



PLAIN LANGUAGE STATEMENT AND CONSENT FORM

TO: *The Participant*

Plain Language Statement

Date: December 21st, 2016

Full Project Title: An evaluation of a smartphone-based program to reduce stress in adult carers

Principal Researchers: Dr Linda Hartley-Clark, Associate Professor, Matthew Fuller-Tyszkiewicz, and Professor Ben Richardson.

1. Your Consent

You are invited to take part in this research project.

This Plain Language Statement contains detailed information regarding this research project. Its purpose is to explain to you as clearly as possible all the procedures involved in this project so that you can make an informed decision about whether to participate or not.

Please read this Plain Language Statement carefully. Feel free to ask any questions about the information in the document. You may also wish to discuss the project with a relative or friend or your local health worker.

Moreover, you can print a copy of the Plain Language Statement to keep as a record.

Purpose and Background

There are 2.7 million Australians currently providing unpaid care or support to loved ones living with disability (including frail age), chronic illness, mental health issues or substance misuse. In economic terms, this investment in the potential improvement of a loved one's condition is a valuable resource that saves the Nation in excess of \$40 billion dollars per annum. Whilst carers themselves place a high degree of value in their caregiving role, such active investment can come at a psychological cost when high levels of stress and low levels of subjective wellbeing are experienced as a result of long-term and often hidden caregiving.

The aim of this project is to explore the effect of tailored intervention delivered via a smartphone app (Stress Less App) to reduce stress and improve wellbeing in adults who support a close friend or family member with a physical or mental condition. We intend to recruit approximately 120 participants to take part in this project. You are invited to participate in this research project if you are an adult (18 years or older), who supports a close friend or family member with a challenge, and have access to an iOS smartphone (iPhone running iOS8 or higher).

2. Funding

This research is funded by Australian Unity and Deakin University.

3. Procedures

Participation consists mainly of downloading and utilising a smartphone application for 5 weeks. Throughout this time, you will use the application to monitor your moods and stress levels, coping styles, and resilience, and if you are in a treatment condition, you will participate in practical activities to reduce stress and improve personal wellbeing. The app will prompt you to complete a short, one-minute survey twice a day (once in the am and once in the pm). In addition to using the smartphone application, you will be asked to complete an online survey at the start of the study (approximately 15-20), once again at the end of the testing phase (5-weeks), and in 3 months time to see if an improvement in your wellbeing is long-lasting. The surveys will evaluate your experiences of stressful events (i.e., *Have you experienced a stressful event in the last 30 mins?*), types of strategies you employed to cope with stress (i.e., *I talked to someone about it*), your perceptions about how you coped with the stressor (i.e., *At the time, how confident did you feel dealing with the stressful situation*), and stress levels (i.e., *How stressed do you feel right now?*).

In recognition of your time, and after completion of the study, you will be eligible to receive either a \$50 Coles Voucher or a \$50 iTunes Voucher. If you would like to take up this option, when completing the initial survey, you will need to respond to an optional question where you choose your preferred eGift, and provide a mobile phone number and email address to which the voucher can be sent. These details are stored separately from the rest of your data and are retained only for the purpose of sending the voucher. Once the voucher has been sent, your email address and mobile phone number will be deleted from our records.

4. Possible Benefits

It is anticipated that the results from this project will be used to inform targeted interventions that may help to reduce the negative consequences that are associated with stress and low wellbeing among adult carers. As a member of this adult population, it is possible that you may indirectly benefit from participation in this project. However, we cannot guarantee or promise that you will receive any benefits from completing this project.

5. Possible Risks

Although we believe that the project is low risk, there is a very small chance you may become distressed while completing the baseline survey and/or mobile phone application. In the baseline questionnaire, there are questions regarding the severity of depression (i.e., *I couldn't seem to experience any positive feeling at all*), anxiety (i.e., *I was aware of dryness in my mouth*), and stress (i.e., *I found it hard to wind down*). If you have scored highly in either of these areas, you will be provided with written information in the online survey regarding relevant counselling and GP services.

In terms of the mobile phone application, you may feel concerned about your stress levels or ability to cope with stressful situations, given the monitoring nature it requires. If this occurs, please feel free to discontinue at any stage. There are no consequences for withdrawing or choosing not to participate.

If, as a result of participation, you become distressed, you may wish to seek help from any of the below services or your GP.

Carers Australia – Carers Free Advisory Line

Ph: 1800 242 636 (free call anywhere within Australia weekdays 8.30am to 5pm).

Carers Australia offer Statewide carer counselling sessions that you can access if you are distressed and/or require support around your carer role. EG:

<http://www.carersvictoria.org.au/how-we-help>

LifeLine Crisis Support

<https://www.lifeline.org.au/About-Lifeline/Contact-Us/Enquiry>

Beyondblue – National Information Line

Ph: 1300 224 636

<http://www.beyondblue.org.au/>

Headspace

Ph: 03 9027 0100

<http://www.beyondblue.org.au/>

e-headspace

Ph: 1800 650 890

<https://www.eheadspace.org.au/>

6. Privacy, Confidentiality and Disclosure of Information

Data collected as part of the project will not be associated with any identifying information (with the exception of an optionally provided email address which we will delete once we have sent the voucher).

Only group data from this study will be reported in any publications. Data obtained as part of the study will be securely stored for a minimum of six years on a password-protected computer, consistent with Deakin University guidelines.

The primary researchers will monitor the conduct and progress of the research during regular supervision meetings. These meetings will involve discussion of the issues surrounding the implementation of the study and management of the collected data.

7. Results of Project

If you are interested in the outcome of the research please contact the primary researcher on the project Dr Linda Hartley-Clark (linda.hartleyclark@deakin.edu.au) who will be able to provide you with a summary of results. In addition, we plan to report the results in a peer-reviewed publication, at peer-reviewed conferences, and as a part of a report to the funding source for this project in Australian Unity.

8. Participation is Voluntary

Participation in any research project is voluntary. **If you do not wish to take part you are not obliged to.** If you decide to take part and later change your mind, you are free to withdraw from the project at any stage. If you do wish to withdraw from the study, contact the researcher via email or phone advising that you wish to withdraw from the study. This communication must contain your anonymous ID code (available within the smartphone app). Upon this request, any data associated with that ID will be deleted from our records. No other identifying details are required as part of that communication. Your decision

whether to take part or not to take part, or to take part and then withdraw, will not affect your relationship with the researchers or Deakin University.

Before you make your decision, a member of the research team will be available to answer any questions you have about the research project (contact details below). You can ask for any information you want. Complete the questionnaire only after you have had a chance to ask your questions and have received satisfactory answers.

8. Ethical Guidelines

This project will be carried out according to the *National Statement on Ethical Conduct in Human Research* (2007) produced by the National Health and Medical Research Council of Australia. This statement has been developed to protect the interests of people who agree to participate in human research studies.

The Human Research Ethics Committee of Deakin University has approved the ethics aspects of this research project.

9. Complaints

If you have any complaints about any aspect of the project, the way it is being conducted or any questions about your rights as a research participant, then you may contact:

The Manager, Ethics and Biosafety, Deakin University, 221 Burwood Highway, Burwood
Victoria 3125, Telephone: 9251 7129, research-ethics@deakin.edu.au

Please quote project number [2016-151]

10. Further Information, Queries or Any Problems

If you require further information please contact any of the researchers involved in the project.

Dr Linda Hartley-Clark
School of Psychology, Deakin University
Ph 9251 7237
Email linda.hartleyclark@deakin.edu.au

A/Prof Matthew Fuller-Tyszkiewicz
School of Psychology, Deakin University
Ph 9521 7344
Email matthew.fuller-tyszkiewicz@deakin.edu.au

Professor Ben Richardson
Head of School, CairnMillar Institute
Ph 9813 3400
Email ben.richardson@cairnmillar.edu.au

If you are interested in participating in this research project please follow this link: <http://goo.gl/08tAKU> and it will provide you with the Phase 1 of the study, the baseline questionnaire. Please note, completing and submitting the questionnaire signifies your consent to take part in the study described. If you would like to later withdraw the consent simply contact Dr Linda Hartley-Clark via email or phone advising that you wish to withdraw from the study. This communication must contain your anonymous ID code. Upon this

request, any data associated with that ID will be deleted from our records. No other identifying details are required as part of that communication.