

Carer Information Sheet – Front Sheet

Insert Local NHS Trust Logo

RANDOMISED CONTROLLED TRIAL TO ASSESS THE CLINICAL- AND COST-EFFECTIVENESS OF PHYSIOTHERAPY AND OCCUPATIONAL THERAPY IN PARKINSON'S DISEASE (PD REHAB)

Carer Information Sheet

PD REHAB logo – To be inserted

Local PI Contact details here

Local Nurse Contact details here

Local PALS Group Contact detail here

BCTU Contact details

Version 9, 11th June 2010

CARER INFORMATION SHEET

You are being invited to take part in a research study. Before you decide it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

Thank you for reading this.

What is the purpose of the study?

We want to know whether occupational therapy and physiotherapy help people with Parkinson's disease. Occupational therapy mainly aims to improve physical function and independence. It involves a qualified therapist assessing a patient's problems with their disease, often at home, then devising practical ways to help them such as providing aids and adaptations (e.g. walking aids, hand rails, raised seating etc). Physiotherapy focuses on working with the patient, carer and family to improve their understanding of the condition, maintain general fitness and independence in mobility, both inside and outside the home.

Currently there is no good evidence whether occupational therapy and physiotherapy benefit patients with Parkinson's disease. This study aims to answer the question do patients benefit from therapy, and does any benefit persist after they have finished their occupational therapy and physiotherapy. This information will be used to help optimise treatment for future Parkinson's disease patients.

Why have I been asked?

The trial will include 750 patients with Parkinson's disease and their carers at over 40 centres throughout the United Kingdom.

We are asking you to take part in the study because you are the main carer for someone with Parkinson's disease who has been asked to take part in the PD REHAB trial.

Do I have to take part?

It is up to you to decide whether or not to take part. If you do decide to take part you will be given this information sheet to keep and be asked to sign a consent form. If you decide to take part you are still free to withdraw at any time and without giving a reason. A decision to withdraw at any time, or a decision not to take part, will not affect the standard of care the person you care for will receive.

What will happen to me if I take part?

We want to find out whether giving the patient you care for occupational therapy and physiotherapy affects your own quality of life. We will do this by asking you to fill in a quality of life questionnaire before the trial begins, then we will post the same questionnaire to you to fill in at home 3, 9 and 15 months after you enter the study.

You will be asked to complete these, then post them back to us in the freepost envelope we will send the participant.

What are the possible disadvantages and risks of taking part?

We do not anticipate any disadvantages or risks in taking part.

What are the possible benefits of taking part?

Although you may not benefit directly from taking part, the information we get from this study may help us to look after future patients with PD better.

Will my taking part in this study be kept confidential?

All information collected in the study will remain strictly confidential in the same way as your other medical records. The information will be put into a computer and analysed, but you will not be identified when the results are reported.

What will happen to the results of the research study?

The results of the study will be published in a medical journal after the study has been completed, but you will not be identified in any report or publication.

Who is organising and funding the research?

The study is being funded by the Health Technology Assessment Programme which is part of the UK National Institute for Health Research. No payments will be made to the patients, therapists, nurses, or doctors taking part in the study.

The study has been approved by National and Local Research Ethics Committees.

Contact for Further Information

Should you want further information about the study please contact: *<Insert details of local PI>*

If you decide to take part in this study, you will be given a copy of this information sheet and a signed consent form to keep.

Thank you for taking the time to read this information sheet

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