



Integrated care for people living with memory problems

INFORMATION SHEET - Carer

Introduction

We would like to invite you to take part in this research study. It will test if support from a nurse is helpful to people with memory problems and their carers.

This sheet tells you about the research and explains what taking part involves. Knowing this will help you decide if you would like to take part. Please read this. Ask questions about things you are not sure about. Please feel free to talk about the study with your family, friends, or your doctor. Then decide whether you should take part in the study or not.

What is the research about?

People living with memory problems may need different services to manage their health. It can be stressful for you as a carer to help the person with memory problems. We will test if talking to a nurse helps to get the right help at the right time.

All people with memory problems who take part in the study will keep seeing their usual doctor and other health workers. We call this *Usual Care*. Some people will also get support from a nurse. We call this the *Intervention*. We will decide whether you get support from a nurse by chance, much like flipping a coin.

This research is led by Mariko Carey from The University of Newcastle. The Department of Health and Aged Care, Medical Research Future Fund is funding this study. A list of other researchers involved is at the end of this sheet.

Who can take part?

Adult family members or friends can take part. You should be the main support for the person with memory problems, who is taking part in this study.

Do I have to take part?

No, you do not have to take part in this research. It is your choice.

If you do take part, you can withdraw at any time without having to give a reason. If you wish, we can also take your information out of the study. Your choice will not affect your care or relationship with any doctors, or health workers involved in your care or the care of the person you care for.

What does taking part in this study involve?

If you agree to take part, please sign the Consent Form when requested.

A researcher will visit you and the person you care for three (3) times over the next 12 months. One survey will be completed after joining the study and follow up surveys will be completed 6 and 12 months later. This will take about 60 minutes each time. You can choose what format you would like to complete – electronic or paper. You can contact the study manager if you don't understand any part of the survey and need help with completing the surveys. Some questions will be about your background and your health and the health of the person you care for. We will also ask about health and other services that you and the person you care for have used. We will also get information about any hospital or emergency visits made by the person you care for from their hospital record. If you are allocated to the intervention group, we will also access some data collected by the nurse about your health and support needs and services provided to you and the person you care for.

Everyone will keep getting their normal care from doctors and other health workers.

If you are in the group that gets nurse support:

1. A nurse will visit you and the person you care for in your home. During the home visit, the nurse will ask your health and support needs. You can talk to them about any concerns you have. They will discuss services and information that may help. The nurse will talk to the GP to plan care for the person you care for.
2. The nurse will make four appointments to talk with you and the person you care for. He or she will talk to you about:
 - living with memory problems and what to expect,
 - what to do about any problems you are having and
 - planning for the future.

These appointments can be in your home or done by phone or video.

3. After six (6) months, the nurse will again ask about the person you care for and your health and support needs. They will talk to you about any other concerns you have. The nurse will once again talk to the GP to plan care for the person you care for. You may be asked to give anonymous feedback about the nurse support program. This will be shared with the nurse support provider, Hunter Primary Care. The researchers will also have access to this feedback.

After 6-months, you and the person you care for may also be asked to take part in an interview with a researcher. This will take about 45 minutes. They will ask questions about how you felt about the nurse support. Taking part in the interview is your choice. You can decide closer to the time if you want to take part in the interview.

What happens with my information?

If you take part, we will replace your name with an ID code. This will keep your information private.

We will keep your information in a database for at least 5 years. Only the research team will have access to this. We will not store your name with your survey or interview answers.

We will publish and present the information we collect at conferences and in reports or articles. We will combine your information with that of other people who take part. Other researchers may use this information. They will have to get approval to do this.

We will securely share the de-identified data we collect with the Hunter Medical Research Institute for the purpose of analysis.

If you choose to withdraw from the study at any stage. If you wish, we can also take your information out of the study. If so, we will not use your information in any reports from this study.

What are the possible benefits of taking part?

By taking part in this study, we cannot promise you or the person you care for any benefits. It is possible that by taking part, you can help improve care for others in the future.

What are the risks of taking part?

We do not expect that there are any risks to taking part. But there is a chance that you may feel worried when talking about how you feel. If you do, please let the researcher know. You can take a break, stop, or come back to the questions later.

You may also want to your doctor about it. You can also get free phone support from:

- National Dementia Helpline on 1800 100 500 or
- Beyond Blue on 1300 224 636.

How do I hear about the study results?

If you wish, at the end of the study, we will send you a summary of the results. Please mark the box on the Consent Form if you would like this.

What will the study cost?

Taking part in the study will not cost any money. As a token of appreciation of your time, you will receive a \$20 gift voucher each time you complete a follow-up survey (in 6 month and 12 months' time).

If interested, how do I get involved in the study?

To become involved in this study or ask any questions, please feel free to contact the research team on memorynurses@newcastle.edu.au or by phoning 1800 271 103.

This sheet is for you to keep.

Thank you for considering this invitation.

The Research Team:

University of Newcastle: Prof Mariko Carey, A/Prof Michelle Kelly, Prof Kichu Nair, L/Prof John Attia, Dr Kylie Wales, Dr Kay Khaing, Dr Jenni White, Mr Simon Deeming, Dr Kristy Fakes and Dr Amelia Bartczak.

University of New South Wales: A/Prof Joel Rhee

University of Tasmania: Prof Dimity Pond

University of Sydney: Prof Yun-hee Jeon

University of Technology Sydney: Prof Anna Williams

Hunter Primary Care: Ms Claudine Ford

Hunter New England Local Health District: Ms Mandy Harden

Maitland Private Hospital: Dr Shahzad Gul

This research has been **approved** by the Hunter New England Human Research Ethics Committee of Hunter New England Local Health District, Reference 2023/ETH01221.

If you have any concerns about your rights as a participant in this research, or you have a complaint about the way the research is conducted, you can give your complaint to the researcher. If you prefer to tell your concerns to an independent person, please contact the **HNE Research Office**, Hunter New England Local Health District, Level 3, POD, HMRI, Lot 1 Kookaburra Circuit, New Lambton Heights NSW 2305. Telephone: 02 4921 4140. Email: HNELHD-ResearchOffice@health.nsw.gov.au and quote the reference number 2023/ETH01221.