



Participant Information Sheet – Informal Stroke Caregivers

Project Title: Exploring the changes in activities and experiences of informal stroke caregivers.

Project Summary: You are invited to participate in a research study being conducted by Ms Melissa Jammal [PhD Candidate – School of Health Sciences] under the supervision of Associate Professor Emma George [Associate Professor, Health and Physical Education, School of Health Sciences], Professor Gregory Kolt [Dean of Health Sciences, Professor of Health Science, School of Health Sciences], Karen Liu [Professor], and Ms. Nariman Dennaoui [Research Assistant].

Globally, stroke is the second leading cause of death and third leading cause of disability contributing significantly to the total burden of disease. In Australia, approximately 88% of stroke survivors with a disability return to live in a household, with at least three quarters of stroke survivors requiring assistance. However, stroke does not only impact on the stroke survivor, evidence suggests that caring for a stroke survivor can have a detrimental impact on the physical and mental health of the caregiver. Informal caregivers (including family members, neighbours, or friends) provide ongoing practical and emotional support to meet the needs of stroke survivors. Overtime, caregiving demands, stress, and lack of time for their own health and social activities can result in caregiver burden and impact the care and institutionalisation of the stroke survivor.

It is well established that insights from participants lived experience, perspectives, and needs are essential to inform the development of relevant client-centred interventions and services. Qualitative research can provide valuable insights into the lived experience and preferences of individuals to inform the development of interventions and resources.

This research will aim to address the current gaps in literature by exploring the experiences and perceptions of informal stroke caregivers on the benefits and difficulties of caregiving, and the impact of caring on caregiver health and wellbeing. This study will also aim to understand the perceptions of health professionals working in stroke care on how to best support caregivers, and what is feasible to deliver within a clinical setting. The findings from this study will be utilised to inform the development of a tailored intervention aimed at promoting valued participation of stroke caregivers and reducing caregiver burden.

How is the study being paid for?

This project is being funded by the Western Sydney University higher degree research training scheme budget.

What will I be asked to do?

Firstly, you will be asked to read the Participant Information Sheet and will be provided an opportunity to ask any questions. Following this you will be asked to complete a Participant Consent Form and Caregiver Questionnaire. The Caregiver Questionnaire will take approximately 10-15 minutes to complete and will ask you to answer a series of questions related to age, gender, language spoken, education, and employment. After the completion of these forms, you will be involved in a semi-structured interview. During this you will be asked to complete a questionnaire that asks about your participation in daily activities such as leisure, social and work activities. This will take approximately 15 minutes to complete. Following this you will be asked to share your lived experiences and perceptions of caring for a stroke survivor, the impact of caregiving, and comment on the design of a caregiver- tailored health and wellbeing program. This questionnaire and semi-structured interview will be approximately 60-90 minutes in duration. After the initial semi-structured interview, you will also be asked to provide your consent for your non-identifiable data to be used in future studies and to be contacted in the case of follow up research.

How much of my time will I need to give?

It is expected that the Socio-Demographic Questionnaire will take approximately 10-15 minutes and the questionnaire and semi-structured interview 60–90 minutes. In total, this study will require around 2 hours of your time.

What benefits will I, and/or the broader community, receive for participating?

The information that you provide will help to inform the development of a caregiver-tailored health and wellbeing intervention for informal caregivers of stroke survivors. You will also be reimbursed with a \$20 Prezzee gift voucher for your time. Reimbursement is contingent on participation being completed in good faith. All participants who participate in an interview will also be entered into a draw to win one of three \$100 gift cards.

Will the study involve any risk or discomfort for me? If so, what will be done to rectify it?

This study will involve discussion and completing a questionnaire regarding your lived experience and perceptions of caregiving and how this has impacted on your life. Due to the discussion and disclosure of personal topics, there may be a risk of experiencing emotional distress. Every measure will be taken to minimise harm or discomfort, however, if you do feel uncomfortable at any time during the completion of the interview or caregiver questionnaire, you can withdraw at any time without consequence. Should you decide to withdraw at any time, there will be no consequence associated with your decision. If you experience any distress and wish to speak with someone, please contact one of the following support services:

- Lifeline 13 11 14
- Carer Gateway 1800 422 737

How do you intend to publish or disseminate the results?

It is anticipated that the results of this research project will be published and/or presented in a variety of forums including a PhD thesis, peer reviewed publications, and conference presentations. In any publication and/or presentation, information will be provided in such a way that you cannot be identified, except with your permission. Only the research team will have access to the identifiable information and all data will be aggregated before being used. No identifiable information will be published.

Will the data and information that I have provided be disposed of?

Please be assured that only the researchers will have access to the raw data you provide. However, your data may be used in other related projects for an extended period of time. There are a number of government initiatives in place to centrally store research data and to make it available for further research. For more information, see <http://www.and.s.org.au/> and <http://www.rdsi.uq.edu.au/about>. Your data will be stored securely and it will be de-identified before it is made available to any other researcher or used in any future projects.

Can I withdraw from the study?

Participation is entirely voluntary and you are not obliged to be involved. If you do participate you can withdraw at any time without giving reason. Withdrawing from this study will not impact your relationship with Western Sydney University. If you do choose to withdraw, any information that you have supplied will be de-identified and retained for analysis. You may withdraw from the study at any time.

Can I tell other people about the study?

Yes, you can tell other people about the study by providing them with the Chief Investigator's contact details. They can contact the Chief Investigator to discuss their participation in the research project and obtain a copy of the information sheet.

What if I require further information?

Please contact Melissa Jammal or Associate Professor Emma George should you wish to discuss the research further before deciding whether or not to participate.

Ms Melissa Jammal

Email: 18989494@student.westernsydney.edu.au

Associate Professor Emma George

Email: E.George@westernsydney.edu.au

Privacy Notice

Western Sydney University staff and students conduct research that may require the collection of personal and/or health information from research participants.

The University's Privacy Policy and Privacy Management Plan set out how the University collects, holds, uses and discloses personal or health information. Further details about the use and disclosure of this information can be found on the [Privacy at Western Sydney webpage](#).

What if I have a complaint?

If you have any complaints or reservations about the ethical conduct of this research, you may contact the Ethics Committee through Research Engagement, Development and Innovation (REDI) on Tel +61 2 4736 0229 or email humanethics@westernsydney.edu.au.

Any issues you raise will be treated in confidence and investigated fully, and you will be informed of the outcome.

If you agree to participate in this study, you may be asked to sign the Participant Consent Form. The information sheet is for you to keep and the consent form is retained by the researcher/s.

This study has been approved by the Western Sydney University Human Research Ethics Committee. The Approval number is H15582.

Explanation of Consent

What will happen to my information if I agree to it being used in other projects?

Thank you for considering being a participant in a university research project. The researchers are asking that you agree to supply your information (data) for use in this project and to also agree to allow the data to potentially be used in future research projects.

This request is in line with current University and government policy that encourages the re-use of data once it has been collected. Collecting information for research can be an inconvenience or burden for participants and has significant costs associated with it. Sharing your data with other researchers gives potential for others to reflect on the data and its findings, to re-use it with new insight, and increase understanding in this research area.

You have been asked to agree to Extended consent.

What does this mean?

When you agree to extended consent, it means that you agree that your data, as part of a larger dataset (the information collected for this project) can be re-used in projects that are

- an extension of this project
- closely related to this project
- in the same general area of this research.

The researchers will allow this data to be used by Ms Melissa Jammal, Associate Professor Emma George, Professor Gregory Kolt, Professor Karen Liu, and Ms Nariman Dennaoui.

To enable this re-use, your data will be held at the University in its data repository and managed under a Data Management Plan. The stored data available for re-use will not have information in it that makes you identifiable. The re-use of the data will only be allowed after an ethics committee has agreed that the new use of the data meets the requirements of ethics review.

The researchers want to keep the data for 5 years for possible re-use. After this time the data will be securely destroyed.

You are welcome to discuss these issues further with the researchers before deciding if you agree. You can also find more information about the re-use of data in research in the [National Statement on Ethical Conduct in Human Research](#) – see Sections 2.2.14 - 2.2.18.

<https://www.nhmrc.gov.au/about-us/publications/national-statement-ethical-conduct-human-research-2007-updated-2018>

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<https://www.nhmrc.gov.au/about-us/publications/national-statement-ethical-conduct-human-research-2007-updated-2018>