



PARTICIPANT INFORMATION SHEET

Study title:	Relationships between physical activity and non-motor symptoms in people with Parkinsons disease and related conditions: Survey	
Principal investigator:	Name: Prasath Jayakaran Department: School of Physiotherapy Position: Senior Lecturer, Associate Dean of Undergraduate studies, and Research supervisor	Contact phone number: (03) 479 7411

Thank you for showing an interest in this project. Please read this information sheet carefully. Take time to consider and you may talk with relatives or friends, before deciding whether or not to participate.

If you decide to participate we thank you. If you decide not to take part there will be no disadvantage to you and we thank you for considering our request.

Why we are doing this research?

We wish to explore the day-to-day influence of non-motor symptoms (e.g., sleep, fatigue, mood, pain, cognition) on physical activity behaviours using a newly developed questionnaire.

We are also assessing the wider use of this questionnaire in clinical studies that may help to inform management strategies for these non-motor symptoms.

Who is funding this study?

This research is funded by the School of Physiotherapy Research Fund and this study is part of Miss Amanda Still's PhD study.

Who are we looking for?

We are looking for fifty adults (age ≥ 18 years) with a diagnosis of Parkinsons disease or a related condition (e.g., atypical parkinsonism's such as Multiple System Atrophy, Progressive Supranuclear Palsy, Corticobasal Degeneration or Dementia with Lewy Bodies) who live in

New Zealand and do not have of the following medical conditions; Stroke, Multiple Sclerosis, Traumatic brain injury, Vertigo, spinal cord injury, or peripheral neuropathy.

If you participate, what will you be asked to do?

If you agree to participate in this study, we will ask you to do three things:

1. Complete 3 daily multichoice questionnaires (sent to your smartphone [or a loaned study smartphone] or paper-based copies) in the morning, afternoon and evening for 7-consecutive days. These questionnaires include 14 items asking about any current non-motor symptoms you are experiencing (mood, fatigue, cognition, pain, sleep and wakefulness problems) and the amount of physical activity you have participated in today. Answering these 14-items is expected take between 5 and 10 minutes to complete.
2. On day 8 you will be asked to complete another set of questions (a web link will be sent to your e-mail or paper-copies will be posted to you). These questions will also ask you about any non-motor symptoms and the physical activity you have completed over the past 7-days. This set of questions is estimated to take no longer than 60 minutes to complete.
3. Have your motor symptoms assessed via ZOOM video call at home. These assessments are likely to be similar to the ones your neurologist might have done with you. Most tasks are completed sitting down with only one standing task and one 20 metre walking task (if your space at home permits). Should you agree, we will video-record this assessment (via ZOOM) to be used for research purposes only. If you have 'ON' and 'OFF' symptoms, we will schedule this assessment at a time when you feel like your medications are effective and your motor symptoms are reduced.

Please be advised that you may decide not to take part in the study at any stage, without any disadvantage to yourself.

We will provide you with a \$50 grocery voucher after completing the 8-days of questionnaires and the motor assessment.

Is there any potential risk of discomfort or harm from participation?

There should be no discomfort caused by any of the at home motor symptom assessment tasks. The main risk of taking part in this study is during the standing (sit to stand from a chair) and walking task (walk 10m, turn around, walk back 10m) when there is a slight risk of losing balance while you are completing the task. We will minimise this risk by: (i) ensuring we have asked you about your balance and walking abilities beforehand to decide whether or not we think the task is safe for you to perform, (ii) ensuring that you use your walking

device (e.g., frame or cane) and/or have a support person present if needed, (iii) ensuring you have taken your medications beforehand so that they are effective during the standing and walking tasks, and (iv) prior to the assessment we will ask for your physical address so that we know where to send help should any medical event occur during the assessment.

If you feel unsure about attempting any task you can say you do not wish to complete that particular task.

You are more than welcome to have a support person with you during your motor symptom assessment.

If any of our questionnaires or assessments show that your non-motor or motor symptoms are greatly impacting your daily function we will advise you to see your General Practitioner or arrange a consult with your local Parkinson's nurse. Alternatively, with your consent we can contact them on your behalf.

What information will be collected, and how will it be used?

An initial set of questions will be delivered over the phone to determine your eligibility to participate. These initial questions will include confirming your diagnosis of Parkinsons disease or a related condition. Once we have confirmed your eligibility we will ask whether or not you have a cell phone and if you can confidently use it. We will also ask you about any medications you are taking for your Parkinsonism (name, dose, times per day) and about your current walking ability to determine your safety to complete the at home motor assessment.

The information collected will help us to know if the daily questionnaires delivered over 7- consecutive days can be used to easily capture the relationship between day-to-day fluctuations in non-motor symptoms and physical activity behaviours. The questionnaire may also be useful in future clinical studies to help inform management strategies for these non-motor symptoms.

What about anonymity and confidentiality?

All information obtained from this study will be kept private and confidential, including the video-recording of the motor assessment. To make sure of this, you will be given a unique identification number. Information used for any publication will be kept anonymous. Information from all participants (~50 people) will be summarised as a group for publication. Your individual data will not be published. The researchers working on this project may have access to the anonymised data, but the data collected will be securely stored in such a way that only these people will be able to gain access to it. At the end of the project, any personal information will be destroyed and any raw data on which the results of the project depend will be kept in secure storage for ten years, after which it will be destroyed.

If you agree participate, can you withdraw later?

Participation in this study is entirely voluntary. You may choose to withdraw from the project before its completion at any time without any disadvantage to yourself. While we would like to use the data collected up until the point of withdrawal in our analysis, you may request this to be removed, if you wish.

Any questions?

If you have any questions about this project now or in the future, please feel free to contact either:

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This study has been approved by the University of Otago Human Ethics Committee (Health).

*If you have any concerns about the ethical conduct of the research you may contact the Committee through the Human Ethics Committee with the reference number **H22/152**. Administrator (phone +64 3 479 8256 or email gary.witte@otago.ac.nz). Any issues you raise will be treated in confidence and investigated and you will be informed of the outcome.*