

PARTICIPANT INFORMATION FOR QUT RESEARCH PROJECT

- Online Survey: Family Carers -

What is "A Good Day Out"? Working towards optimal day centre respite care and ways to measure it.

QUT Ethics Approval Number 1600000561

RESEARCH TEAM

Principal Researcher: Dr Elaine Fielding Senior Research Fellow, School of Nursing

Queensland University of Technology (QUT)

Associate Researchers: Professor Elizabeth Beattie Professor, QUT

Professor Richard Fleming University of Wollongong Associate Professor Belinda University of Wollongong

Goodenough

Dr Margaret MacAndrew Lecturer, QUT

Associate Professor Christine Neville

Dr Maria O'Reilly

Associate Professor Christine Stirling

University of Queensland

Research Fellow, QUT

University of Tasmania

Ms Kasia Bolsewicz Senior Research Assistant, QUT Ms Catherine Wyles Senior Research Assistant, QUT

DESCRIPTION

The purpose of this project is to understand from multiple perspectives (i.e. managers, staff and family carers), whether Australian day centre respite care is optimal and dementia-friendly. The project also hopes to identify the perceived gaps and concerns of these groups.

You are invited to participate in this project because you are a family carer of a person with dementia living in the community (that is, not in a residential aged care facility).

PARTICIPATION

Participation will involve completing an anonymous online survey that will take approximately 15-20 minutes of your time.

You will be asked about how well you think centre-based day respite responds to dementia-specific issues. You will also be asked about your satisfaction with the centre and any suggestions you have for improvement.

Examples of questions include:

- How satisfied are you overall with the day centre respite your family member attends/attended?
- 2. How well do you believe that this centre responds to the dementia-specific needs of your family member?
- 3. How do you find that the staff at the centre are with people with dementia?
- 4. Do you have any recommendations for this centre, or for day respite providers in general, about caring for people with dementia?

Your participation in this project is entirely voluntary. If you agree to participate you do not have to complete any question(s) you are uncomfortable answering. Your decision to participate or not participate will in no way impact upon your current or future relationship with QUT or any organisation you use for respite care.

EXPECTED BENEFITS

It is expected that this project will not benefit you directly. However, it may improve the provision of day care respite services to people with dementia, so the information you provide may benefit other people like yourself in the future.

RISKS

You may experience discomfort whilst completing the interview. Some of the questions asked might contribute to emotional distress. You are encouraged to take breaks during the survey if you need to and you may discontinue the survey at any time.

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.

You may also contact the **National Dementia Helpline** (Alzheimer's Australia) on **1800 100 500** (Monday–Friday only 9am–5pm) for private and confidential counselling and information about dementia.

PRIVACY AND CONFIDENTIALITY

All comments and responses will be treated confidentially unless required by law. The names of individual persons are not required in any of the responses.

Any data collected as part of this project will be stored securely as per QUT's Management of research data policy.

This project is funded by the Dementia Collaborative Research Centre: Carers and Consumers (DCRC: CC) as part of the Commonwealth's Dementia Initiative. Neither the DCRC: CC or the government will have access to the individual data obtained during the project.

Please note that non-identifiable data collected in this project may be used as comparative data in future projects or stored on open access database for secondary analysis.

CONSENT TO PARTICIPATE

Submitting the completed online survey is accepted as an indication of your consent to participate.

QUESTIONS / FURTHER INFORMATION ABOUT THE PROJECT

If you have any questions or require further information please contact one of the researchers listed below.

Elaine Fielding 07 3138 5772 elaine.fielding@qut.edu.au Elizabeth Beattie 07 3138 3847 elizabeth.beattie@qut.edu.au

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 ethicscontact@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.