Clinical Validation of a specific pain scale for Parkinson’s disease

Patient information sheet

Pain and Parkinson’s

Pain is a common problem in Parkinson’s disease (PD). Types of pain that can affect people with Parkinson’s include musculoskeletal pain (aching muscles and bones), dystonia (involuntary muscle contractions or cramps), radicular pain (shooting down an arm or leg), dyskinetic pain (associated with involuntary movements), restless leg syndrome (an irresistible urge to move your legs) and orofacial pain (hurting mouth, teeth or pain across the face).

There has been very little research about the relation of Parkinson’s and pain. Therefore there are currently no recommendations for its management by the National Institute for Health and Clinical Excellence (NICE). Parkinson’s UK has produced an information sheet with the help of Professor K Ray-Chaudhuri on this subject. Bedside assessment of problems such as pain can only be attempted if there is a “tool” or “scale” which is easy to use, relevant to day to day life of people with Parkinson’s and one that has then shown to be effective in clinic.

What is the purpose of this study?

You have been invited to participate in this study to validate PD specific pain scale. Pain is a subjective experience which means that only the person experiencing it knows how it feels. This can make it difficult to determine the effectiveness of certain medications and treatments. A pain scale will help to measure the type and severity of pain, which in turn will help to improve the management of pain. It is important that we know the type of pain, as different types may respond better to different medications. We are also approaching people without Parkinson’s to ensure that the scale is specific to patients with Parkinson’s. This pain scale has been checked by Parkinson’s specialists and reviewed by the King’s expert patient group for people with Parkinson’s.
to make sure that it is relevant and valid. We hope and anticipate that once validated in this study, the scale will be used by GP’s, specialists and PD nurses all across the UK to ensure that the issue of pain in Parkinson’s is addressed and managed in clinic, to improve quality of life of people with Parkinson’s.

**Who has reviewed the study?**

This study has been reviewed by the Newcastle and North Tyneside 2 Research Ethics Proportionate Review Sub-Committee.

**Do I have to take part?**

It is up to you to decide to take part and it will not affect the care you receive if you do not. If you do decide to take part then you will be asked to sign a consent form and will be given a copy of this leaflet.

**What will happen if I take part?**

Participation in this study will involve the completion of a number of already validated (and regularly used) scales in the clinic and the new PD Pain Scale with the clinic doctor/nurse. You will be asked questions about motor- as well as other problems that might be part of your condition or your treatment. Also questions regarding your health-related quality of life and the type of pain you are suffering from will be asked. For most people this takes about 45 minutes.

All of the details you provide will be kept confidential. 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 routine clinical care you receive. If you decide to withdraw at any stage, all data that have been collected by that time might still be used, but no further data will be collected. You will still receive your planned treatment.

**Who is organising and funding the study?**

Validation of this PD pain scale is supported by EUROPAR, a European initiative, and the European PD association (EPDA), as well as by Parkinson’s UK.
What are the possible benefits of taking part?

The information we get from this study will help to look into one of the most poorly treated and yet one of the most common symptoms in Parkinson’s, which is pain. It will also alert the clinicians to try and treat symptoms which might not have been otherwise addressed.

What if something goes wrong?

It is unlikely that you will come to any harm by taking part in this study. There are no “interventions such as injections, drugs” etc. as part of the study apart from routine care for your Parkinson’s. However if you do, there are no special compensation arrangements. If you are harmed due to someone's negligence, then you may have grounds for a legal action but you may have to pay for it. Regardless of this, if you wish to complain, or have any concerns about any aspect of the way you have been approached or treated during the course of this study, the normal National Health Service complaints mechanisms are available to you: ask to speak to the complaints manager of the hospital.

If you have a concern about any aspect of this study you should ask to speak to the researcher who will do their best to answer your questions. If you remain unhappy and wish to complain formally you can contact your local PALS group.

What will happen to the results of the research study?

It is expected that the results of the study will be published in medical journals after the study has been completed, but you will not be identified in any report or publication. The results will also be discussed in patient group meetings, international meetings on Parkinson’s and disseminated through your local branch of Parkinson’s UK.

Contact for further information

If you would like any further information please contact:

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