

INFORMATION SHEET FOR PARTICIPANTS



Ethical Reference Number: LRU-21/22-28386

Coping and mental wellbeing of carers for people with Parkinson's disease – an anonymised online survey

Thank you for participating in this study sponsored and led by King's College London. Before you decide whether you want to participate, you need to understand why the research is being done and what your participation will involve. Please take time to read the following information carefully and discuss it with others if you wish. Ask us if anything is unclear or if you would like more information.

What is the purpose of the study?

The study aims to understand coping strategies and mental wellbeing in carers for people with Parkinson's. Being a carer for people with Parkinson's is a long and stressful process, and as the symptoms vary and fluctuate, the carers need to adapt continuously. This can be exhausting and daunting, with different repercussions on daily activities, physical health and general wellbeing, including mood.

As such, the role of caring for people with Parkinson's can be an increasingly demanding experience, with ramifications for the carer. This study aims to understand this experience better and explore how the role of caring affects the lives of carers and how they cope with the challenges and their emotional wellbeing.

It would provide us insights and a more comprehensive understanding of carers' perspectives regarding their role. Helping clinicians and researchers be aware and develop better and more appropriate care and management tailored to their needs and coping strategies. This could potentially make their lives as carers and to those they care for easier and hopefully better, with more comprehensive support.

Why have I been invited to take part?

You have been invited to participate because you are a carer for a person with Parkinson's and are interested in taking part in studies. We are giving you the opportunity

to take part in this survey study because it may help us understand more about the coping ways and mood of care providers of people with Parkinson's.

All participants invited are 18 years old or above and can complete the questionnaire in English and on their devices. Participants are unpaid carers (family, partner or friend) of people with Parkinson's. You are eligible even if you have additional help from paid carers.

What will happen if I take part?

If you agree to participate, you will complete an anonymised online survey. The survey will take approximately 10 minutes to complete and must be completed at one go and submitted.

We would like to collect information on your role as a carer, for how long have you provided this type of care, and information relating to how you generally cope with this role and if there have been any changes to your sleep, mood, physical activities, smoking habits, alcohol use, etc.

Some questions may seem sensitive to some people and the examples of the most sensitive questions with the response choices are as below:

I have changed my smoking habits to make myself feel better

- a. I started smoking
- b. I restarted smoking
- c. I increased my smoking
- d. I decreased my smoking
- e. I never smoked

I try to make myself feel better by drinking alcohol

- a. Never
- b. Rarely
- c. Sometimes
- d. Quite frequently
- e. Nearly always

I have been feeling down and/or depressed

- a. Not at all
- b. Several days
- c. More than half the days

d. Nearly everyday

Do I have to take part?

It is up to you to decide whether you wish to participate in this survey study, as it is entirely voluntary. If you choose to take part, you will be emailed a copy of this information sheet and asked to indicate 'I agree' on the online survey with a sentence on your consent.

You are free to withdraw at any point during the completion of the survey without giving a reason. You may withdraw mid-survey without completing it or modify your responses manually by backtracking through the survey. Withdrawing from the study will not affect you in any way.

Once you submit the survey, it will no longer be possible to withdraw from the study because the data will be entirely anonymous. Please do not include any personal identifiable information in your responses.

What are the risks of taking part?

We do not foresee any risk to you if you choose to take part. Some of the questions relate to sensitive topics, but you are free to stop completing the questions at any time. There is a small risk that some people may find certain questions challenging to answer or distressing. For example, some of the questions about mental health may be distressing for some participants.

Data handling and confidentiality

King's College London is the study's sponsor to undertake it and act as the data controller. This means that we are responsible for looking after all the information which will be anonymised form and use it appropriately. Anonymised information collected in this survey study will be kept following the KCL privacy policy.

Your data will be processed per the General Data Protection Regulation (GDPR). All data collected as part of this project will be strictly confidential and held securely until the research is finished. No study data will be available in any identifiable format to anyone outside of the immediate research team.

This research is anonymous. This means that nobody, including the researchers, will be aware of your identity and that nobody will be able to connect you to the answers you

provide, even indirectly. Your responses will nevertheless be treated confidentially, and the information you provide will not allow you to be identified in any research outputs/publications. Your data will be held securely at password encrypted computers at the King's College London, only accessible by specified members of the research team who have been given the authorisation to access the database.

All research staff are provided with training regarding GDPR and KCL standards for handling data. All the responses from the survey will be held securely. Individuals from King's College London may look at research records to check the accuracy of the research study. The only people in King's College London who will have access to information will be people who need to audit the data collection process. We will not ask any personal data collected independently of the anonymous survey.

If you would like more information about how your data will be processed under the terms of UK data protection laws please visit the link below:

<https://www.kcl.ac.uk/research/support/research-ethics/kings-college-london-statement-on-use-of-personal-data-in-research>

What will happen to the results of the study?

The study results will be analysed, summarized into a report for dissemination to service user groups, presented to clinicians and scientists involved in the field of Parkinson's disease and, where possible, published in peer-reviewed journals.

Whom should I contact for further information?

If you have any questions or require more information about this study, don't hesitate to contact the principal investigator and the team through the contact details below:

Name: Latha Velayudhan

Email: latha.velayudhan@kcl.ac.uk.

Phone number: 020 7848 0544/ 0508

KCL address: Strand, London WC2R 2LS, United Kingdom

What if I have further questions, or if something goes wrong?

If you would like to speak to someone about how you are feeling, a few mental health organisations that can help you are:

1. Mind: The mental health charity (www.mind.org.uk): You can call 033 123 3393, or email at info@mind.org.uk.
2. Samaritans (<https://www.samaritans.org>): You can call 116 123, or email jo@samaritans.org.
3. Your GP would also be able to help, should you wish to contact them.

If you would like to speak to someone about concerns you have regarding your alcohol consumption, these organisations may help you:

1. Drinkline: the national alcohol helpline: You can call 0300 123 1110 (weekdays 9am to 8pm, weekends 11am to 4pm).
2. We are with you: UK wide-treatment agency (<https://www.wearewithyou.org.uk/>): You can call 0808 8010 750

Suppose you wish to complain or have concerns about any aspect of how you have been approached or treated during this study. In that case, you can contact King's College London using the details below for further advice and information:

The Chair, PNM Research Ethics Subcommittee

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