Supporting Spouses of Residents with Dementia

QUT Ethics Approval Number 1800000273

RESEARCH TEAM
Principal Researcher: Mrs Deborah Brooks PhD student
Associate Researchers: Professor Elizabeth Beattie Principal Supervisor
Professor Helen Edwards Associate Supervisor
Dr Elaine Fielding Associate Supervisor
Faculty of Health, Queensland University of Technology (QUT)

DESCRIPTION
This project is being undertaken as part of a PhD study for Deborah Brooks, and is supported by a Dementia Australia (formerly known as Alzheimer’s Australia) and Dementia Centre for Research Collaboration Consumer Priority PhD scholarship.

You are invited to participate in this project because you are an English-speaking husband/wife/partner providing support or assistance to a person with dementia who has moved into residential care.

The purpose of this project is to test the effectiveness of a new support program designed to improve the psychological and emotional health of spouses and partners of people with dementia who have moved into permanent residential care. If you agree to participate, we would like you to complete a series of questionnaires via interview on two separate occasions. You will also be randomly allocated, based on the care facility where your partner resides, to receive either a telephone support program (consisting of six telephone calls of one hour’s duration over 12 weeks) or a written information pack about coping with placement, managing feelings, working in partnership with residential care staff, and details of support services.

PARTICIPATION
Your participation will involve completing a series of questionnaires via two interviews; the first interview will be following recruitment to the study and the second after 4-6 months. Interviews will take place by telephone. The interviewer will read out the questions to you and write down your answers. Each interview will take approximately one hour of your time. To help make things easier for you, you will be sent a copy of these questionnaires in advance of the interview by post and/or by email. These interviews will not be audio-recorded.

The first questionnaire will ask you to give information about yourself and your partner with dementia who has moved into residential care. This questionnaire will only be completed during the first interview.
During both the first and second interviews, the interviewer will ask you questions from six questionnaires about feelings that you might be experiencing related to stress (10 questions), guilt (22 questions), depression (20 questions), and grief (11 questions), your quality of life as a carer (40 questions), and satisfaction with the care being provided to your partner (28 questions). You will be asked to answer on a four or five point scale (for example, never; almost never; sometimes; fairly often; very often). You do not have to answer any questions you are uncomfortable with.

The questionnaires will include questions and responses such as:

- In the last month, how often have you found that you could not cope with all the things that you had to do? Never; almost never; sometimes; fairly often; very often
- In the last week, how often have you had trouble keeping your mind on what you were doing? Rarely; some of the time; occasionally; most of the time
- Do you feel able to get the help and information you need? Never; some of the time; a lot of the time; always.

After the first interview is completed you will be randomly assigned (for example like the flip of a coin) into one of two groups; either a group that receives the telephone support program (called the Residential Care Transitions Module) or a comparison group that will receive a written information pack.

If you are assigned to receive the telephone support program, you will be asked to participate in six telephone support sessions, over 12 weeks. These will be delivered by a trained counsellor and will focus on your emotions and stress concerning your partner’s admission into residential care, education about dementia and the residential care environment, discussion of communications skills with residential care staff, and processing the impact of any feelings of guilt, loss and grief. Each session will be tailored to your needs and last approximately one hour. Telephone support sessions may be audio-recorded with your consent, for quality control purposes only.

If you are assigned to receive the written information pack, you will be given printed material about caring partnerships with residential care staff, carer well-being and coping with placement, and available support services.

Your participation in this project is entirely voluntary. If you do agree to participate you can withdraw from the project without comment or penalty. You can withdraw anytime during the project. If you withdraw data obtained from you will be withdrawn on request. Your decision to participate or not participate should in no way impact upon your current or future relationship with QUT or the residential care facility where your partner lives.

EXPECTED BENEFITS

This project may benefit you directly as you may find it helpful to receive telephone or printed support resources. This project may also benefit spouses and partners of residents with dementia in the future by providing appropriate support.
RISKS
There are some risks associated with your participation on this project. We are aware that some of the questions asked might contribute to emotional distress. If you experience any anxiety or distress during any contact with the study researchers or counsellors, and/or you are in need of continued emotional support at the end of the study, we will provide you with details of appropriate counselling and support services. You may also experience mental fatigue whilst completing the interviews. You are encouraged to take breaks if you are tiring, and you may stop the interview at any time. We will post or email questionnaires in advance of the interview to help prepare you. You do not have to answer any questions you are uncomfortable with.

QUT provides for limited free psychology, family therapy or counselling services (face-to-face only) 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 call the Clinic Receptionist on 07 3138 0999 (Monday–Friday only 9am–5pm), QUT Psychology and Counselling Clinic, 44 Musk Avenue, Kelvin Grove, and indicate that you are a research participant.

Alternatively, Lifeline provides access to online, phone or face-to-face support, call 13 11 14 for 24-hour telephone crisis support.

PRIVACY AND CONFIDENTIALITY
If you are allocated to the telephone support group information discussed with and recorded by the study counsellor (Psychologist) will be kept confidential within this research project with limited exceptions. Exceptions include disclosure of information to relevant persons or authorities, if there is the potential of serious physical danger to self or someone else, risk of child or elder abuse, or information legitimately subpoenaed by a court or otherwise authorised for release by law (psychological records have no special legal privilege). You will also be asked to provide details of your GP and next of kin for referral or support purposes only.

All interview comments and questionnaire responses will be treated confidentially unless required by law. The answers you give will be de-identified and coded for use in the study. Data will be retained for analysis, and for 15 years following completion of the project. The file linking ID numbers and codes will be destroyed at the end of the project period and once the need to locate data for removal in the case of withdrawal has passed.

As the project may involve an audio recording of telephone support program sessions for quality assurance purposes:

- The recording will be destroyed 5 years after the last publication.
- The recording will not be used for any other purpose.
- Only the named researchers will have access to the recording.
- It is possible to participate in the project without being recorded.

Any data collected as part of this project will be stored securely as per QUT’s Management of research data policy.
Only the project research staff will have access to this information.

The project is funded by a PhD scholarship from Dementia Australia (formerly Alzheimer’s Australia) and the Dementia Centre for Research Collaboration, QUT. They will not have access to the data obtained during the project.

No identifying information about facilities or individuals will be included in any reports or publications produced by the project.

CONSENT TO PARTICIPATE
We would like to ask you to sign a written consent form to confirm your agreement to participate. Please discuss your participation with family, friends or professionals such as your GP, before signing the consent form. You are also encouraged to discuss your participation with the research team before signing the consent form.

QUESTIONS / FURTHER INFORMATION ABOUT THE PROJECT
If you have any questions or require further information, please contact one of the listed researchers:

Deborah Brooks  deborah.brooks@qut.edu.au  07 3138 3882
Elizabeth Beattie  elizabeth.beattie@qut.edu.au  07 3138 3389
Helen Edwards  h.edwards@qut.edu.au  07 3138 4523
Elaine Fielding  elaine.fielding@qut.edu.au  07 3138 5772

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 Advisory Team on 07 3138 5123 or email humanethics@qut.edu.au. The QUT Research Ethics Advisory Team 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.