

The true costs of Parkinson's



Emma

Project information

Lead researcher	Dr Emma McIntosh
Location	University of Oxford
Cost	£250,000 over 3 years
Start date	February 2011
Type of project	Senior Research Fellowship
Project code	F-1001

Project background

Parkinson's is a complex condition and the impact it has on people's lives is often hidden. This makes the true costs of Parkinson's and the value of treatments and services difficult to measure. But it's absolutely vital that we have strong evidence about the costs of living with Parkinson's so that we can:

- **Make the case to funding bodies.** The National Institute for Health and Clinical Excellence (NICE) makes decisions about which treatments and therapies are made available on the NHS. If we can prove the value for money of new and existing treatments and therapies, it will lead to better services and care for people living with Parkinson's.
- **Show the wider impact of Parkinson's.** Parkinson's is a complex condition that affects everyone differently. Living with Parkinson's can affect things like mood, ability to communicate, confidence and self-esteem which can all have a major impact on people's ability to look after themselves. But these vital features of Parkinson's are

rarely measured or monitored. We need to highlight the full impact of the condition so that we can demand services and care that meet the diverse needs of people with Parkinson's and helps them stay independent for as long as possible.

- **Recognise the contribution of carers.** Recent research suggests that the care provided by carers may account for up to 80% of annual Parkinson's costs. Emma also wants to understand and measure the impact caring has on the quality of life and health of carers of people with Parkinson's. Highlighting the vital role that carers play and how caring affects them will hopefully lead to greater support and services for carers.

What the researchers are doing

In this project, Emma aims to find the answers to two questions. First, which treatment benefits do people with Parkinson's and their carers most value? And second, how much do these treatments and services actually cost?

How the research will help people with Parkinson's

By the end of Emma's fellowship she hopes to show what treatments and services people living with Parkinson's most want, and information on the costs of these treatments. This means that when we campaign for better services for people with Parkinson's, we'll have the numbers and evidence to back up our case. This is crucial when funding is limited.

The results will also be made available to key decision-makers like NICE and the Department of Health. This will mean they have accurate information when deciding whether to fund existing and future treatments for people with Parkinson's.

For more information, please talk to the Research Team

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