**Combined Participant Information Sheet and Consent Form for Anonymous Paper Surveys for Adult Participants**

**Study Title:** Self-care behaviour in family caregivers of individuals with acquired brain injury: Applying an extended version of the Theory of Planned Behaviour and exploring the influence of valued living

**Researcher(s):** Bethanie Jones (Trainee Clinical Psychologist). The study is being supervised by Dr Warren Dunger (Consultant Neuropsychologist, University of Southampton) and Dr Andrew Merwood (Clinical Psychologist, University of Southampton).

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**Ethics/ERGO no: 67678**

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**What is the research about?**

My name is Bethanie Jones and I am a Trainee Clinical Psychologist studying on the Doctorate in Clinical Psychology course at the University of Southampton in the United Kingdom.

I am inviting you to participate in a study regarding self-care behaviour in spouse and partner caregivers of individuals with an acquired brain injury. Self-care behaviours refer to actions that individuals may take to improve and maintain their general health and well-being, for example exercising regularly, eating a healthy diet and engaging in activities that promote enjoyment and connection to others. Research has shown that family caregivers of individuals with ABI often find it difficult to engage in self-care, which may have negative consequences for physical and emotional well-being. To improve the health and well-being of family caregivers, it is therefore important to understand the factors that may influence self-care behaviour.

Specifically, the study aims to look at the components of the Theory of Planned Behaviour in relation to self-care behaviour. The Theory of Planned Behaviour is a psychological model which suggests that behaviour is determined by attitudes about the behaviour, perceptions about how others view the behaviour, the level of control that we feel we have in carrying out the behaviour and our intentions to engage in the behaviour. The study also aims to look at the impact of caregiver guilt on self-care. Lastly the study aims to understand the relationship between valued living and self-care behaviour. Valued living is the extent to which someone is living a life that is in line with their values.

This study was approved by the Faculty Research Ethics Committee (FREC) at the University of Southampton (Ethics/ERGO Number: 67678).

**What will happen to me if I take part?**

This study involves completing an anonymous questionnaire which should take approximately 30minutes of your time. If you are happy to complete this survey, you will need to tick (check) the box below to show your consent. You will then need to return this form with your completed questionnaire, using the stamped addressed envelope included in the questionnaire pack. As this survey is anonymous, the research team will not be able to know whether you have participated, or which answers you provided. Should you have any questions before or after taking part in this study, you can contact the researcher by email.

**Why have I been asked to participate?**

You have been asked to take part because you are a caregiver to your spouse or partner who has experienced an acquired brain injury. The study is open to anyone over 18 years of age who lives in the UK and provides care to a spouse or partner with an acquired brain injury.

We have contacted charities who support people with an acquired brain injury (e.g. Headway, Stroke Association) to invite them to share this research with their service users. However, they have not shared any details about you with us. It is completely up to you if you would like to take part.

We are aiming to recruit around 100 participants for this study.

**What information will be collected?**

The questions in this survey ask for information in relation to self-care. The survey has three sections:

* The first section of the questionnaire will involve questions about you and your loved one. This includes some demographic questions about gender, age and ethnicity. This section of the questionnaire will also ask about your relationship to your loved one, e.g., the length of your relationship and whether you live together. It will also include questions about your loved one’s injury, such as the type of injury/ diagnosis that they have and when this occurred.
* The second section of the questionnaire will involve questions about your lifestyle, specifically relating to self-care behaviour.
* The third section of the questionnaire will involve questions to explore the factors that may be associated with self-care, including attitudes towards self-care, your thoughts and feelings about caregiving and your experiences of living by your values.

Some of the survey questions contain space where you will be asked to write in your own answers, e.g., if your preferred response is not one of the listed options. Please note that in order for this survey to be anonymous, you should not include in your answers any information from which you, or other people, could be identified.

Please answer all questions in the survey.

**What are the possible benefits of taking part?**

By taking part, you will be helping us to understand the factors that may influence self-care behaviour in spouse and partner caregivers of individuals with an acquired brain injury. This information may help us to identify interventions to promote self-care behaviour and thus potentially improve the health and well-being of family caregivers.

By participating in this study, you also have the option of entering a prize draw for a £50 Amazon voucher. If you wish to be entered into this prize draw, you can visit the website listed at the end of the questionnaire and enter your email address. Email addresses will be stored separately to the questionnaire data to ensure that your questionnaire responses remain anonymous. Only the research team will have access to the email addresses entered into the prize draw. Email addresses will not be used for any reason other than to contact the winner of the prize draw. Email addresses will not be passed on to any third party and will be deleted once the winner has been selected and contacted.

**Are there any risks involved?**

The content of the questionnaire focuses on your experiences as a caregiver. This may bring up difficult thoughts and feelings for you. Thus, there is a possibility that taking part in this study could cause you some psychological discomfort and/or distress. At the end of this survey booklet, there is information about support services should you wish to access these.

**What happens if I change my mind?**

You have the right to change your mind and withdraw at any time without giving a reason and without your participant rights being affected. Should you decide you do not wish to continue with the questionnaire whilst you are completing it, then you can dispose of the questionnaire and are under no obligation to return it to the researchers. However, once your questionnaire has been returned to the researcher, it will not be possible to withdraw it. This is because the questionnaire is anonymous and so the researchers will not be able to identify which questionnaire you submitted.

**What will happen to the information collected?**

Paper copies of questionnaire that are returned to the researcher will be stored in a locked cupboard and the information will be entered into a password protected database. All information collected for this study will be stored securely on a password protected computer and backed up on a secure server. In addition, all data will be pooled and only compiled into data summaries or summary reports. Only the researcher and their supervisors will have access to this information.

The information collected will be analysed and written up as part of the researcher’s doctoral thesis. It is also the intention to submit the same report for publication. As participation in the study is anonymous, it will not be possible to share the findings of the research or a copy of the final report with participants.

The University of Southampton conducts research to the highest standards of ethics and research integrity. In accordance with our Research Data Management Policy, data will be held for 10 years after the study has finished when it will be securely destroyed. This includes paper copies of this questionnaire.

**What happens if there is a problem?**

If you have a concern about any aspect of this study, you should speak to the researchers who will do their best to answer your questions. You can contact either Bethanie Jones ([bj3n19@soton.ac.uk](mailto:bj3n19@soton.ac.uk)), Dr Warren Dunger ([W.N.Dunger@soton.ac.uk](mailto:W.N.Dunger@soton.ac.uk)) or Dr Andrew Merwood ([A.T.Merwood@soton.ac.uk](mailto:A.T.Merwood@soton.ac.uk)).

If you are unhappy about any aspect of this study and would like to make a formal complaint, you can contact the Head of Research Integrity and Governance, University of Southampton, on the following contact details: Email: [rgoinfo@soton.ac.uk](mailto:rgoinfo@soton.ac.uk), phone: + 44 2380 595058.

Please quote the Ethics/ERGO number above. Please note that by making a complaint you might be no longer anonymous.

More information on your rights as a study participant is available via this link:

<https://www.southampton.ac.uk/about/governance/participant-information.page>

**Thank you for reading this information sheet and considering taking part in this research.**

Please tick (check) this box to indicate that you have read and understood information on this form,

are aged 18 or over and agree to take part in this survey.