

Participant Information Sheet (Online Version)

Self-compassion and social support in the wellbeing of carers of people with Parkinson's.

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 Katy and I am conducting this research as a student in the Doctorate of Clinical Psychology programme at Lancaster University, Lancaster, United Kingdom.

What is the study about?

The purpose of this study is to increase understanding of the roles that self-compassion and social support may have in the wellbeing of carers of people with Parkinson's.

Why have I been approached?

You have been approached because you are currently providing support or care to someone with Parkinson's. You may provide support or care to a friend, neighbour, or relative, but this should not be in a professional (paid or registered volunteer) capacity. This support may be in the form of physical or emotional support, help with day-to-day tasks, such as shopping or managing medication, or financial support. You must have been providing care or support for at least one year and be 18 or over to take part.

Do I have to take part?

No. It's completely up to you to decide whether or not you take part. You can leave the survey at any time by closing the browser window. However, please be aware that any answers you have already entered up to that point will still be retained.

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

If you decide you would like to take part, you will be asked to answer a series of questions. First you will be asked to provide us with some information about yourself (you will not be asked to provide your name and none of the questions will ask you anything which could make you personally identifiable) and the kind of care you provide. You will then be asked a series of multiple-choice questions related to your caring experiences, self-compassion, social support, and wellbeing.

What will happen to my data?

The data you provide will be stored securely by the Lancaster Doctorate of Clinical Psychology programme for 10 years, in line with university policy on data storage. Following this time period, all data will be securely destroyed.

Will my data be identifiable?

The data collected for this study will be stored securely on a password protected file and only the researchers conducting this study will have access to this data.

- Hard copies of questionnaires will be uploaded as electronic copies at the earliest opportunity. Physical copies will be destroyed immediately after uploading.
- The files on the computer will be encrypted, and no-one other than the researchers will be able to access them.
- All reasonable steps will be taken to protect the anonymity of the participants involved in this project. If you provide your name and address to receive paper copies of the questionnaires, this information will be destroyed immediately after posting and will not be retained for any other purposes.
- Your responses are anonymous, and all data is confidential.

What will happen to the results?

The results will be summarised and reported in a thesis and may be submitted for publication in an academic or professional journal and presented at conferences. The results will also be given to the organisations that help with recruitment, so they can disseminate them to their members.

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 inform the researcher and you can access additional support by contacting the resources listed below.

Are there any benefits to taking part?

Although there are no direct benefits to individual participants, you may find participating interesting, and the results of this study may be used to make recommendations around future care and support provided to carers of people with Parkinson's.

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:

Katy Brooks – k.brooks2@lancaster.ac.uk

Fiona Eccles – f.eccles@lancaster.ac.uk

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, DCLinPsy Research Director

Tel: (01524) 592282

Email: i.smith@lancaster.ac.uk

Clinical Psychology
Lancaster University
Lancaster
LA1 4YG

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

Dr Laura Machin Tel: +44 (0)1524 594973
Chair of FHM REC Email: l.machin@lancaster.ac.uk
Faculty of Health and Medicine
(Lancaster Medical School)
Lancaster University
Lancaster
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Resources in the event of distress

If you are experiencing distress as a result of caring, please speak to your General Medical Practitioner (GP) or another professional who is involved in the care of the person with Parkinson's. Should you feel any distress as a result of taking part in this survey, you may find the following helpful:

Parkinson's UK

www.parkinsons.org.uk
Tel: 0808 800 0303
Email: hello@parkinsons.org.uk

Parkinson's Association of Ireland

www.parkinsons.ie
Tel: 01-8722234
Email: nationaloffice@parkinsons.ie.

Parkinson's New Zealand

www.parkinsons.org.nz
Tel: 0800 473 4636
Email: info@parkinsons.org.nz

Parkinson's Australia

www.parkinsons.org.au
Tel: 1800 644 189

The Michael J Fox Foundation (Canada)

www.michaeljfox.org

Tel: 1-212-509-0995
Email: info@michaeljfox.org

American Parkinson's Disease Association

<https://www.apdaparkinson.org>
Tel: 800-223-2732
Email: apda@apdaparkinson.org

If you are accessing this study from outside the countries listed, you can still access information on any of the websites above. Alternatively, you can seek support from your local or national Parkinson's organisation.

Other support services:

Carers UK:

www.carersuk.org
Tel: 0808 808 7777
Email: advice@carersuk.org

Samaritans:

www.samaritans.org
Tel: 116 123
Email: Jo@samaritans.org

Mind:

www.mind.org.uk
Tel: 0300 123 3393
Email: info@mind.org.uk

Thank you for taking the time to read this information sheet. If you would like to download a copy of this information, you can do so here: [Information sheet](#)

You can now continue to the questionnaires by clicking the arrow at the bottom right of this page.