FoCCuS4HEART

Development of a program to support physical and emotional health among female carers of stroke survivors (FoCCuS4HEART)

Participants Information Statement

Introduction

You are invited to take part in a workshop at Hunter Medical Research Institute (HMRI) to help design a program for female carers of stroke survivors to support them throughout the caregiving journey, and ultimately improve their quality of life. The FoCCuS4HEART research project will work with female carers to develop strategies for managing their own emotional and cardiovascular (heart, brain and blood vessel) health.

To make sure that this program meets the needs of those who use it, the researchers will talk with carers and teams of health professionals, including psychologists, social workers, physiotherapists and other experts in heath behaviour research. Feedback from all these people will be used to build a support program that best suit the needs of female carers of stroke survivors.

This is the **first step of a 4 step process** that makes up the FoCCuS4HEART research project.

Step 1 , which has been completed, involved understanding the health behaviours and emotional health of female carers of stroke survivors. This step involved the completion of surveys and expressing an interest in taking part in an interview.

Step 2, which is in progress, is to interview female carers of stroke survivors (who expressed an interest in Step 1) to gain a more in-depth understanding of their health and wellbeing.

Step 3, which you are being invited to take part in, will work with female carers of stroke survivors to build a program to support carers' emotional and cardiovascular health. This will involve workshops and surveys with female carers.

Step 4 will involve changing the support program based on information gained in Step 3 and further testing the program with a much larger group of female carers who are at all different stages of the caregiving journey

Please read this information carefully.
Ask questions about anything that you don't understand or want to know more about.

Where is the research being done?

The study is being conducted at a room in Hunter Medical Research Institute and on online platforms such as Zoom (ie. virtual interview).

Who can participate in the research?

Participating in this research is suitable for you if:

- Aged 18 years and over
- Female
- Can speak English
- Are a current or former informal carer of a person who has had a stroke. An informal carer refers to a person or spouse, family member and or friend that cares for a person with stroke.

What choice do you have?

Participation in this research project is entirely your choice. Only people who give their informed consent will be included in the project. Whether or not you decide to participate, your decision will not disadvantage you in any way, or be disclosed to anyone outside of the research team. If you do decide to participate, you may stop your involvement in the project at any time without giving a reason and have the option of asking the research team to remove any information you may have provided which identifies you.

What would you be asked to do?

If you agree to take part in this study, you will be asked to sign the Participant Consent Form. You will then be asked to come to one workshop (ie., a group of people discussing ideas together) held at the Hunter Medical Research Institute in-person or through an online platform such as Zoom. We will contact you to arrange a time and date to attend a workshop that suits you at least 2 weeks beforehand, and we will call you to confirm the time and location the day before the workshop. The workshops will go for no longer than 2 hours.

COVID safe practices in line with government regulations will be in place. For example, providing alcohol-based hand gel, physical distancing, additional cleaning, and the use of face masks where required or wanted.

During the workshop we will tell you about the initial ideas we have for the support program to support female carers of stroke survivors in managing their emotional and cardiovascular health. The research team will then invite you to share your knowledge, experience and opinions. The discussion will focus on what you and others in the workshop think will be important to include in the program and to consider when providing it to female carers.

You will be asked to complete a brief survey at the beginning of the workshop. This will collect information such as your age and how long you have been caring for a

stroke survivor, and what your caring role has or does currently, involve. It will also ask you about your health behaviour and emotional health. This will take approximately 15 minutes to complete. We can help you complete this survey as needed.

We will record the workshop interviews, and take notes as needed to ensure we make note of all your suggestions and experiences. All notes, surveys and audio recordings are confidential, will be stored securely at HMRI, and will only be used by members of the research team included in the ethics approval.

Following this workshop, you may be invited to attend future workshops. You can choose whether or not you continue to remain involved and stop your involvement whenever you like.

What are the risks and benefits of participating?

We cannot promise you any specific benefit from participating in this research. However, we hope that by getting a better understanding of the emotional health and health behaviours of female carers of stroke survivors, we will be able to build supportive programs and services to help female carers remain healthy and experience a good quality of life long term.

There is a risk that talking about your experience as a carer and other topics covered in the workshops may cause you to become upset and/or emotionally distressed. Should you become distressed either during or following the workshop, please contact a member of the research team who can support you in- seeking help from (i) your GP or current counsellor or (ii) through online services and resources found at Beyond Blue and The Black Dog Institute as below:

Beyond Blue https://www.beyondblue.org.au/get-support

Black Dog Institute https://www.blackdoginstitute.org.au/resources-support/

How will your privacy be protected?

All the information collected from you for the study will be treated confidentially, and only authorised members of the research team will have access to it, unless the information is required by law. All hard-copy information will be stored in a locked filing cabinet at 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 7 years at Hunter Medical Research Institute after which time all paper documents will be shredded and all electronic information permanently deleted.

How will the information collected be used?

The information collected may be published in scientific journals and be presented at relevant scientific conferences Individual participants will not be identified in any reports arising from the project. A summary of the results of this study will sent to you by either email or postal mail conclusion.

What do you need to do to participate?

Please read this Information Statement and be sure you understand everything we have written about before you consent to participate. If there is anything you do not understand, or you have questions, you are welcomed to discuss this research study with other family members, friends or health professionals you trust, and you are also welcome to contact members of the research team listed below.

If you would like to participate, please complete the consent form. This will be taken as your informed consent to participate

Further information

If you would like further information, please contact the research team at FoCCuS4HEARTproject@newcastle.edu.au or Heidi.Janssen@health.nsw.gov.au or on phone number (02) 40420417.

Thank you for considering this invitation.

Dr Alexandra Denham Dr Heidi Janssen

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 Dr Sarah Moberley, Manager, Research Ethics and Governance Office, Hunter New England Human Research Ethics Committee, 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+