

## **A survey of the health behaviours and emotional health among female carers of stroke survivors INFORMATION FOR PARTICIPANTS**

### **Introduction**

You are invited to take part in a research study into the health behaviours and emotional health of female carers of stroke survivors. The aim is to assess the prevalence of health behaviours (such as smoking status, alcohol consumption, physical activity, fruit and vegetable consumption, and blood pressure) and risk of anxiety and depression among female carers of stroke survivors. With this information, we will be able to develop helpful tools and resources to support female carers of stroke survivors to support their health and wellbeing.

### **What is the research about?**

Informal carers of stroke survivors, such as spouses and family members, may experience changes to their lifestyle and health after they take on the caregiving role. Despite the positive aspects of caregiving, research has shown that caregiving can impact on carers' health and well-being. Carers may experience a change in lifestyle after they take on the caregiving role. Lifestyle changes may include changes to physical activity levels, diet, as well as smoking and alcohol use. Furthermore, female carers are the most at risk of experiencing changes to mood, for example having more symptoms of anxiety and depression than previously. However, there is limited information concerning the relationship between health behaviours and emotional health among female carers of stroke survivors.

Our research aims to explore health behaviours and emotional health of female informal carers of stroke survivors. With this information, we will be able to develop helpful tools and resources to support informal carers in achieving healthier lifestyles.

### **Where is the research being done?**

The study is being conducted within this institution by Dr Alexandra Denham.

The study is being supported by a philanthropic grant through the Hunter Medical Research Institute (HMRI).

### **Who can participate in the research?**

Participating in this research is suitable for you if you are:

- Aged 18 years and over
- Female
- Can speak English
- A current or former informal carer of a person who has had a stroke. This includes unpaid spouses, family members, friends

### **What choice do you have?**

Participation in this study is entirely voluntary. You do not have to take part in it. If you do take part, you can withdraw at any time without having to give a reason. Whatever your

decision, please be assured that it will not affect your relationship with The University of Newcastle, and Hunter New England Health, or Hunter Research Volunteer Stroke Register. If you do decide to participate, you may withdraw from the project at any time prior to submitting your completed survey. Please note, due to the anonymous nature of the survey, if you do not provide any identifying details such as your phone number or e-mail, you will not be able to withdraw your response after it has been submitted.

### **What would you be asked to do if you agree to participate?**

If you agree to participate in this study, you will be asked to sign the Participant Consent Form and return your completed consent form to the Hunter Stroke Research Volunteer Register, or directly to the research team.

You will be asked to complete a paper-based survey with questions about you such as your age and education. The survey will also include questions about your health behaviours and emotional health. It is expected to take 15 minutes to complete.

You may request to complete this survey online via a link provided by email, or over the phone with the research team. If you choose to complete the survey online, please contact the research team and we will send you an e-mail containing the survey. If you wish to complete the survey over the phone, please contact our research team and we will arrange a time for you to answer the survey over the phone.

### **What are the risks and benefits of participating?**

#### **Risks**

The research team does not expect you will experience any risk from participating in this study. You may withdraw at any time without providing a reason. If at any point you feel distressed during or after participating in our survey, please consider contacting the following sources of support: <http://www.mentalhealthcommission.gov.au/get-help.aspx> or phone Lifeline on 131114.

#### **Benefits**

We cannot promise you any specific benefit from participating in this research. However, we hope that by obtaining a better understanding of the health behaviours and emotional health of female informal carers of stroke survivors, we will be able to develop effective programs and services to assist carers in achieving healthier lifestyles.

### **Will the study cost you anything?**

Participation in this study will not cost you anything, nor will you be paid.

### **How will your privacy be protected?**

All the information collected from you for the study will be treated confidentially, and only the researchers named above will have access to it, unless the information is required by law. All hard-copy information will be stored in a locked filing cabinet in the Principal Investigator's (Dr Alexandra Denham) rooms in the Hunter Medical Research Institute. All electronic information will be stored in password protected files on a secure, University-hosted online platform, with access available only to authorised research team members. At the end of the study, all information will be stored securely for at 7 years at the University of

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Newcastle, after which time all paper documents will be shredded and all electronic information permanently deleted. The study results may be presented at a conference or in a scientific publication, but individual participants will not be identifiable in such a presentation.

### **What do you need to do to participate?**

Please read this Information Statement and be sure you understand its contents before you consent to participate. If there is anything you do not understand, or you have questions, please contact the research team.

***If you would like to participate, please sign the Consent form and complete the Survey attached. Please return both documents by post in the pre-paid addressed envelope provided. You may also scan the survey and signed consent form and e-mail it to the research team at [FoCCuS4HEARTproject@newcastle.edu.au](mailto:FoCCuS4HEARTproject@newcastle.edu.au) or to the Principal Investigator Dr Alexandra Denham at [Alexandra.Denham@newcastle.edu.au](mailto:Alexandra.Denham@newcastle.edu.au) or on phone number (02) 4055 3232***

***If you would prefer to complete the survey online or over the phone with a team member, please contact the research team at [FoCCuS4HEARTproject@newcastle.edu.au](mailto:FoCCuS4HEARTproject@newcastle.edu.au) or the lead investigator Dr Alexandra Denham at [Alexandra.Denham@newcastle.edu.au](mailto:Alexandra.Denham@newcastle.edu.au)***

### **Further Information**

When you have read this information, the research team or Principal Investigator Dr Alexandra Denham will discuss it with you further and answer any questions you may have. If you would like to know more at any stage, please feel free to contact the research team at [FoCCuS4HEARTproject@newcastle.edu.au](mailto:FoCCuS4HEARTproject@newcastle.edu.au) or Dr Alexandra Denham at [Alexandra.Denham@newcastle.edu.au](mailto:Alexandra.Denham@newcastle.edu.au) or on phone number (02) 4055 3232

Participants who complete this survey may be eligible to participate in a follow-up interview to further explore the topics in the survey. If you wish to participate in this interview, please let us know at the end of the survey by providing us with your contact details or contacting the research team directly. From there, we will provide an information statement and consent form for this study (Hunter New England Human Research Ethics Committee of Hunter New England Local Health District, Reference 2020/ETH02830).

This information statement is for you to keep.

Thank you for considering this invitation. We greatly appreciate your thoughts and feelings on these issues.



**Dr Alexandra Denham**

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**Ethics:**

This research has been approved by the Hunter New England Human Research Ethics Committee of Hunter New England Local Health District, Reference 2020/ETH02830

**Governance:**

The conduct of this research has been authorised by the Hunter New England Local Health District to be conducted at the John Hunter Hospital site.

**Complaints about this research:**

Should you have concerns about your rights as a participant in this research, or you have a complaint about the manner in which the research is conducted, it may be given to the researcher, or, if an independent person is preferred, 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 2020/ETH02830