



Enhancing well-being and coping skills of informal carers of stroke survivors

INFORMATION SHEET FOR PARTICIPANTS

This project is being undertaken as part of a doctoral (PhD) thesis. Thank you for showing an interest in this project. Please read this information sheet carefully before deciding whether or not to participate. If you decide to participate we thank you. If you decide not to take part there will be no disadvantage to you and we thank you for considering our request.

What is the Aim of the Project?

A stroke is a sudden event and the person surviving the stroke and their families have to quickly learn to cope and adjust to the changes to life caused by the stroke. Assisting a family member after they have had a stroke can thus be challenging and stressful.

In this project we will explore how informal carers' of stroke survivors cope and adjust to their caring role, and how this affects their well-being. We would also like to know from informal carers what would best help them to cope with their role of caring. This information will assist us to develop a mental wellness intervention to help support and guide informal carers to better cope with the burden and strain of caring.

What Types of Participants are being sought?

We wish to recruit informal carers – adult family members or friends who provide unpaid personal care, support and assistance to a person who had a stroke six or more months ago.

If you are a paid caregiver or caregiver of people other than stroke survivors you will not be eligible for this study.

A \$20 grocery voucher per participant will be provided to compensate for time or as reimbursement of travel related expenses incurred whilst taking part in the interview.

What will be the benefit for the participant as a result of participating in the study?

You may not directly benefit from taking part in this study but your knowledge will help us develop a mental wellness intervention to assist future informal carers.

Should you agree to take part in this study, at the end of the interview we will ask you if we could contact you at a later stage to see if you would like to be part of the next phase of our research? The next phase will be to test whether the intervention we develop works well or not. Participating in the test project may help you to learn skills to better cope and adapt to the carer role.

What will Participants be asked to do?

If you agree to participate in this study, you will be asked to take part in a 45-60 minute interview. Preferably we wish the interview to be done face-to-face at a mutually agreeable venue, which could be your home or the School of Physiotherapy, University of Otago. However, considering the COVID-19 pandemic circumstances and keeping in view the health and safety of the community members, interviews may have to be held via e-conferencing (using Zoom, Skype or other platforms) or via the telephone. In the interview, the PhD student researcher, following the initial introductions, will ask you to complete a short questionnaire to collect some personal information about you, such as your contact details, gender, relationship with the stroke survivor you care for, ethnicity, whether you are employed and nature of employment. She will then ask about your experiences of providing care to your family/whānau member with stroke and how you cope with this caring role on top of everything else you have to do. She will also ask your opinion about a mental wellness intervention programme to assist informal carers (for example, she will ask if you prefer to learn about coping skills or would you prefer counselling sessions? Would you prefer the intervention to be provided individually or in a group, once a week or twice a week, and for how many weeks?).

The PhD student researcher will use an open questioning technique, in which the precise nature of the questions she will ask participants have not been fully planned as it will depend on the way in which the discussion between the researcher and the participant develops. Consequently, although the School of Physiotherapy Ethical Committee is aware of the general areas to be explored in the

interview, the Committee has not been able to review the precise questions to be used. In the event that the line of questioning or discussion develops in such a way that you feel hesitant or uncomfortable you are reminded of your right to decline to answer any particular question(s).

You are very welcome to bring a support person with you to the interview.

Is there any risk of discomfort or harm from participation in research?

During the group discussion session you may become tired, or the discussion may make you feel uncomfortable or cause you some emotional distress. If you feel you would like to stop or have a rest, please let the PhD researcher know, or you can also withdraw altogether. If you feel emotional distress during the interview please let the PhD researcher know and she will suggest some places where you may seek assistance.

If you agree to participate, can you withdraw later?

Participation in this study is entirely voluntary. You may withdraw from participation in the research any time without any disadvantage to yourself. You will also have the opportunity to verify or correct any of the information you provide in case you think that it has been incorrectly recorded. The information could be your personal details you provided at the time of interview or your responses to researcher's questions.

What Data or Information will be collected and what use will be made of it?

As described above, you will be asked to complete a short questionnaire to collect some personal information, for example, your contact details, gender, relationship with the stroke survivor you care for, ethnicity, whether you are employed and nature of employment.

All interviews will be audio-recorded and then typed out word for word. Information from each participant's interview will be analysed and collated together to inform us about the needs of informal carers to cope during the caring journey. These responses will also help us to develop a mental wellness intervention programme to support informal carers and help improve their mental health and strength during the caring process.

We may wish to ask you to explain some of your thoughts a bit more or ask you your opinion of the findings of the interview. For these reasons we will ask for your consent for us to contact you again at a later stage after the interview process.

All data collected will be securely stored in such a way that only the researchers named below will be able to gain access to it. Data obtained as a result of the research will be retained for at least 5 years in secure storage. Any personal information held on the participants (such as contact details and audio files after they have been transcribed) will be destroyed at the completion of the research while the research information from the interviews may be kept for much longer. No commercial use of the data will be made.

Results of this research may be published. No material that could personally identify you will be used in any reports on this study. The results of the project may be published and will be available in the University of Otago Library (Dunedin, New Zealand) but every attempt will be made to preserve your anonymity.

You will also be invited to a de-briefing session where we will present the preliminary findings of this study and ask for feedback and comments. Participation in the de-briefing session is entirely your choice.

If you have any questions about our project, either now or in the future, please feel free to contact either:-

Ayesha Nisar Qureshi

PhD Researcher

School of Physiotherapy

Tel: 03 479 5422

ayesha.qureshi@postgrad.otago.ac.nz

Professor Leigh Hale

Primary Supervisor

School of Physiotherapy

Tel: 03 479 5425

leigh.hale@otago.ac.nz

Other researchers in this project include:

Associate Professor Nicola Swain (Psychological Medicine (Dunedin School of Medicine))

Dr Daniela Aldabe (School of Physiotherapy)

This study has been approved by the School of Physiotherapy Ethics Committee. However, if you have any concerns about the ethical conduct of the research you may contact the University of Otago Human Ethics Committee through the Human Ethics Committee Administrator (phone 03 479 8256 or email gary.witte@otago.ac.nz). Any issues you raise will be treated in confidence and investigated and you will be informed of the outcome.