

## Specialist Parkinson's Integrated Rehabilitation Team Trial (SPIRITT)

### Participant Information Sheet for Live-in carer of people with Parkinson's

You are invited to take part in a research study. Before you decide, please take the time to carefully read the information below. This explains why the research is being done and what it will involve for you. You may find it helpful to discuss the study with your friends, relatives and anyone involved in your care. Thank you.

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#### What is the purpose of the study?

This study is investigating whether specialist treatment provided by a team of healthcare professionals is helpful to people with Parkinson's and their carers. The purpose is to help with the planning of services for people with Parkinson's in the future.

#### Why have I been invited?

The study is for people with Parkinson's, living in the community in their own homes, who could benefit from a programme of rehabilitation. You have been invited because you are a live-in carer of a person with Parkinson's. You will be able to take part, if the person you care for agrees and is eligible to participate in the study.

#### Do I have to take part?

It is up to you to decide whether you would like to take part. If you decide not to take part, the medical care you, or the person with Parkinson's receive, will not be affected in any way.

#### What will happen to me if I take part?

A researcher, who is a qualified nurse, will make an appointment to visit you and the person you care for, in your home at a time convenient to you. During this visit, she will go through this information sheet with you and answer any questions you may have. If you decide to take part, she will ask you to sign the consent form. She will provide you with a copy of this for your records. She will then ask you to complete some questionnaires about your background, health and caring role. The nurse will assist you as necessary. This visit may take up to two hours. She may leave some of the questionnaires for you to complete and return by freepost to the research team. Once all of this information has been gathered, the research team will check to make sure that you meet all of the study's inclusion criteria.

Once your eligibility has been confirmed, you will be assigned to the same group as the person you care for. The person you care for will have equal chances of being allocated into any of the three study groups. The groups are:

- People with Parkinson's in Group A will receive treatment in their homes, from a specialist Parkinson's team, over six weeks. The team has a Parkinson's specialist nurse, physiotherapist, occupational therapist, and can call in other professional as required. The team will form a care plan, in discussion with the person with Parkinson's and yourself. The person with Parkinson's will receive visits from the healthcare professionals over the six week period, according to his/her assessed needs.
- People with Parkinson's in Group B will receive the same treatment as those in Group A, and additional visits and follow up telephone calls from a care assistant for another four months.
- People with Parkinson's in Group C will be given information about Parkinson's from the Parkinson's Disease Society booklets, and an assessment from a member of the specialist team at the end of the study.

You will receive three further home visits from the research nurse at 6, 24 and 36 weeks after the person you are caring for has been assigned to his/her group. You will be asked to complete similar questionnaires to those used in the first home visit. Some questionnaires will be sent for you to fill out in advance of these follow up visits. The purpose of these follow up visits is to see what effect the treatment is having on the person with Parkinson's and on your wellbeing.

**Will my General Practitioner (GP) be involved?**

The consent form will ask for your permission, to inform your GP that you taking part in this study, and the group you are in.

**What are the possible benefits of taking part?**

There may be no obvious personal benefit to you, but your participation will enable us to improve the care of people with Parkinson's, and in particular to help design future services.

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

Yes. All the information collected about you during this study will be kept strictly confidential as required by the Data Protection Act (1998). All questionnaires will have a unique identification number, specific to you. No names or personal information will be kept on or stored with these questionnaires. Information will be kept in locked filing cabinets and password protected computers, in a room with restricted access at the University of Surrey. The information collected will be analysed to meet the aims of the study. Under no circumstances will any of your personal details be passed onto third parties, or appear in any reports on this study.

**What will happen if I do not want to carry on with the study?**

You can withdraw from the study at any time, without giving any reason, and this will in no way affect the usual care that you receive. Any information that has already been collected will be kept and used in the study's analysis.

**What happens when the research study ends?**

The treatment input is for a set amount of time only. At the end of the allocated time, participants will have the opportunity to reflect on their involvement during a short semi-structured interview with the researcher.

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

The results of this study will be presented to the funder of the study as a report. The research team will write papers for publication in journals and make presentations at conferences, to help influence the development of future services for people with Parkinson's. Summaries of the study's results will be available from the project's website [www.spiritt.surrey.ac.uk](http://www.spiritt.surrey.ac.uk) or the research team.

**Who is funding the research?**

The research is funded by the Department of Health (National Institute for Health Research, Service Delivery and Organisation Programme).

**Who has reviewed the study?**

All research in the National Health Service (NHS) is reviewed by a Research Ethics Committee, which is responsible for protecting your interests and safety. This study has received favourable opinion by the Surrey Research Ethics Committee.

**What if there is a problem?**

If you have a concern about any aspect of this study, you should speak to the researchers who will do their best to answer your questions. You can contact the principal investigator, Dr Heather Gage or the project manager, Sharlene Ting, using the details provided below. If you would like to make a formal complaint, you can do this through the University of Surrey complaints procedure. Details can be obtained from the research team.

**Contact details for further information**

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