

Funded by
PARKINSON'S^{UK}
CHANGE ATTITUDES.
FIND A CURE.
JOIN US.

**Sheffield
Hallam
University** | Centre for Health
and Social Care
Research

Putting people with Parkinson's in control: exploring the impact of quality social care

Prof Ann McDonnell

Dr Fiona Kennedy

Brendan Wood

Bhanu Ramaswamy

Prof Malcolm Whitfield

Prof Angela Mary Tod

February 2014

Acknowledgements

This research was made possible by the help and support of a large number of people, and a debt of gratitude is owed to them all. In particular the research team would like to thank the following:

- Parkinson's UK for funding the study and for the advice and support of Donna O'Brien and Sarah Gray from Parkinson's UK.
- Dr Oliver Bandman (Sheffield Teaching Hospitals NHS Foundation Trust) and Joanne Rose (Rotherham NHS Foundation Trust) for their clinical advice and expertise.
- Pamela Goff, (Sheffield branch, Parkinson's UK) and Errol Guest (Doncaster support group, Parkinson's UK) for their valuable advice at key points in the study and their contributions on the Advisory Group.

We would like to express our thanks especially to the participants of the study, in particular the four people with Parkinson's who agreed to be case studies. We are very grateful to the participants for their willingness to share their experiences and views.

PUTTING PEOPLE WITH PARKINSON'S IN CONTROL: EXPLORING THE IMPACT OF QUALITY SOCIAL CARE

INTRODUCTION

Parkinson's is a progressive and incurable condition. It is the second most common neurodegenerative condition in the UK. There are approximately 127,000 people with Parkinson's in the UK. This number is expected to increase as people live longer.

Cost-effective social care services are a priority in the future delivery of adult social care. This study aimed to explore how the provision of quality social care interventions impacts on quality of life, health and wellbeing and future care costs for people with Parkinson's and their carers.

In the current period of austerity, there are now increasing cuts to services such as carers' breaks and advocacy services and reduced access to aids and adaptations. Many local authorities are tightening service eligibility criteria.

Social care includes a variety of interventions such as personal care at home, support for the person's carer, Telecare, aids and adaptations at home or support to engage in hobbies and interests outside the home. Social care can be provided by a number of different agencies including formal care provider organisations as well as family and friends.

This report presents the findings from a research project conducted by Sheffield Hallam University and in partnership with Parkinson's UK. Parkinson's UK is a national charity which aims to improve life for everyone affected by Parkinson's.

METHODS

The study was conducted in three stages and adopted case study, individual interview and focus group methods.

The research developed insight into social care needs and requirements, criteria for a segmentation model, pen portraits, an economic model, and a communications strategy. These are all available in the full report from Parkinson's UK.

KEY FINDINGS

Finding out and accessing what's available

There was a consistent theme that people with Parkinson's did not know what was available or how to access it in terms of social care.

What's important about social care

Control, choice and maintaining independence emerged as important aspects of social care for all. Valued aspects of social care that were specific to Parkinson's requirements were that services:

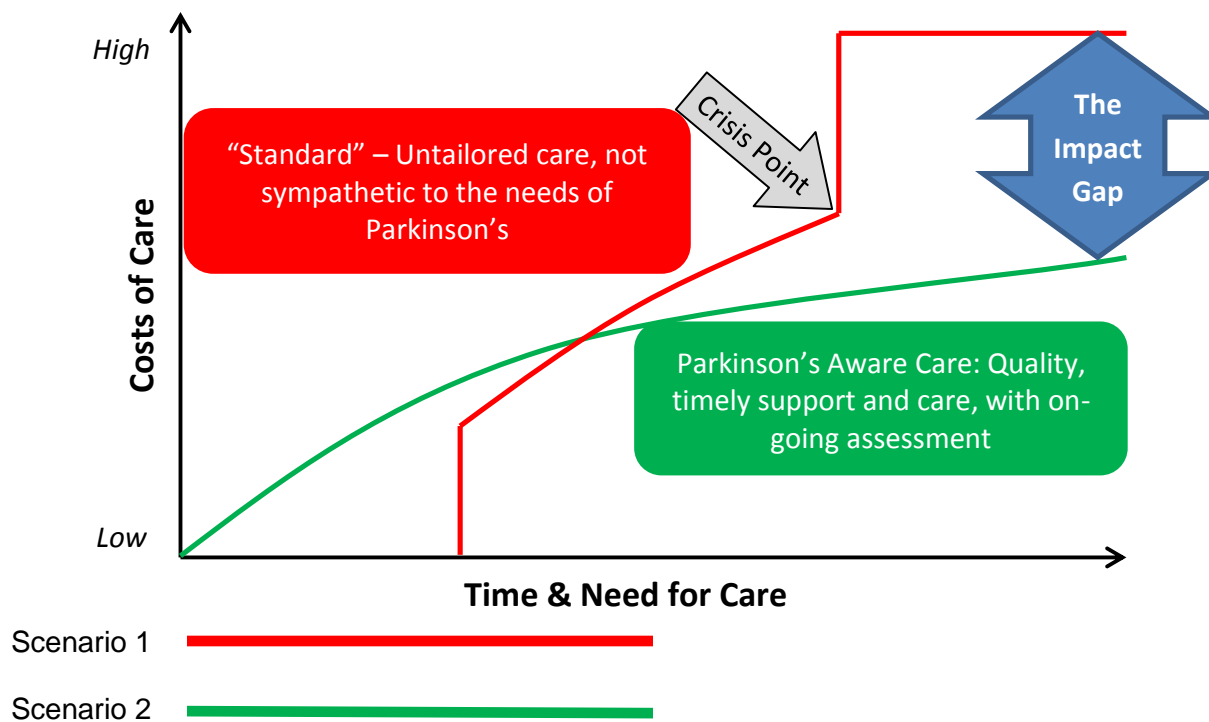
- *Understand Parkinson's*
- *Understand medication (especially timing)*
- *Allow the person with Parkinson's time*
- *Understand the person with Parkinson's is the expert*
- *Recognise the impact of social inclusion*
- *Have regular reassessment of needs relating to Parkinson's symptoms and treatment*

Benefits of social care

Benefits of social care were interrelated - for example if there is a benefit to the person with Parkinson's (e.g. improved safety) this might reduce the burden for the carer, or result in the avoidance of wider societal costs such as residential care or hospital admissions. While some of the benefits take immediate effect, some of these benefits also have long term implications and can result in prevented events and reductions in the need for increased health and social care resource in the future.

The Impact Gap

The study developed the concept of the 'Impact Gap' illustrating how the costs of social care can be reduced by the timeliness and quality of "Parkinson's aware" social care.



KEY RECOMMENDATIONS

Key recommendations included implications for commissioners and providers of social care services. The overarching recommendations were as follows.

1. Commissioners and providers should ensure that people with Parkinson's receive good quality social care that maximises control, self-management, independence and social contact.
2. There should be an anticipatory approach to social care provision and commissioning that ensures timely access and receipt of social care for people with Parkinson's and their carers. The benefits are:
 - prevention of avoidable events
 - prevented or delayed admission to residential care homes
 - averting crisis
 - more accurate prediction of future care and resource requirements through better care planning
 - reduced health and social care costs
 - improved patient and service user experience
3. Social care for people with Parkinson's and their carers should be characterised by control and choice for the service user. This is irrespective of whether the care package is managed directly by the person with Parkinson's or their carer or provided by an outside agency.
4. Service user experience should be a key performance indicator to inform the allocation and renewal of care provider contracts for patients with Parkinson's and similar neurological conditions.

CONCLUSION

The research demonstrated very powerfully the need for care packages sympathetic to those with neurological disorders such as Parkinson's. It explored how this impacted on their quality of life and wellbeing and what this could mean in terms of the escalating need for, and the cost of care.

Sheffield Hallam University

Putting people with Parkinson's in control: exploring the impact of quality social care

MCDONNELL, Ann, KENNEDY, Fiona, WOOD, Brendan, RAMAWSWAMY, Bhanu, WHITFIELD, Malcolm and TOD, Angela

Available from the Sheffield Hallam University Research Archive (SHURA) at:

<http://shura.shu.ac.uk/7965/>

Copyright and re-use policy

Please visit <http://shura.shu.ac.uk/7965/> and <http://shura.shu.ac.uk/information.html> for further details about copyright and re-use permissions.