

Research title: Moving forward with Parkinson's: A new online group psychotherapy program

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What is this study about?

This study will investigate the effectiveness of a new online intervention that has been specifically tailored for people with Parkinson's. You will be asked to complete up to 7 sessions of psychotherapy, this will include 1-1 sessions with the student researcher and group sessions with 3 to 8 other participants. These sessions will focus on value-based living and techniques that address unhelpful thoughts and feelings. In between group sessions, you will be asked to complete brief 1-1 check-ins with the researcher and simple homework tasks. You will have the opportunity to provide feedback following the program. The sessions will be conducted by the named student researcher, who has experience running similar sessions and providing mental health support and supervised by a professor with expertise in Parkinson's.

What am I required to do if I participate?

The program is made up of group and 1-1 sessions, all which take place online via Microsoft Teams. Group sessions will focus on value-based living and techniques to deal with difficult thoughts and feelings. Information about mental health difficulties and Parkinson's will be provided. You will be asked to share your own experiences and practice techniques in the sessions.

1-1 sessions will take place at the start and end of the program, as well as regular check-ins to ensure understanding and improve motivation. You will be encouraged to complete activities outside of sessions to enhance learning.

You will be asked to complete questionnaires before starting the program, immediately after the sessions has finished and then 3 months and 6 months after your completion of the program. This will help us to examine the effectiveness of the program.

If you agree to participate, you will be assigned to a group to complete the programme with. You may be asked to wait up to 8 weeks before the programme starts, depending on time and resource availability.

There will be an opportunity to provide feedback after the program and you will be invited to take part in an interview to share your experiences.

Sessions will be video recorded for the investigators to examine feedback in detail.

Are there any potential risks?

We foresee very few risks in this study. However, as the sessions involve discussions around wellbeing and experiences with Parkinson's, this may be upsetting for some. These sessions will allow you both the time and space to explore these feelings. If you do find this difficult, you will be reminded of your right to withdraw at any point during the study. We will signpost to you to relevant services and support if required. Ground rules will be set at the start of each group session to ensure a safe and supportive environment.

Can I participate?

Participation is completely voluntary. To be eligible to participate we ask that you meet the following criteria to take part in the study:

- You have a diagnosis of Parkinson's.
- You are currently experiencing anxiety or low mood and would be happy and willing to access psychotherapy, including group and 1-1 sessions.
- You are not currently accessing psychotherapy and have not accessed it in the past 12 months.
- You have not been recently diagnosed with a serious mental health condition, including psychosis or suicidal ideation.
- You can understand and speak English for communication with the researcher, and are able to understand this information sheet and decide for yourself if you would like to participate in this study
- You have access to a computer, tablet, or phone with access to the internet.
- You are over the age of 18 years.

To ensure you understand what the study consists of and what you will be asked to do, please take some time to read carefully through this information sheet and contact us if you would like to discuss the study or ask any questions.

Will my participation and details be confidential?

Your data will be kept confidential and securely stored. Your information will be held in coded form that will not directly identify you. The data collected in this study will be preserved for teaching and learning purposes.

How will data be stored?

All personal and confidential information will be stored in an access-controlled folder in a file share managed by the research team on the University network.

You have the right to have inaccurate personal data rectified and the right to have your personal data erased or restricted. If you would like to access your personal and confidential data, you can do so by contacting imps@reading.ac.uk.

Ethics:

This application has been reviewed by the University Research Ethics Committee and has been given a favourable ethical opinion for conduct.

Who do I contact if there is a problem?

If you have any concerns or complaints relating to this study, please do not hesitate to contact the principal investigator noted above.

Data Protection:

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, or in writing to: University of Reading, Information Management & Policy Services, Whiteknights House, Pepper Lane, Whiteknights, Reading , RG6 6UR, UK.

The University of Reading collects, analyses, uses, shares and retains personal data for 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.

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.

Consent form

	I agree
I have read the information sheet about this study and the procedure of the study has been explained to me.	
I understand that participation is entirely voluntary and that I have the right to withdraw from the project any time, and that this will be without detriment.	
I have been given the opportunity to ask any questions that I may have about the study, and these have been answered to my satisfaction.	
I understand that the session will be audio/video recorded and preserved for teaching and learning purposes.	
I am happy to be contacted about future studies (optional)	

First Name:

Last Name:

Signature: