The only people who will know that you are participating in the research project are direct members of the research team. No identifying information about facilities or individuals will be included in any reports or publications produced by the project.

Any data collected as part of this project will be stored securely as per QUT’s Management of research data policy. Please note that non-identifiable data collected in this project may be used as comparative data in future projects.

**CONSENT TO PARTICIPATE**

If you participate by phone, you will be asked for verbal consent to participate in this project.
If you participate online, submitting the completed survey is accepted as an indication of your consent to participate in this project.

**QUESTIONS / FURTHER INFORMATION ABOUT THE PROJECT**

If you have any questions or require further information please contact one of the research team members below.

Dr Elaine Fielding  
elaine.fielding@qut.edu.au  
Dr Maria O’Reilly  
m2.oreilly@qut.edu.au  
Mr Mitchell McMaster  
07 3138 3852

**CONCERNS / COMPLAINTS REGARDING THE CONDUCT OF THE PROJECT**

QUT is committed to research integrity and the ethical conduct of research projects. However, if you do have any concerns or complaints about the ethical conduct of the project you may contact the QUT Research Ethics Unit on 07 3138 5123 or email ethicscontact@qut.edu.au. The QUT Research Ethics Unit is not connected with the research project and can facilitate a resolution to your concern in an impartial manner.

*Thank you for helping with this research project. Please keep this sheet for your information.*