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**Title of Study:** Effects of an online Brief Exercise in Guided & Reflective Writing (BEGREW) on Informal PD-caregivers' anxiety: an external pilot study

**PARTICIPANT INFORMATION SHEET**

We would be grateful if you could assist us by participating in our online study. We are investigating whether completing our guided writing exercises will improve the compassion that you show towards yourself.

**What will I be asked to do?**

You will complete four writing exercises about your caregiving experience during a minimum two-week period. Each exercise will have some guidance that asks you to consider a particular aspect of the care that you provide. Whilst we ask that you write for at least 15 minutes, we want you to write an amount that you are comfortable with and is practical for you.

These exercises can be completed at any time that suits you. You will have the function to save a writing exercise that you have started and return to it later. Although we want to give you the maximum flexibility possible, we will email you reminders if we see that it has been a few days and you have not yet started writing.

Before the first and last of the exercises, you will complete questionnaires. These include demographic information, alongside validated psychological measures. If you need it, assistance to complete these surveys will be available from one of the study team. These surveys are completely anonymous. We foresee few risks in completing the tests or surveys.



A final question will ask if you are willing to take part in an online interview about your experiences of completing the exercises. Interviews will be a one-to-one MS Teams video call with one of the study team. We will ask you pre-prepared questions, alongside any relevant follow-up questions based on what you tell us. To limit access to you and the study team relevant security settings will be activated. These include restricted lobby settings and limits on sharing the meeting invites with anyone outside of the study.

We do not anticipate these interviews taking longer than one hour. We will take a video-recording of the interviews to produce a verbatim transcript afterwards. To ensure confidentiality, any reference to your name will be replaced with a pseudonym and other information that could identify you will be redacted. All transcripts from calls will be analysed, with the findings helping us to establish if a larger study is possible.

Taking part in this study is completely voluntary; you may withdraw your consent at any time without having to give any reason. Please feel free to ask any questions that you may have about this study at any point.

### **Why have I been invited to participate in this study?**

You are an adult caregiver who provides non-institutional, unpaid care to another individual with either Parkinson's Disease or Parkinsonism. You have access to an internet-enabled device such as Smartphone, Personal Computer or tablet.

### **Are there any benefits to taking part?**

Research suggests that many of us struggle to show ourselves self-compassion during difficult times. When we are facing struggles, our minds can be taken over by self-critical thoughts which can be cruel, harsh and attacking. Putting ourselves down can lead to more stress and keep us stuck in our emotional suffering.

Compassion for ourselves can help us deal with this. It involves recognising our own pain and accepting that this is a hard, but normal human experience. It can help us direct feelings of kindness and care towards ourselves, just as we might to someone else we care about who is struggling. It can help us treat ourselves with respect, support and forgiveness.

We believe this writing exercise will help you to face your feelings and become more tolerant of them, rather than fighting with them. It will help you refocus your attention



and energy on how you might alleviate your pain. We feel that in completing this writing exercise, you will be able to acknowledge and develop a non-judgmental, understanding response toward your difficulties.

### **Are there any risks or disadvantages to taking part?**

We foresee few risks in completing these writing exercises. However, as this study is about your caregiving experiences, you may be asked questions that could cause you to feel upset or distressed. If you did feel this way, it may be helpful to refer to the sources of support below:

- Your General Practitioner (GP): Your GP will be able to offer support and advice on possible treatment options for any mental health concerns.
- Carers UK: Carers UK is a charity that can give expert information and guidance, to champion your rights and support you in finding new ways to manage at home, at work, or wherever you are. Call their [Helpline](tel:08088087777) on 0808 808 7777 from Monday to Friday, 9am-6pm, or email [advice@carersuk.org](mailto:advice@carersuk.org) at any time.
- Mind Charity: Mind provide advice and support to empower anyone experiencing a mental health problem. Call 0300 123 3393 or email: [info@mind.org.uk](mailto:info@mind.org.uk) to find out

### **What will happen to my data/how will it be protected?**

During the study, any personal data collected will be kept confidential and securely stored. Any findings and results shared from the study will be de-identified.

Data collected from this study will be preserved, and subject to safeguards will be made available to other authenticated researchers

### **Who can I contact about data privacy and storage?**

The organisation responsible for protection of your personal information is the University of Reading (the Data Controller). Queries regarding data protection and your rights should be directed to the University Data Protection Officer at [imps@reading.ac.uk](mailto:imps@reading.ac.uk), or in writing to: University of Reading, Information Management & Policy Services, Whiteknights House, Pepper Lane, Whiteknights, Reading, RG6 6UR, UK.

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the purposes of research in the public interest. Under data protection law we are required to inform you that this use of the personal data we may hold about you is on the lawful basis of being a public task in the public interest and where it is necessary for scientific or historical research purposes. If you withdraw from a research study, which processes your personal data, dependant on the stage of withdrawal, we may still rely on this lawful basis to continue using your data if your withdrawal would be of significant detriment to the research study aims. We will always have in place appropriate safeguards to protect your personal data.

If we have included any additional requests for use of your data, for example adding you to a registration list for the purposes of inviting you to take part in future studies, this will be done only with your consent where you have provided it to us and should you wish to be removed from the register at a later date, you should contact

You have certain rights under data protection law which are:

- Withdraw your consent, for example if you opted in to be added to a participant register
- Access your personal data or ask for a copy
- Rectify inaccuracies in personal data that we hold about you
- Be forgotten, that is your details to be removed from systems that we use to process your personal data
- Restrict uses of your data
- Object to uses of your data, for example retention after you have withdrawn from a study

Some restrictions apply to the above rights where data is collected and used for research purposes.

You can find out more about your rights on the website of the Information Commissioners Office (ICO) at <https://ico.org.uk>

You also have a right to complain the ICO if you are unhappy with how your data has been handled. Please contact the University Data Protection Officer in the first instance.

**Who has reviewed this study?**



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This application has been reviewed by the School of Psychology and Clinical Language Sciences Research Ethics Committee and has been given a favourable ethical opinion for conduct ([2024-086-AH](#)).

Where can I get more information/who I can contact about this study?

If you have any questions or concerns about the research, please feel free to contact Neil Boyt:

Email: [n.boyt@pgr.reading.ac.uk](mailto:n.boyt@pgr.reading.ac.uk), Tel: +44- (0)118 378 8523

Thank you for your help.



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