

Participant Information Sheet

The Role of Self-compassion and Experiential Avoidance in Functional Seizures

For further information about how Lancaster University processes personal data for research purposes and your data rights please visit our webpage: www.lancaster.ac.uk/research/data-protection

My name is Megan Hawkes, and I am conducting this research as a student in the Doctorate of Clinical Psychology programme at Lancaster University, Lancaster, United Kingdom. A downloadable copy of the information sheet can be accessed here: <u>Link</u>

What is the study about?

The purpose of this study is to explore psychological factors which could affect outcomes in people who experience functional seizures. In particular we are looking at self-compassion (whether people are kind to themselves) and experiential avoidance (e.g., trying to avoid difficult feelings) to see whether they are important for wellbeing in people with functional seizures. We hope that this will contribute to the research base and understanding of functional seizures and that this will influence the psychological support available for those who experience functional seizures.

Why have I been approached?

You have been approached because the study requires information from people who are aged 18 years and over and who have diagnosed functional seizures (or Non-Epileptic Attack Disorder or Psychogenic Non-epileptic Seizures or any similar diagnosis), but who do not also have a diagnosis of epilepsy.

Do I have to take part?

No. It's completely up to you to decide whether or not you take part.

What will I be asked to do if I take part?

If you decide you would like to take part, you would be asked to complete an online questionnaire, which will ask you questions about; how you feel towards yourself, how you manage difficult feelings, how often you experience functional seizures, the impact of functional seizures on your daily life, your current mental health and demographic information. At the end of the questionnaires, there is an option to complete an additional questionnaire about trauma if this is something you have experienced. It will take approximately 25 minutes to complete the online questionnaire and an additional 10 minutes if you choose to complete the trauma questionnaire at the end.

Will my data be Identifiable?

The information you provide will be anonymous, so no one will know that the data is yours. The data collected for this study will be stored securely using university approved secure cloud storage.

- At the end of the study, data will be kept securely in on the university's secure server for ten years. At the end of this period, they will be destroyed.
- The dataset may be published; but data will be anonymous, and any identifiable elements will be excluded.
- **Please note:** Due to the data being anonymous, we will be unable to delete your data if requested as we will not be able to identify the data as yours.

What will happen to the results?

The results will be summarised and reported as part of a thesis within the Lancaster University Doctorate in Clinical Psychology programme. Following this, the report may be submitted for publication in an academic or professional journal. The outcomes of this study will be shared with the charity FND Hope who will disseminate to their audiences. The study may be presented at appropriate conferences and will also be presented during Lancaster University's Thesis presentation day.

Are there any risks?

There are no risks anticipated with participating in this study. However, if you experience any distress following participation you are encouraged to contact the resources provided at the end of this sheet. If you experience any distress after participating in the study, please also contact these organisations.

Are there any benefits to taking part?

Although you may find participating interesting, there are no direct benefits in taking part.

Who has reviewed the project?

This study has been reviewed and approved by the Faculty of Health and Medicine Research Ethics Committee at Lancaster University.

Where can I obtain further information about the study if I need it?

If you have any questions about the study, please contact the lead researcher by post or email:

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Complaints

If you wish to make a complaint or raise concerns about any aspect of this study and do not want to speak to the researcher, you can contact Dr Ian Smith.

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If you wish to speak to someone outside of the Lancaster Doctorate Programme, you may also contact:

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Thank you for taking the time to read this information sheet.

Resources in the event of distress

Should you feel distressed either as a result of taking part, or in the future, please contact your General Practitioner for support. In addition, the following resources may be of assistance.

Rethink Mental Illness Mind for better mental health Website: https://www.rethink.org Website: http://www.mind.org.uk

FND Hope International https://fndhope.org/contact/