

Participant Information Sheet

Study Title: Understanding and documenting loneliness in stroke and brain injury

Researcher: Dr. Stephen Dunne

Contact details: stephen.dunne@sunderland.ac.uk

What is the purpose of the study?

The aim of this study is to investigate the experiences and perceptions of loneliness in stroke and brain injury survivors through individual interviews. We are interested particularly in how many people may experience loneliness, and if there are particular factors associated with or the impact of stroke and brain injury that can make experiencing loneliness more likely.

Why have I been invited to take part?

You have been invited to take part in this study because we are interested in the experiences of stroke and brain injury survivors. You do not have to have personal experience of loneliness to take part because we are interested in the views of those who have not felt this way, as well as those of people who have experienced loneliness.

Do I have to take part?

Your participation is voluntary and you do not have to agree to take part. If you do agree to take part, you can withdraw at any time, without giving a reason.

What will happen to me if I take part?

If you agree to take part in the study, you will be interviewed regarding your personal experiences, and opinions about loneliness. The audio of the interview will be recorded, although this will be anonymised (i.e., your name will not be included in the recording). The interview can take place online or over the phone if more convenient. The interview will last no longer than one hour, and you will be able to take regular breaks as required.

Are there any potential risks involved?

The interview questions will relate to your stroke/brain injury, and your perceptions and experiences of loneliness. The topic is therefore sensitive and if you think that this would be distressing for you then we would recommend that you do not participate.

Will my data be kept confidential?

All information obtained during the study will be kept confidential. If the data is published it will be entirely anonymous and will not be identifiable as yours.

What will happen to the results of the project?

The current project is the first stage in a wider aim to understand loneliness in stroke/brain injury survivors. We therefore expect the anonymised data collected to be used to inform future projects. We also expect to publish the results in an academic journal. All data included will however be anonymised, and therefore you will not be identifiable in any of the material published. Any quotes used from interviews would also be anonymous. All data from the current study will be stored securely for 5 years.

Who do I contact if I have any questions or concerns about this study?

If you have any further questions or concerns about this study, please speak to the researcher. If you remain unhappy or wish to make a formal complaint, please submit a complaint to Dr. John Fulton whose contact details can be found at the bottom of this sheet.

Thank you for reading this information and considering taking part in this study.

Contact for further information

Dr. Stephen Dunne (Lead Investigator)
Email: stephen.dunne@sunderland.ac.uk

Dr. John Fulton (Chair of the University of Sunderland Research Ethics Group)
Email: john.fulton@sunderland.ac.uk