Participant Information Sheet

A Survey of fatigue among People with Parkinson’s (Ethics ID 23735)

Thank you for taking time to read this information sheet. We are Veena Agarwal (Neuro-degenerative diseases Research Physiotherapist and PhD Student), Dr Emma Stack (Principal Research Fellow and movement scientist specialising in Parkinson’s and PhD Supervisor) and Prof. Ann Ashburn (Professor of Rehabilitation Medicine, Faculty of Health Sciences and PhD Supervisor). We are based with University of Southampton. We would like to invite you to take part in a survey, which is the first part of a PhD studentship funded by University of Southampton, exploring ‘Fatigue in Parkinson’s’. This study has been reviewed and approved by the University of Southampton, Faculty of Health Sciences Research Ethics Committee.

What is the research about?
Fatigue is considered to be one of the three most debilitating symptoms in Parkinson’s. Yet there are many things that we don't understand about it. Fatigue is difficult to diagnose, it often goes unrecognised, and is challenging to treat. This questionnaire aims to explore specific features of fatigue associated with Parkinson’s so that we have better understanding of what makes people with Parkinson’s tired and how they manage it. Knowing more about fatigue will help us suggest ways of managing it better.

Why have I been chosen?
We would like you to participate if you have Parkinson’s and would like to tell us about whether or not you feel fatigued and how it affects you.

What will happen to me if I take part?
We would like you to fill in the enclosed questionnaire and return it by the pre-paid envelope provided within a month. We hope to follow this study with two other projects. One study will look at views of people with Parkinson’s regarding fatigue through in-depth interviews. Another part of this PhD project will also look at whether people with Parkinson’s walk differently when they are tired. If you are interested in taking part in any of these studies, you can provide us with your contact details at the end of the questionnaire. You don’t have to take part in any more research. You can simply complete this questionnaire and return it to us anonymously.

Benefits and Risks
There may be no direct benefits to taking part, but this study will help build on our current knowledge of fatigue in Parkinson’s. There are minimal risks to taking part in this study. In case you are concerned about
the questionnaire with your contact details going astray in the post, you can return your questionnaire anonymously. We hope you find taking part in this study interesting.

**Will my participation be confidential?**

All data will be stored in compliance with the Data protection Act and the University data protection policy. You can return your questionnaire to us anonymously. All returned questionnaires will be coded. Should you send us your questionnaire with contact details, your identifiable data will be kept separate from the main questionnaire. Coded data will be stored on a password protected computer. Hard copies of the questionnaires and identifiable data will be stored in a locked cupboard in a secure office at Southampton General Hospital.

**What happens if I change my mind?**

Participation in this study is completely voluntary, you can chose whether or not you wish to fill and return the questionnaire. After sending us the questionnaire, if you change your mind, please just give us a call, and we will withdraw you from the study. If you return a questionnaire anonymously, you need to quote the ID on the top right of page 1 of this information sheet which will help us locate your questionnaire for withdrawal. Withdrawal from the study will not affect your medical or legal rights.

**What happens if something goes wrong?**

In the unlikely case of concern or complaint, you can contact the Research Governance Office (Rgoinfo@soton.ac.uk) who is independent of this study. You can also contact Professor Ann Ashburn (ann@soton.ac.uk; 02381204583) who is the lead investigator on the SPHERE project.

**End of the study**

We will analyse the data and present the results to professionals and people with Parkinson’s at various forums and conferences. We will also write up the study for a publication in a journal. A report of the findings will also be sent to Parkinson’s UK. Please let us know your contact details if you would like to hear about the study results. This study will be followed by two other projects for another 3-4 years.

**Where can I get more information?**

We hope you find this information satisfactory. If you have any more questions please do not hesitate to contact us. Veena Agarwal can be contacted on vaa1v15@soton.ac.uk and Dr Emma Stack via E.L.Stack@soton.ac.uk. Our address is MP 807, CE 119, Level E, Centre Block, Southampton General Hospital, Tremona Road, Southampton SO16 6YD. Our telephone number is **023 8120 6379**.