



The University of Sydney

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# CDDS

Centre for

Developmental

Disability

Studies

ABN: 69 082 298 575

## **An investigation into the significance and impact of bowel and bladder dysfunction on personal burden for people who have Parkinson's disease.**

### Participant Information Statement

You are invited to participate in a telephone survey that will ask you about any bowel and or bladder problems you may be experiencing following a diagnosis of Parkinson's disease. This invitation is hoping that you or someone you may know would be interested in contacting us to inform this important research with first hand information about some of the difficulties people with Parkinson's disease have with their bowel or bladder functions.

Bowel and bladder difficulties are reported widely in the Parkinson's disease (PD) literature. Many people who have PD complain of constipation and of waking up frequently at night to pass urine to name but a few. However little is known about what affect these and other bowel and bladder difficulties have on the sufferer's lifestyle and while bowel and bladder problems are often seen as an inevitable part of PD there is little scientifically rigorous evidence which demonstrates or supports this perception.

It is expected that this study will provide scientifically rigorous evidence by gathering information that will recognise and confirm the impact of bowel and bladder difficulties on personal burden, within a population of people with PD.

**If you meet the following criteria we would very much like to talk with you.**

- **If you have been diagnosed as having PD.**
- **If you are able to converse in English via a telephone line.**
- **If you are or have experienced some difficulties with either; your bowel or your bladder or both your bowel and bladder.**

### **What do you need to do?**

If you are interested in participating in this telephone survey please contact Joanne Lawrence on (02) 9739 2367, to arrange a suitable time to telephone you to complete the survey. The telephone survey will take about 30 minutes to complete.

### **Who is conducting this study?**

This study is being conducted by Joanne Lawrence who is a continence nurse working in NSW. Joanne is undertaking her PhD at the University of Sydney, Faculty of Medicine. She is supervised by Professor Parmenter (University of Sydney) Professor McDonald (Australian Catholic University); and Professor Madden (University of Sydney).

Your participation is voluntary and, should you decide to withdraw at any time, your decision will be respected and not challenged in any way. All people participating in this research will be allocated a unique code number that will be used only to monitor the response rate and will not allow you to be

personally identified.

All information will be stored securely and archived in accordance with the National Health and Medical Research Council recommendations. Information obtained from this survey will eventuate in a research report and publications. No individual participants will be able to be identified in any of these reports or publications.

If you have any further questions, please contact Ms Joanne Lawrence on (02) 9739 2367.

This information sheet is for you to keep. It is anticipated that results from this study will help inform consumers with PD as well as their health practitioners who work in a variety of specialist and community health areas. To help them better understand the significance and impact that bowel and bladder problems have in the life of a person with Parkinson's disease.

We hope you will agree to participate.

Yours sincerely

Ms. Joanne Lawrence      Professor Trevor Parmenter      Professor Richard Madden

Professor Tracey McDonald

The Human Research Ethics Committees at The University of Sydney has approved this study. In the event that you have any complaint or concern about the way you have been treated during the study, or if you have any query that the Investigator has not been able to satisfy, you can contact the Senior Ethics Officer, Ethics Administration, University of Sydney on (02) 9351 4811 (Telephone); (02) 9351 6706 (Facsimile) or [gbriody@usyd.edu.au](mailto:gbriody@usyd.edu.au) (Email).

Any complaint or concern will be treated in confidence and will be fully investigated and the participant making the complaint will be informed of the outcome.

**This information sheet is for you to keep**