



STEADY TOGETHER

A study to design a guide to help people with Parkinson's who fall, and those who help to look after them

We Invite you to take part in a study

Before you decide whether or not you would like to take part, we would like you to read this information booklet. This is important for you to understand why the study is being done and what it might involve.

Please read this booklet carefully. Please ask the researchers any questions that you might have.

It is up to you to decide whether or not to take part.

Why have I been invited

You have been invited because you have a diagnosis of Parkinson's and have had at least one fall in the last year, or help to look after somebody with Parkinson's who has fallen.

Summary of the study

The purpose of this study is to design a guide to help people with Parkinson's who fall, and the people who help to care for them at home.

We want to find out the views and experiences of falling in people with Parkinson's, and how it affects people who are close to them.

We would like to invite you to complete a questionnaire to help us to design this guide. You may complete this anonymously.

We will also be interviewing some people with Parkinson's and those close to them. If you would like to take part in these interviews, please provide us with your contact details.

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How to contact us

If you have any questions about the study, please contact Dr Charlotte Owen at:

University Hospital Southampton
Room CE 114B
Tremona Road, Southampton, SO16 6YD

Tel: 07824 895791

Email: c.l.owen@soton.ac.uk

Alternatively, the research administrator, Angela Dumbleton, can be contacted on:
Tel: 02381 206128

1 Why are we doing this study?

The purpose of this study is to design a guide to help people with Parkinson's, and the people who help to care for them, to self-manage falling.

We want to find out the views and experiences of falling in people with Parkinson's. We also want to know how it affects people who are close to them.

2 What will I need to do if I take part?

If you agree to take part, please complete the two questionnaires and return them in the stamped addressed envelope provided. You can complete these anonymously.

Questionnaire one is to be completed by the person with Parkinson's and a close friend or relative.

Questionnaire two is to be completed by the close friend or relative only.

We will invite some people to participate in an interview, where we will ask questions about your Parkinson's, falling and what concerns you. These interviews will take place at a time convenient to you and at your home address. If you are happy, we will audio-record these interviews, to allow us to concentrate on what you are saying. If you would like to be considered for this stage of the study, please provide us with your contact details at the end of the questionnaire.

3 What are the possible benefits and disadvantages of taking part?

The information you provide will assist us in knowing what information people with Parkinson's, and those who are close to them, would like to know about falls and how to manage them. It will also allow us to find out different ways that you commonly use to find information, which will help us to decide what the guide should look like.

The questionnaire does not ask any personal or sensitive issues. However, please do not answer any questions that you feel uncomfortable with.

4 What happens if I don't want to carry on with the study?

If after choosing to take part in the study you change your mind, you can withdraw at any time without giving a reason, and your usual NHS care will not be affected. However, any information you had given until that point would still be used in the study results.

5 Will my taking part in the study be kept confidential?

Yes, all information about you will be handled in confidence.

All data collected from you will be anonymised. Data will be stored on a password protected computer or locked filing cabinet in a secure office in our research unit and will be accessible only by the research team.

If you participate in the interviews, with your permission, these interviews will be audio- recorded to make an accurate record of what is said. Recordings will be typed up and identifiable data will be removed. The original audio-recordings will be destroyed.

When analysing the results of the study, your data will be used anonymously and will not be attributable to you. Data collected may be used to support research in the future, and your data may be shared anonymously with other researchers.

6 What will happen to the results of the research study?

The results of the research will be published in medical scientific journals, and may be presented at conferences and local meetings. The results may contain quotes from participants, however, these will be anonymised and will not be attributable to any individual. We will send you a summary of the findings if you would like one.

7 Who is organising and funding the research?

The research study is organised and funded by the National Institute for Health Research (NIHR) Collaborations for Leadership in Applied Health Research and Care (CLAHRC) based at the University of Southampton, which is funded by the government.

The lead researcher is Dr Helen Roberts, associate professor in Geriatric Medicine at University Hospital Southampton. The study is being managed by Dr Charlotte Owen, a clinical research fellow in Geriatric Medicine, and supported by Dr Emma Stack and Dr Laura Dennison, researchers at the University of Southampton.

8 Who has reviewed the study?

This study has been reviewed and approved through the Faculty of Medicine Ethics Committee at The University of Southampton; ERGO reference 25364.

9 What if there is a problem?

If there is a problem or you have any concerns, you can contact the researchers on the details provided in section 10 of this information sheet.

If you remained unhappy, you could contact the research governance office at the University of Southampton on:

Tel: 02380 598566 Email: Rgoinfo@soton.ac.uk

10 Contact details of the researchers for further information

If you have any questions about the study please contact the researchers, using the contact details provided below.

Dr Charlotte Owen
University Hospital Southampton
Academic Geriatric Medicine
Room CE114B
Tremona Road
Southampton, SO16 6YD

Tel: 07824 895791

Email: c.l.owen@soton.ac.uk

The research administrator, Angela Dumbleton, can be contacted on:

Tel: 02381 206128

Alternatively, the lead researcher, Dr Helen Roberts, can be contacted at the address above, or on Tel: 023 81204354

11 What do I do now?

If you would like to take part, please complete the questionnaires and return them to us in the stamped addressed envelope provided.

The questionnaires can be completed anonymously. However, should you wish to be involved in the interviews, or in the later review process of the self-management guide, then please provide your contact details.

Thank you for taking time to read this information sheet and considering taking part in this study