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

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

## **INTRODUCTION**

This report presents the findings from a research project funded by and conducted in partnership with Parkinson's UK.

## **AIMS**

The 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.

## **BACKGROUND**

There are approximately 127,000 people with Parkinson's in the UK. Parkinson's is the second most common neurodegenerative condition in the UK and is set to become increasingly common as life expectancy increases. Parkinson's is a progressive and incurable condition. Although it can be well-managed with medication and treatment, there is no prospect of a person's condition improving over time and there is no cure currently.

Parkinson's UK is a national charity which aims to improve life for everyone affected by Parkinson's. Central to this aim is to be able to make the case to key organisations that provision of appropriate health and social care interventions improves the wellbeing and enhance positive outcomes of both the person affected by Parkinson's and their carers. Although there is a wealth of anecdotal evidence that low-level social care interventions can improve outcomes for people living with Parkinson's, there is little data or hard evidence to confirm these beliefs.

Social care can include 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. 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. Parkinson's UK believe it is timely to begin to focus on the positive outcomes that can be gained from these types of interventions.

## **METHODS**

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

### **Stage 1 – Collective case study of social care interventions**

Four individual cases were identified with each case representing a person with Parkinson's. For each case an in-depth interview was conducted with the person with Parkinson's. Following this initial interview up to three additional interviews were conducted with the person's family members, voluntary sector or social care providers. In-depth interviews focused on the nature and impact of the social care interventions.

### **Stage 2 – Consultation with wider stakeholders**

Two focus groups were undertaken to test out, expand upon and verify the preliminary findings from the case studies. The first focus group included people with Parkinson's and their carers (both current users and non-users of social care) and Parkinson's Information and Support Workers (ISWs). The second focus group involved professionals who delivered, organised and managed services for people with Parkinson's and their carers. A further telephone interview took place with a former service commissioner who was working in an integrated health and social care trust.

Data analysis for stage 1 and 2 was undertaken using the 'framework approach' to qualitative analysis outlined by Ritchie & Spencer (1994).

### **Stage 3 – Development of project outputs**

#### *Segmentation*

Cross-case and cross theme analysis was conducted to identify key client characteristics and themes that influence quality social care requirements. This was used to segment the findings to explain how social care needs should be delivered to different segments of the target audience. Pen portraits were developed to illustrate variations in social care need and provision.

#### *Modelling clinical and economic impact*

Following a selective literature review we developed a simple, preliminary logic model based upon a number of hypothesis and assumptions. This reflects that although bespoke "Parkinson's aware" care does not affect the progress of neurological degeneration it can impact positively on the effect of the social care itself by affecting the trajectory of deterioration associated with good management of symptoms and complications. At present the assumptions are populated with numbers based upon the 'best guess' of the author and are for demonstration purposes only. Further research would provide robust figures and to develop the model further. However, the initial version of the economic model does demonstrate the potential for future cost savings by commissioning "Parkinson's aware" social care.

## Outputs

The research developed insight into social care needs and requirements, the 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

Table 1 provides an overview of the themes identified in the study.

Table 1: Themes

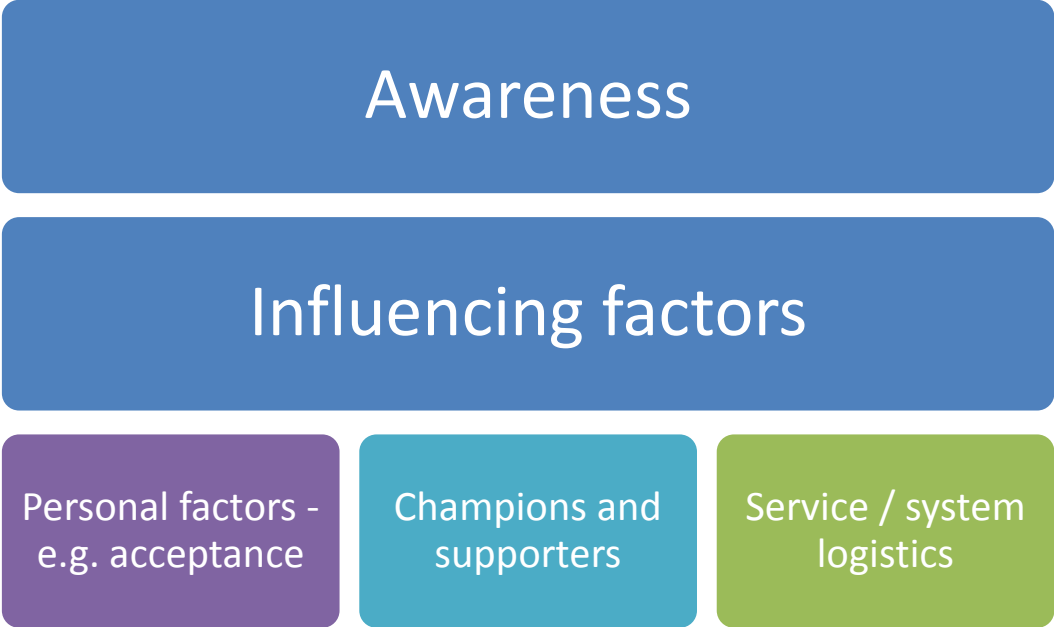
Themes	Sub-themes
<b><u>Social care</u></b> interventions	<ul style="list-style-type: none"> <li>• Received</li> <li>• Desired</li> </ul>
<b><u>Finding out</u></b> and <b><u>Accessing</u></b> what's available	<ul style="list-style-type: none"> <li>• Awareness</li> <li>• Influencing factors               <ul style="list-style-type: none"> <li>○ Personal factors – e.g. acceptance</li> <li>○ Champions &amp; supporters</li> <li>○ Service/system logistics</li> </ul> </li> </ul>
<b><u>What's important</u></b> about social care in <b><u>general</u></b>	<ul style="list-style-type: none"> <li>• Choice</li> <li>• Control</li> <li>• Maintaining independence</li> <li>• Positive personal qualities of the care worker</li> <li>• Demographics of the care worker</li> <li>• Seeing the person as a whole</li> <li>• Continuity/consistency</li> <li>• Flexibility</li> <li>• Respecting dignity</li> <li>• Timing</li> <li>• Regular re-assessment of needs</li> </ul>
<b><u>What's important</u></b> about social care relating to <b><u>Parkinson's specifically</u></b>	<ul style="list-style-type: none"> <li>• Understanding Parkinson's (symptoms &amp; fluctuations)</li> <li>• Understanding medication (especially timing)</li> <li>• Allowing the person with Parkinson's time</li> <li>• People with Parkinson's are the expert</li> <li>• Social inclusion</li> <li>• Regular reassessment of needs</li> </ul>
<b><u>Benefits</u></b> of social care (including <i>prevented events</i> )	<p><u>Psychological benefits</u></p> <ul style="list-style-type: none"> <li>• Psychological wellbeing &amp; quality of life of the person with Parkinson's</li> <li>• Social contact/<i>prevent social isolation</i></li> <li>• <i>Prevent relationship breakdown</i></li> </ul> <p><u>Physical benefits</u></p> <ul style="list-style-type: none"> <li>• Mobility</li> <li>• Independent living</li> <li>• Improved safety – e.g. <i>reduced falls/</i></li> </ul>

	<p><i>accidents</i></p> <ul style="list-style-type: none"> <li>• <i>Prevent deterioration of condition or general health</i></li> </ul> <p><u>Carer benefits</u></p> <ul style="list-style-type: none"> <li>• Psychological wellbeing of carer</li> <li>• <i>Prevent carer becoming ill</i></li> <li>• <i>Prevent relationship breakdown</i></li> </ul> <p><u>Service/societal benefits</u></p> <ul style="list-style-type: none"> <li>• <i>Avoiding live-in/residential care</i></li> <li>• <i>Avoid hospital admissions/GP visits</i></li> <li>• <i>Saving in costs of health and social care</i></li> </ul>
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**Finding out and accessing what’s available**

One of the key aspects relating to finding out and accessing social care for people with Parkinson's and their carers was the need for awareness of 'what might be out there' in terms of social care.

*Figure 1: Finding out and accessing what's available*



**Awareness**

Across both the case studies and the focus groups it was evident that the process of finding out about social care services was often by chance rather than in any systematic way. Many individuals with Parkinson's and their carers highlighted that they didn't know where to go to start the process of getting help. There was a strong sense that 'you don't know what you don't know'.

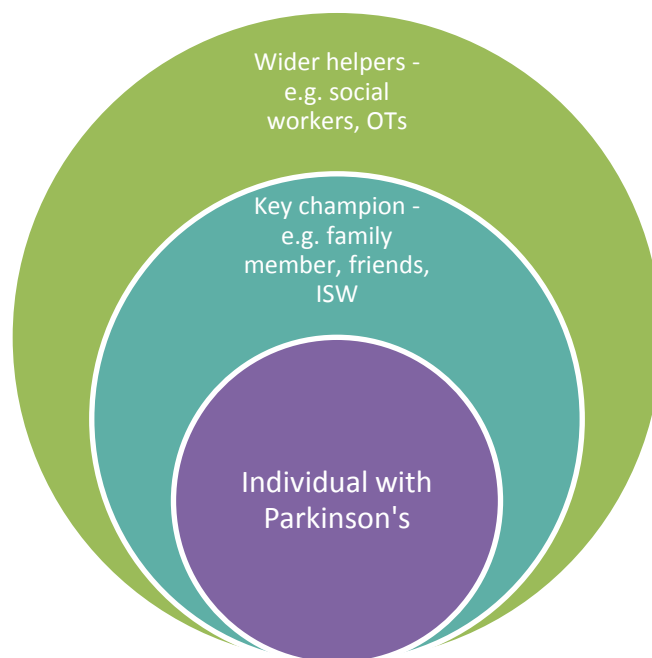
Often it was evident that people with Parkinson's and their carers couldn't see what might be helpful until they were in a crisis situation and really needed immediate help. There were no reported instances of individuals being informed about, given advice or offered social care support or information at the time of diagnosis. Being unable to access social care when needs first arose, rather than when crises occurred, meant that the preventive benefits of early social care failed to be realised. It was also highlighted that it was important for professionals (e.g. GPs, social workers, ISWs) to keep up-to-date about what social care was available.

## Influencing factors

The important factors that influenced the process of finding out and accessing what's available in terms of social care are:

- Personal factors
- Champions and supporters
- Service/system logistics

*Figure 2: Champions and supporters of people with Parkinson's*

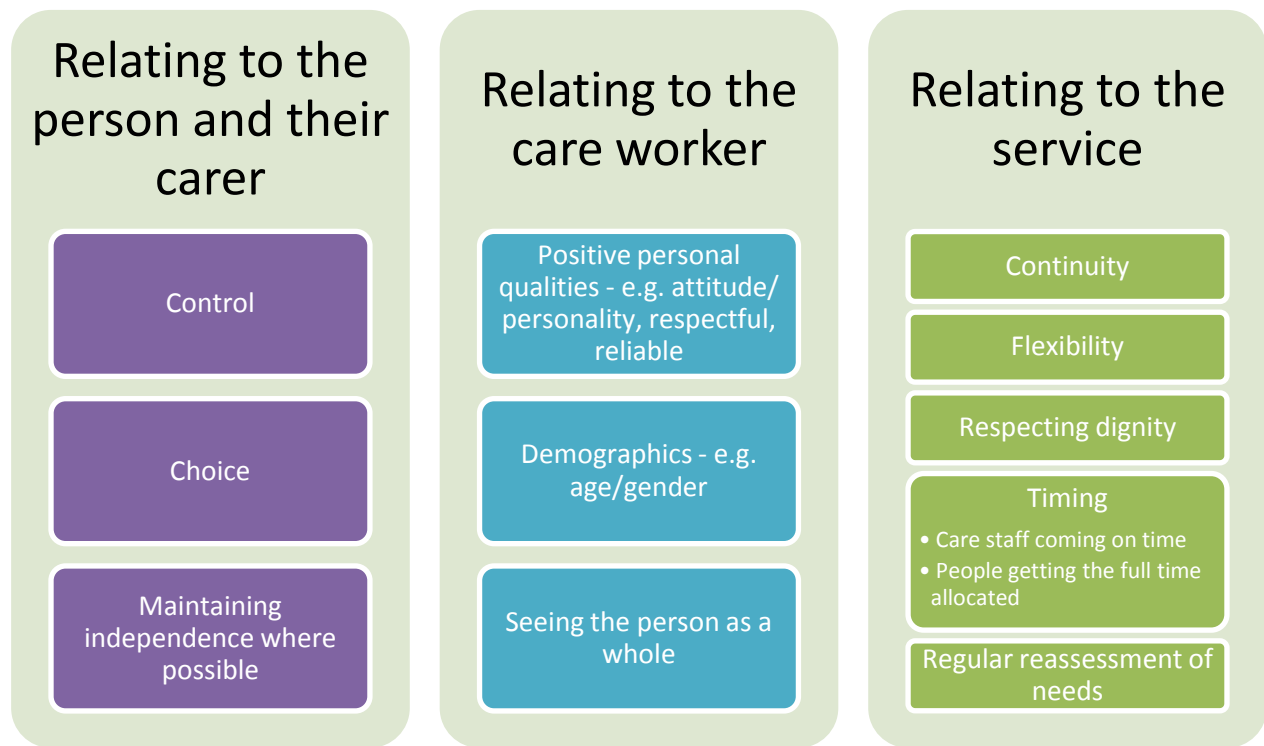


## What's important about social care

The study identified what was important about social care in general, as well as specifically for people with Parkinson's. In terms of what was valued about social care in general, aspects related to three key groups in terms of relevance for the person themselves, carers (formal and informal) or the service.



Figure 3: What's important about social care in general



The figure overleaf illustrates these, which all centre around the importance of understanding Parkinson's.

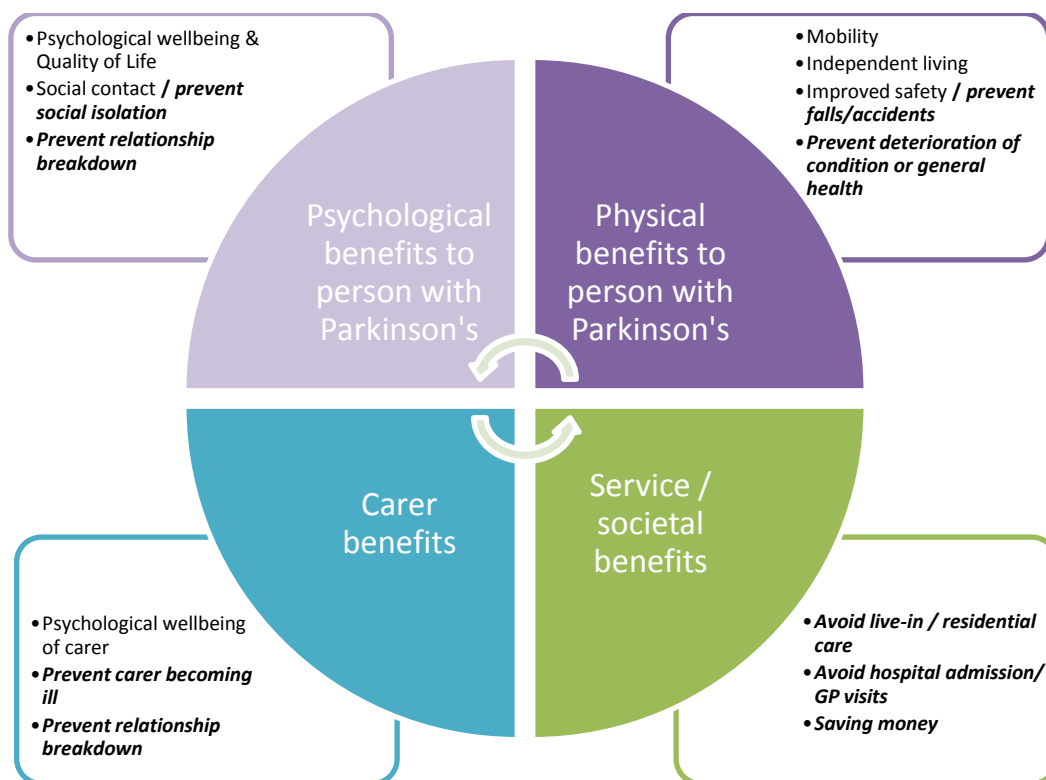
Figure 4: What's important about social care relating to Parkinson's specifically



### Benefits of social care

The diagram overleaf indicates how benefits of social care are 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.

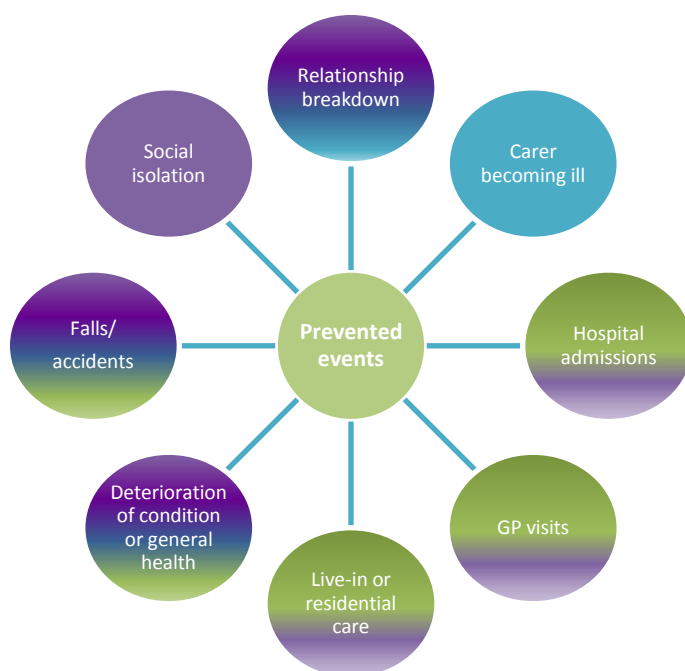
Figure 5: Benefits of social care (**preventive benefits in bold**)



## Prevented events

In addition to the immediate impact of social care for people with Parkinson's and their families, there was also evidence of the potential prevention of a number of negative and costly consequences. These prevented events are integrated into the previous figure but they are also specifically highlighted in figure 6 overleaf.

Figure 6: Prevented events



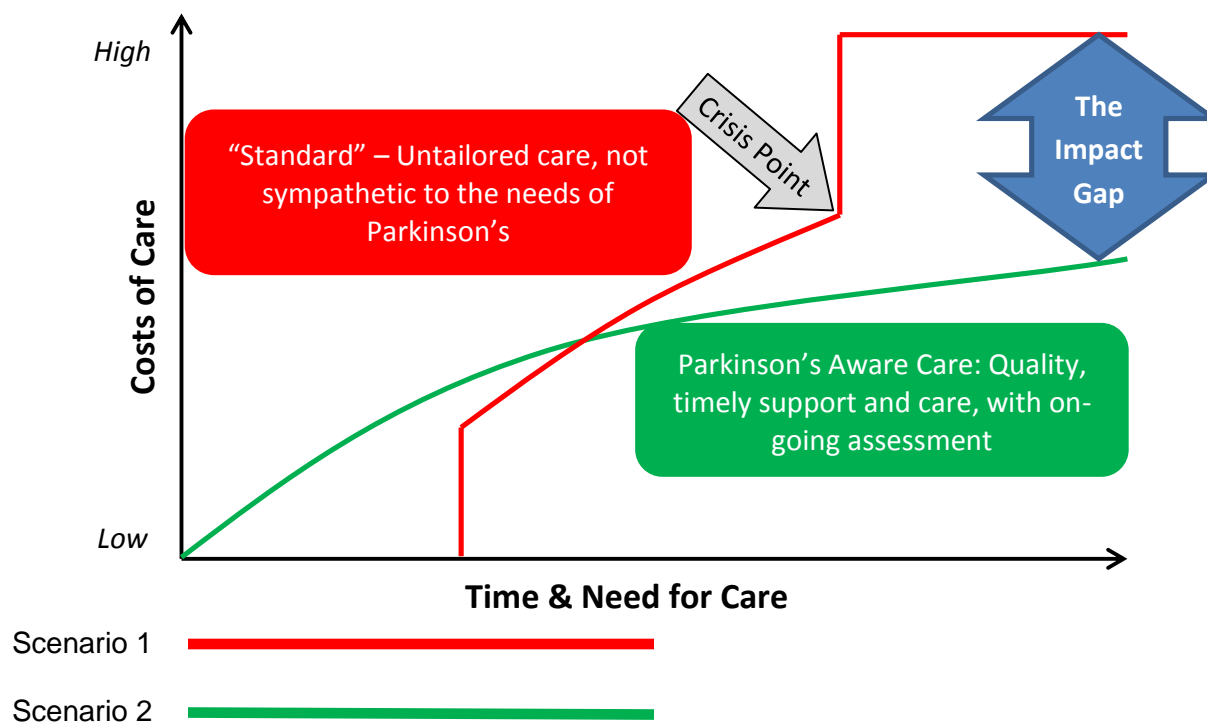
### ***The Impact Gap***

We attempt to show the difference between what might happen if poor care or inadequate planning for the future occurs and when high quality and timely care that is tailored to the needs of someone with Parkinson's is received. We have called this the '**Impact Gap**'

The diagram overleaf illustrates the Impact Gap using two possible outcome scenarios using the same case. The case is a person living with a partner who cares for them. Both are increasingly frail.

Within scenario 1, a standard care package of domiciliary visits is in place. There is no care for the carer and the package does not take into account the timing of medication and the needs of someone with a neurological disorder such as Parkinson's. Time passes and the disease trajectory increases. Although small amounts of standard additional care are added, the couple come to a crisis point. The carer becomes ill and can no longer cope and an accident happens at home. Both individuals required hospital treatment and ongoing residential care.

Scenario 2 attempts to illustrate how the outcome could have been different with an earlier, timely care package which is sympathetic to the needs of the person with Parkinson's. The needs of the carer in terms of respite are addressed as well as additional social and wellbeing needs. Planning ahead is encouraged through support and easy access to information. The outcome is very different in terms of the need for expensive residential and hospital care. However, more importantly, the couple receive a quality care experience and remain independent, in control and able to live in their own home.



## KEY RECOMMENDATIONS

Key recommendations based on the findings are provided here. These were linked to the relevant domains of the Adult Social Care Outcomes Framework (Department of Health 2013). Additional recommendations were made regarding implications for Parkinson's UK.

### Domain 1. Enhancing quality of life for people with care and support needs

#### ***Overarching recommendation 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.

#### ***Implications for commissioners***

- Systems and structures need to be put in place to facilitate effective joint commissioning between CCGs and local authorities. This will enable the commissioners to meet the national metrics outlined in the Better Care Fund requirements including delayed transfer in care and avoidable hospital admissions.

- Commissioners should use existing contracting mechanisms with local service providers such as enhanced care provision to ensure that social care provided to people with Parkinson's is tailored to meet the specific care needs which are associated with their symptoms and disease trajectory. This should include a requirement to provide staff in provider organisations with training to ensure that their services are 'Parkinson's aware'.
- Commissioners should take steps to include in the contracting process a recommendation that this training is provided by approved organisations who have the specialist knowledge required.
- Effective and efficient commissioning would be supported by identifying populations with similar care needs to Parkinson's e.g. other neurological conditions and contracting enhanced services on a needs-led basis for this wider population. The needs of this wider population would be reflected in the Joint Strategic Needs Assessment (JSNA).

### ***Implications for providers***

- Providers should take positive steps to ensure that their services are 'fit for commissioning' and tailored to the needs of people with neurological conditions. This should include the provision of training in the needs of people with a range of neurological conditions including Parkinson's.
- Providers should actively seek out the endorsement or accreditation of their services by organisations such as Parkinson's UK.

## **Domain 2. Delaying and reducing the need for care and support**

### ***Overarching recommendation 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. Such early intervention will achieve the following benefits:***

- 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

### ***Implications for commissioners***

- Commissioners should use existing contracting mechanisms with local service providers such as enhanced care provision to ensure that social care provided to people with Parkinson's (and similar conditions) includes early assessment and regular reassessment to identify changing care needs.

- Local population level data e.g. epidemiological and demographic data should be analysed to identify current and predicted service need for people with neurological conditions. The need identified should form part of the JSNA.

### **Domain 3. Ensuring that people have a positive experience of care and support**

#### ***Overarching recommendation 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.***

#### ***Implications for commissioners***

- Commissioners should ensure through the contracting process that there is sufficient flexibility in how services are delivered to ensure that all services include some element of user control and choice.
- The provision of control and choice should be equitable so that no individual or group of services users is disadvantaged through the inability to exercise control and choice.

#### ***Overarching recommendation 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.***

#### ***Implications for commissioners***

- Commissioners should only contract with organisations to provide care for patients with Parkinson's and similar neurological conditions who can demonstrate positive service user experience. These organisations should be required to demonstrate that they have used robust evaluation methods to capture and measure this.

### **Domain 4. Safeguarding adults whose circumstances make them vulnerable and protecting from avoidable harm.**

This research did not focus on safeguarding issues relating to people with Parkinson's and their carers. However, it is clear from the findings that provision of good social care as described here enhances safety and reduces harm both for people with Parkinson's and their carers. If social care services are commissioned and delivered in line with the recommendations outlined here, this would enhance the provision of safer care to this vulnerable population.

## **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.

As social care is a devolved issue, and the report focussed on the experiences of those in receipt of social care in England, the recommendations are directed at relevant audiences in England. However the messages are likely to be of interest to audiences in the rest of the UK.

The findings indicate that in order to achieve improved outcomes for those with Parkinson's and their carers, some behaviour changes are required by significant stakeholders. This includes:

- Parkinson's UK
- People with Parkinson's
- National and local policy makers
- Local commissioners of health and social care
- Partner organisations such as other third sector
- Champions, supporters and interest groups
- Influencers – media, health organisations and politicians



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