

## ReThink Respite Online

### Participant Information Sheet – Education and support program

**Researchers:** Dr Liz Cridland, Dr Lyn Phillipson, and Dr Trevor Crowe.

**This is an invitation to participate in an online education and support program for carers of people with dementia.**

#### What is the purpose of the project?

Researchers at the University of Wollongong (UOW) are conducting an online education and support program for carers of people with dementia which aims to improve carers' knowledge about, attitude towards, and use of respite services and strategies. The research aims to establish what components are important to produce an effective an online education and support program.

#### Who can participate?

Eligible participants for the program include people that:

- Identify as a carer of a person with a formal diagnosis of a dementia-related condition
- Live in QLD, NSW, ACT, TAS, SA, or NT
- Have an interest in learning more about respite services and strategies
- Have basic internet experience (e.g., have an email address)
- Have access to the internet

#### What is involved?

Participating in the online educational program will involve:

- Completing a 20 minute online survey about supporting someone with dementia (Example questions: 'How certain are you right now that you can handle any problems that might come up in the future with your family member/friend's care', 'To what extent to you believe respite services are useful and beneficial to you as a carer')
- Completing up to 8 x 60 minute online sessions each week at a time convenient for you.
- Goal setting and motivation building activities, as well as information about respite services and strategies.
- Where possible, working towards your personal goal/s in your own time. This may involve researching respite services, practising strategies covered in the sessions, and having discussions about respite with their family/friends.
- Your program may also include coaching and peer support.
- Completing a 20 minute online follow-up survey and providing project feedback.

### **What are the benefits in participating?**

Potential benefits of being involved in the study include:

- Improved knowledge about dementia
- Improved knowledge of available respite services and ways to organise services
- Informed attitude towards the potential benefits of respite service and strategy use

Results of the study will be reported via community education sessions, conference presentations, and journal publications.

### **Are there any risks in participating?**

It is possible that being involved in the project will raise sensitive issues in regards to the impact of caring for someone living with dementia (e.g., issues of stress, burden/coping, and previous negative experiences using of respite services). As such, you may experience some psychological distress. To address this potential issue, we will provide you with information regarding services that can provide immediate support. The education and support program will also focus services and strategies that are available to provide you with support.

### **Will my information be kept confidential?**

Names and identifiable information will not be disclosed in the reporting of the study. Sessions may be audio-recorded for research purposes only. All identifying information (e.g., consent forms) will be stored in a locked filing cabinet in the Australian Health Services Research Institute (AHSRI), UOW. All other data collected (e.g., electronic surveys, audio recordings) will be stored on a password protected computer accessible only to the research team.

The consent forms, surveys and other research data will be destroyed after the required time period (5 years)

### **What if I do not want to participate?**

If you do not wish to be involved, just ignore this invitation to participate. Declining to participate will not affect your relationship with UOW.

Your participation is entirely voluntary and you are free to discontinue at any stage during project by contacting a member of the research team.

### **What if I feel I need help or assistance for myself or the person I care for?**

If you feel you need additional assistance in your caring role, please contact the 24 hour National Dementia Helpline (Alzheimer's Australia) on 1800 100 500. The helpline is a confidential support line staffed by trained and experienced advisers who provide:

- Support for people with dementia, their family and carers
- Practical information & advice
- Up to date written material about dementia
- Information about the services provided by Alzheimer's Australia and other organisations.

Alternatively, you may contact your GP who can assist you to access assistance. Please see the enclosed Carer Support Services Information Sheet for further information.

### **Funding Source**

This project has been funded by the Alzheimer's Australia Dementia Research Foundation.

### **Ethics Review and Complaints**

This study has been reviewed by the Human Research Ethics Committee (Health and Medical) of the University of Wollongong (Ethics Approval Number: HE16/276). If you have any concerns or complaints regarding the conduct of this research, contact the Ethics Officer (phone: 02 4221 4457 or email: [rso-ethics@uow.edu.au](mailto:rso-ethics@uow.edu.au))

#### **Research Team contacts:**

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**To be involved or for more information please contact Liz Cridland**