

Care of Late Stage Parkinsonism (CLaSP Study)

Information for Care Homes

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Reason for the study

The aim of this study is to determine the needs of patients in the late stages of parkinsonism and their carers, how they are currently met in different European countries, and how their care could be improved. We suspect that there are number of unmet needs and that these can be addressed better. We will therefore assess the problems and needs of patients with late stage parkinsonism and their carers through examination and questions, and interrogate existing health care databases. We will also study the effect of a specialist assessment with treatment recommendations compared to those who receive their normal care.

In addition, we are collecting saliva samples in order to allow genetic analysis by ourselves or our collaborators in future studies that are approved by a Research Ethics Committee. These samples will help us study markers that could help in the future diagnosis of Parkinson's disease or in monitoring how the condition progresses.

Research question

- What is the impact of late stage Parkinsonism on patients and their carers and families and what are their medical and social needs, costs and use of health-care resources?
- How appropriate and valid are the existing assessment tools in this population?
- How do disability and disease severity milestones (psychosis, dementia, falls, wheelchair-bound, institutionalisation) progress over 12 months in these patients?
- What are the health-care and social determinants of outcome once disease variables are accounted for?
- What is the impact of different health-care pathways?
- What are management strategies that have been shown to be effective in late stage Parkinsonism?
- What is the impact of a specialist review with management recommendations, provision of guidance and access to telephone assistance?

The Research Study

This is a longitudinal, multicentric, observational cohort study in six European countries with different health-care and social care models. It uses clinical assessments, questionnaires and interviews with patients, carers and health care staff, and interrogation of existing databases.

Study Participants

(1) Patients who are suffering from late-stage Parkinsonism classified according to Hoehn and Yahr stage (HY) IV or V in the “On”-state or have developed significant disability (Schwab and England stage 50% or less) in “On”, and (2) their informal carers.

Inclusion Criteria - Late stage Parkinsonism will be defined as patients who are in Hoehn and Yahr stages IV or V during On, or have developed significant disability (Schwab and England stage 50% or less) in “On” and have a disease duration of at least 7 years.

Exclusion criteria: We will exclude patients with PD in Hoehn and Yahr stages I-III., and patients with symptomatic Parkinsonism such as normal pressure hydrocephalus or drug-induced Parkinsonism (onset following treatment with drugs known to cause Parkinsonism), except if persisting following discontinuation of the causative drug. We will exclude patients with Parkinsonism with a clear history of dementia occurring before the onset of Parkinsonism as care pathways for this patient group may differ from that of patients initially presenting with motor problems. In addition, the occurrence of Parkinsonism in the context of advanced dementia is likely to be recorded unreliably.

Specific Information for Care Homes

Research staff will work with care homes to identify potential participants who meet the inclusion criteria. They will provide information sheets for potential participants and for their “consultees” - family carers and care home staff – explaining what the study is about. The researchers will ensure that when indicated a consultee has given written informed consent before a participant is entered into the study.

On the day of the assessment the researcher will ask the patients and an attending carer (care home staff, or family member if one would like to be present) to answer questions about the participants memory, circumstances and the health care received, and the carer’s health and social needs.

The appointment will involve an assessment of movements and physical ability and taking their lying/standing blood pressure, collection of a saliva sample and, with their permission video-/audiotape of the assessment and interview.

After the assessment the researcher will discuss the findings with a specialist in movement disorders who will also watch the video made of movements and replies given to questions. If the participant, and/or carer agrees, they will then be given the opportunity to participate in the open trial. This would mean they will be either receive their normal care, or the research doctor will contact the primary care physician to inform them about the assessment results, and make , recommendations on possible changes to treatment and care,. During this time there will be access to a helpline. The decision on implementation of any recommendations given will remain with the primary health care team. Participants will be offered further assessments after six and twelve months, with two additional short telephone interviews in between and after the last assessment.

Care homes are invited to contribute to the interview if they would like to. We will explore current management arrangements, knowledge needs and experiences of caring for people with Parkinsonism from the perspective of the patient, carers and health care professionals. We hope to learn more about the difficulties of both

providing and accessing care for people with Parkinsonism and how this can be improved.

Governance

The study has been reviewed and approved by NRES Committee London – Camden and Islington Research Ethics committee.

Recruitment Timescale

We started recruiting participants in 2015

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