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

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## ***Executive Summary***

### **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:

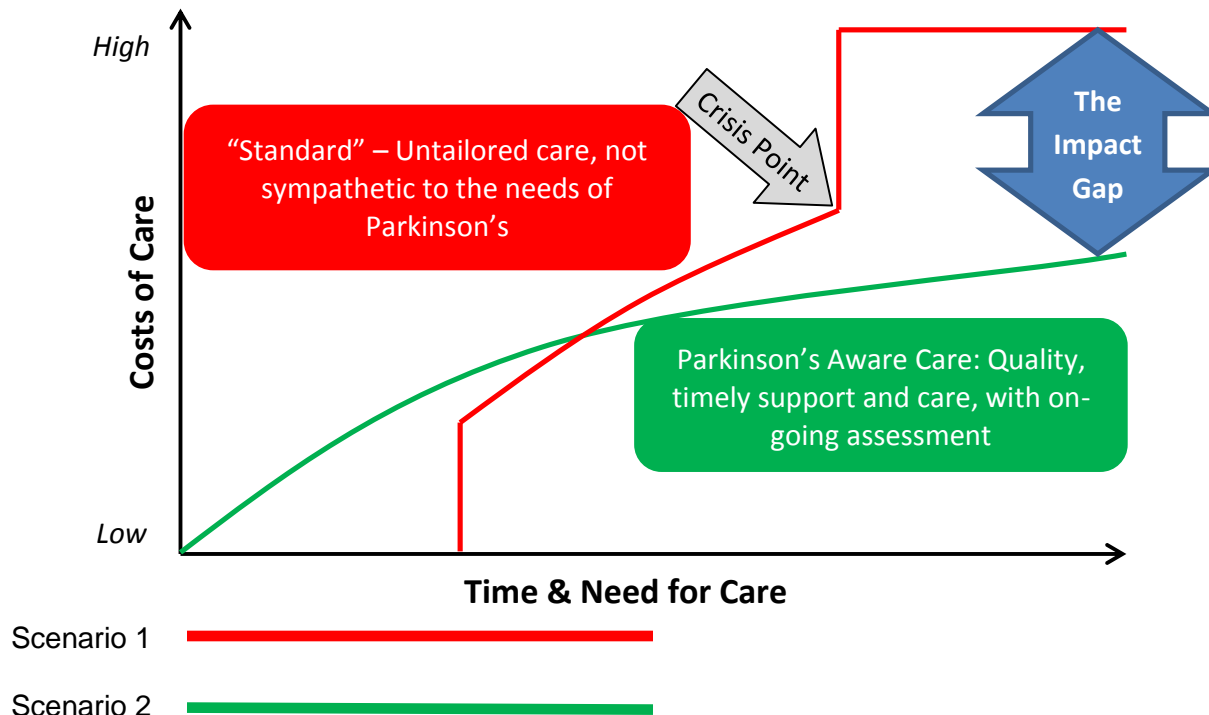
- *Understand Parkinson's*
- *Understand medication (especially timing)*
- *Allow the person with Parkinson's time*
- *Understand the person with Parkinson's is the expert*
- *Recognise the impact of social inclusion*
- *Have regular reassessment of needs relating to Parkinson's symptoms and treatment*

### 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.

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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. 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.

Following a brief overview of the background and methods, a summary of the main findings will be presented. Recommendations for different audiences regarding interventions and action to support people with Parkinson's and their carers are also highlighted.

## **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. The average age of onset of Parkinson's is between 50-60 years of age, although one in seven people will be diagnosed before the age of 50 and one in 20 will be diagnosed before the age of 40 (Parkinson's UK 2014).

Parkinson's is a progressive and incurable disorder. 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 is a fluctuating and unpredictable condition. Everyone with Parkinson's is different but many people report that symptoms can fluctuate rapidly during the day or week by week. This can include sudden freezing, tremor, muscle rigidity and slowness of movement, or other less visible symptoms such as pain and fatigue, sleep problems or anxiety. There are also side effects from medication.

Parkinson's UK is a national charity which brings people with Parkinson's, their carers and families together via a network of local groups, a website and free confidential helpline and information and training on every aspect of Parkinson's.

One of the goals for Parkinson's UK is to ensure that they 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. Target audiences for this message include adult social care departments, national policy makers, Clinical Commissioning Group leads, Health and Wellbeing Boards, commissioners and health and social care professionals.

In 2009 the All Parliamentary Group on Parkinson's report 'Please Mind the Gap: Parkinson's Services Today', people with Parkinson's reported poor information provision and signposting,

especially with regard to social care. The report also identified lack of awareness of the cost effectiveness of elements of care for people with Parkinson's among service planners and commissioners. One of the recommendations was that commissioners and planners of health and social services should consider the long-term cost implications of providing services that only respond to those with high-end needs, and the benefits of a more preventative approach for Parkinson's services.

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. Quantifying the impact of social care cuts on those with Parkinson's is difficult as no data is collected in social care "by condition". However for a recent BBC Newsnight investigation (2013) Parkinson's UK analysed NHS data on the condition and found that people over 65 with Parkinson's are three times more likely to have an unplanned or emergency admission to hospital than the rest of the over 65 population. Subsequently length of stay in hospital is longer, with £21 million a year spent on excess bed days. While these admissions cannot be attributed to cuts in support in the home, this analysis is timely in assessing the benefits that can be gained in social care interventions and the relationship this can have in reducing crisis events.

## **AIMS AND OBJECTIVES**

The aim of this study was 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. More specifically, the objectives were:

- To identify a range of good quality social care interventions for people with Parkinson's.
- To explore what people with Parkinson's and their carers value in terms of social care.
- To characterise the impact that high quality social care interventions can make on quality of life, health and wellbeing for people with Parkinson's and their carers.
- To identify the key cost vectors associated with these social care interventions.
- To identify likely potential offsets to the costs of these interventions in terms of future savings in health and social care costs.
- To construct a simple logic model illustrating the possible relationship between costs, benefits and cost offsets.
- To develop key messages from the data in a form designed to engage target audiences.



- To make recommendations on social care service content and mechanisms of delivery.
- To make recommendations on how to develop additional resources to communicate study findings to target audiences.
- To make recommendations regarding future evaluations of effectiveness of social care interventions including assessments, of costs, benefits and utility.

## **METHODS**

### **Design**

A three stage study design was adopted using case studies and focus groups.

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

#### *Sampling*

A collective case study, comprising four individual cases (Stake, 1995) was undertaken, with each case representing a person with Parkinson's. The cases were identified in collaboration with Parkinson's UK. The Project Advisory Group was consulted to generate detailed and specific criteria to identify different cases to inform the development of a sampling frame for potential cases. The sampling frame was then populated with a number of potential cases selected by Parkinson's UK staff (Information and Support Workers - ISWs) to reflect variation in terms of the criteria identified within the sampling frame which included gender, demographics, living circumstances (e.g. housing, rural/urban), family and social connections, income and benefits, Parkinson's diagnosis and impact, care needs and provision.

A purposive sample of potential cases was then selected by the research team to reflect maximum variation in these criteria. Potential cases were initially contacted by Parkinson's UK representatives who sent the person the study information sheet and asked them if they were interested in participating. If they agreed, with their permission, the study team were informed. A researcher then contacted the 'case' directly to discuss the study further, answer any questions and confirm their willingness to participate.

#### *Data collection*

Informed consent was obtained from all interviewees prior to any data collection. Each case study began with an initial in-depth interview with the person with Parkinson's. In two of the case studies these initial interviews also included a carer (e.g. husband) and/or close family member (e.g. daughter). The interviews followed an interview schedule informed by related literature and discussions with the Project Advisory Group. This included questions on the support they currently received (including how they found out about and accessed this support), what they wanted from social care, what they valued about social care and the impact that social care had upon their lives.

Following this initial interview up to three additional interviews were conducted with the person's other family members, social, voluntary sector or social care providers. Potential additional interviewees were identified by the person with Parkinson's. They were asked to identify a range of individuals who were able to give insights about providing them with formal or informal support or care. The additional individuals selected for interview by the research team ranged from social workers, Parkinson's UK Information and Support Workers, care workers and informal carers such as family and friends. The person with Parkinson's made an initial approach to these individuals, where possible gave them a copy of the relevant study information sheet, and requested their permission for the study team to make contact. The

research team were then given the contact details and made contact to further discuss the study.

In-depth interviews with additional interviewees also focused on the nature and impact of the social care interventions from the interviewee's perspective and allowed for further exploration of the issues that had arisen in the interview with the person with Parkinson's.

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

### *Sampling*

Following the case study interviews in Stage 1 two focus groups were undertaken to test out, expand upon and verify the preliminary findings from the case studies. These focus groups were set up and recruited to by Parkinson's UK. The first focus group included people with Parkinson's and their carers (both current users and non-users of social care) and Parkinson's UK Information and Support Workers (ISW). The second focus group involved professionals who delivered, organised and managed services for people with Parkinson's and their carers. These focus group participants were sampled to represent a range of individuals from different backgrounds and included a social worker, occupational therapists, an operations manager for care organisation, a director of a housing group and a Lead Parkinson's disease specialist nurse. The second focus group sought to explore the implications of the case study findings for service provision.

A further telephone interview took place with a former service commissioner who was working in an integrated health and social care trust.

### *Data collection*

The focus groups were guided by a topic guide generated from the preliminary findings of the case studies. Informed consent was obtained from all participants and discussions were audio recorded. Participants were also asked to respect each other's confidentiality and agreed not to disclose any specific details outside of the focus group discussion.

### *Data analysis for Stages 1 and 2*

All interviews and focus group discussions were digitally recorded, transcribed verbatim and anonymised. The computer package NVivo (version 10) was used to organise and code the data. Data analysis was undertaken using the 'framework approach' to qualitative analysis outlined by Ritchie & Spencer (1994). A thematic framework was developed shaped by the study's aims and the issues identified during the data collection relating to the impact of high quality social care interventions. The following five stages were undertaken:

- Familiarisation with the content on the interviews.
- Identification of a thematic framework for coding data.
- Systematic coding of the interviews by applying the thematic framework.
- Organising the coded data into major themes.

- Mapping the relationships between themes by interpreting the data set as a whole in order to demonstrate the dynamics of the phenomenon under investigation.

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

#### *Segmentation*

Through the team analysis meetings 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 develop the criteria for a segmentation model (Appendix 1). This helps to explain how interventions need to be delivered to different segments of the target audience, in this case social care for people with Parkinson's (The National Social Marketing Centre, 2007). The criteria also informed the development of the project report and the social marketing outputs to engage target audiences e.g. commissioners.

#### *Modelling clinical and economic impact*

Following a selective review of key literature outlining the progressive pathway associated with Parkinson's it became apparent that a standard burden of disease model would not apply to this project. This was because:

- Progression of Parkinson's appears to be to some extent independent of the care and treatment of the illness. That is, good social care may affect the trajectory of the condition associated with good management of symptoms and complications, but it will not influence the progression of the condition itself.
- The symptom profile and thus care needs tend to be individual to each person and their families.

Normally an intervention will delay the progression of a diagnosed long-term condition or prevent / delay the development of co-morbidities or complications. Sometimes a new treatment might have the same impact on the disorder as current treatment but present a different profile of side effects which might reduce problems elsewhere. In these instances a "cost offset" model can demonstrate how the cost of the new intervention can be reduced or totally compensated for by the benefits accrued. Because the provision of "Parkinson's aware" care does not in itself effect the development of the disorder it was difficult to use this approach. Instead, having considered the case studies we developed a simple logic chain approach. This reflects that although "Parkinson's aware" care does not affect the progress of neurological degeneration it can impact positively on the trajectory of deterioration associated with good management of symptoms and complications. This logic model is based upon a number of hypotheses and assumptions (see pages 38-43). At present the assumptions are populated with numbers based upon the 'best guess' of the author for demonstration purposes. Ideally the assumptions will be replaced by evidence from future research. Evidence-based numbers could be derived from a pilot of a "Parkinson's aware" care service evaluated against a control group. Alternatively, as an interim measure, more robust assumptions could be generated from a small study including a focus group or consensus conference of experts in the field.

## KEY FINDINGS

### Introducing the case studies

#### *Case study 1 (CS1) - Mr & Mrs Brown*

Mr and Mrs Brown are both in their early 70s and Mrs Brown has been living with Parkinson's for over 30 years. She lives with her husband who is her main carer. She receives an individual budget/direct payment (nil contribution) managed by her husband to employ friends/personal carers to sit with her to provide respite for her husband. She also attends an exercise class, has a variety of aids and adaptations at home and a Motability car through receipt of Disability Living Allowance (DLA).

#### *Case study 2 (CS2) - Mr & Mrs Clark*

Mr & Mrs Clark are an elderly couple and Mrs Clark was diagnosed with Parkinson's 2-3 years ago. She lives with her husband who provides daily support. She also has the support of family close by. She has a 30 minute visit each day from a carer from a formal care organisation who helps her to wash and dress (part-funded by council but they contribute towards). She has also received a reablement package in the past, various aids and adaptations at home and a Telecare system.

#### *Case study 3 (CS3) - Mr Norton*

Mr Norton is in his late 60's and has been living with Parkinson's for around 6 years. He lives on his own. Through his disability living allowance (DLA) he pays for meals on wheels, a cleaner and gardener and a Telecare system in his home. He has also received some aids and adaptations around the house.

#### *Case study 4 (CS4) - Mr Rogers*

Mr Rogers is in his early 50s and was diagnosed with Parkinson's 16 years ago. He lives on his own in a housing association flat. His sister and a number of close friends live nearby who provide informal ad-hoc support. He receives an individual budget/direct payment managed by an organisation to pay for formal care workers to visit 3 times a day (he contributes a small amount towards this). He also has had various aids and adaptations in the flat and a Telecare system. He has recently found a psychotherapist whom he will be paying for himself.

Table 1 overleaf illustrates an overview of the themes identified in the data collected.

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><b><u>Psychological benefits</u></b></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><b><u>Physical benefits</u></b></p> <ul style="list-style-type: none"> <li>• Mobility</li> <li>• Independent living</li> <li>• Improved safety – e.g. <i>reduced falls/accidents</i></li> <li>• <i>Prevent deterioration of condition or general health</i></li> </ul> <p><b><u>Carer benefits</u></b></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><b><u>Service/societal benefits</u></b></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>

## Social care interventions

A broad definition of social care was used in this project to include 'extra support which could be a variety of things e.g. aids, adaptations, advice or help with day to day activities such as getting dressed or help with things the person enjoys doing'. The social care interventions received by the case study and focus group participants included both formal and informal social care and support. Table 2 illustrates the social care interventions accessed for each case study participant and a summary of those mentioned by focus group participants.

*Table 2: Received social care interventions*

<p><b>Case study 1: Mr and Mrs Brown</b></p> <ul style="list-style-type: none"> <li>• Day to day care/support received from husband e.g. washing, dressing, preparation of meals</li> <li>• Direct payment to cover informal carer (up to 7 hours per week) – befriending/sitting service which is mainly carried out by long-term friends</li> <li>• Conductive education</li> <li>• Aids and adaptations to the home (including bath seat, stair lift, grab rails, wetroom)</li> <li>• Attendance at Parkinson's UK branch meetings and activities</li> <li>• Carer's assessment</li> <li>• Motability scheme/allowance – scooter, wheelchair</li> <li>• Blue badge</li> <li>• Emergency care plan</li> </ul>	<p><b>Case study 2: Mr and Mrs Clark</b></p> <ul style="list-style-type: none"> <li>• Day to day care/support from husband and children – e.g. cooking, cleaning, shopping, maintenance</li> <li>• Daily 30 minute formal care provided by a caring organisation – e.g. washing and dressing (part-funded but contributes towards)</li> <li>• Attendance at Parkinson's UK branch meetings</li> <li>• Reablement package (6 week duration of care when home from hospital)</li> <li>• Aids and adaptations to the home (including wet room, stair lift, toilet upstairs, grab rails, walking sticks/frames, wheelchair, bars around bed)</li> <li>• Telecare (e.g alarm)</li> <li>• Benefits – Attendance Allowance, Carers benefit, full housing &amp; Council Tax Benefit</li> <li>• Short term physio exercise group at Rehab centre</li> </ul>
<p><b>Case study 3: Mr Norton</b></p> <ul style="list-style-type: none"> <li>• Benefits – DLA/mobility</li> <li>• Advice and support from Parkinson's UK ISW</li> <li>• Blue badge</li> <li>• Cleaner / gardener (pays for)</li> <li>• Meals on wheels (pays for)</li> <li>• Attendance at Parkinson's UK branch meetings</li> <li>• Support from friends/minister/freemasons</li> <li>• Mobility scooter (donated by friend)/wheelchair</li> <li>• Alarm/beep/key safe</li> <li>• Community transport service</li> <li>• Aids adaptations to the home – including bath lift</li> </ul>	<p><b>Case study 4: Mr Rogers</b></p> <ul style="list-style-type: none"> <li>• Support from family and friends – emergencies, social activities, emotional support</li> <li>• Direct payment to cover formal care organisation visits 3 times a day (contributes towards)</li> <li>• Adaptations to house – including bathrooms, special toilet, grab rails, profiling bed</li> <li>• Benefits and financial management advice</li> <li>• Telecare – red cords, alarm/beeper</li> <li>• Parkinson's UK website/forum and social networking</li> <li>• Psychotherapist (pays for)</li> </ul>
<p><b>Focus group participants:</b></p> <ul style="list-style-type: none"> <li>• Assessment of home / adaptations to home – including wetroom/bathroom, ramp, stair lift – via social services or through organisations such as Age UK</li> <li>• Daycare centre</li> <li>• Respite care / rest home</li> <li>• Befriending service</li> <li>• Parkinson's UK branch meetings</li> <li>• Direct payments for daily care – formal caring organisation and private individuals</li> <li>• Formal caring organisation to give medication, personal care</li> </ul>	

- Support to help shop / attend pub quiz
- Benefits – DLA, attendance allowance
- Regular/daily support/care from family and friends – including washing, cleaning,
- Telecare
- Parkinson's UK ISW
- Parkinson's UK grants for bed/motor for wheelchair

During the discussions about social care, a variety of additional interventions (see Table 3) were identified and characterised by people with Parkinson's and the other interviewees that were perceived as potentially helpful or would be desired/required in the future.

*Table 3: Desired social care interventions across case studies and focus group*

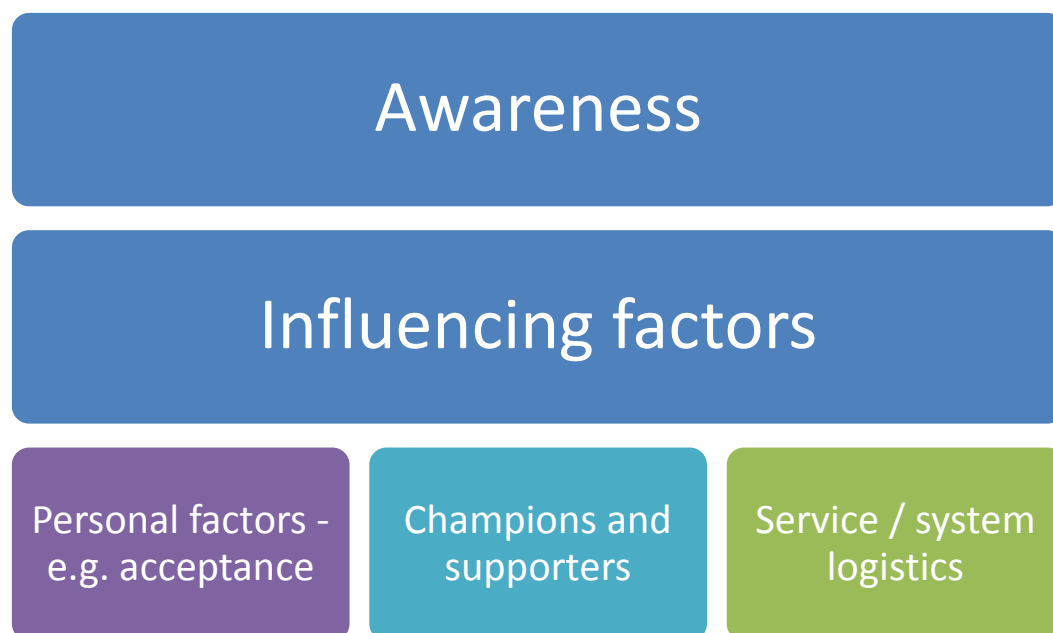
- Clear mechanism of referral for social care and provision of information about social care (e.g. leaflet and a point of contact at diagnosis)
- More care/support in the future
- Mental health/psychological support
- Family support/parental support
- Support for carer
- Housing – e.g. bungalow / on-site support commune for younger people
- Individualised care
- Consistent quality care
- Mentorship/better training for carers
- Conductive education, exercise, physio, massage
- Emergency care plan
- Advocacy support
- Social events or the support to engage with activities that make life enjoyable/meaningful

## **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, but there were also a number of influencing factors that impacted on their experiences of finding out and accessing 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:

*"I liken it to a pinball machine that you sort of hit against this or that or, you know, you get your information by happenchance and bumping into people and speaking to people"*  
(Person with Parkinson's - focus group)

Many individuals with Parkinson's and their carers highlighted that they didn't know where to go to start the process of getting help, often not even knowing what help or support was available or what support they might need:

*"And not until you do another review do you see whether there is anything else. I suppose we, if we knew what was available could actually call them in and say what about this."* (Carer of person with Parkinson's - case study 1)

This was especially evident in the focus group with individuals with Parkinson's because some of the participants were not currently accessing any social care:

*"You don't know where to start really. **Researcher: You don't?** No, and you don't know how much you don't know until you start finding out."* (Carer - focus group)

There was a strong sense that 'you don't know what you don't know':

*"I was aware of some things through the work that I'm involved with anyway, so I've been able to access things because of some knowledge I have. But there might be a whole raft of things out there that could benefit both Mum and Dad or help them that I don't know about, because there's nobody there telling us what there is, I think is an issue. So the things that they've got mostly it's been because I've known about them, but there might be other things that I could access". (Daughter of person with Parkinson's - case study 2)*

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. This was when the majority of individuals found out about social care services, for example after being discharged following a hospital stay a reablement package may be instigated or on the realisation that they could no longer manage certain day-to-day tasks due to the deterioration of their condition (e.g. falling asleep whilst dinner was in the oven prompted meals-on-wheels for one participant):

*"When I got to breaking point, I got everything. **Researcher: Right, so you had to get to that breaking point.** Yeah. **Researcher: Okay, and do you think that was okay, or?** No, it shouldn't have come to that" (Carer - focus group)*

Therefore it was evident that the timing of finding out about social care was often not ideal, with many individuals only finding out and accessing care at times of crisis or some time after they could have ideally starting receiving help, rather than finding out about what might be available/helpful in advance and then planning to access when it was needed.

*"...you've got to get to a point where you need some help, but if you get to that point where you need the help you haven't got the energy or the wherewithal to take it to that nth degree... **Carer: I feel sorry for people that are on their own that can't fight...** And as night follows day we're not seeing a cure for Parkinson's and there's no sort of future planning or future proofing for our lives" (Person with Parkinson's - focus group)*

This is further highlighted by the fact that there were no reported instances of individuals being informed about, given advice or offered social care support or information at the time of diagnosis. Although it was recognised that at diagnosis most individuals are not in need of any social care, it was discussed by various interviewees that it would be advantageous to 'plant the seed' early and alert individuals to the sorts of help and support available should they need it in the future:

*"right at the outset I'm sure lots of people don't get the...benefits of what is available. Because nobody's there to tell them, which is where I feel strongly about right at the outset, from the doctor's consultation at the time you've got Parkinson's. He ought to kick off a machine that will bring those benefits to you, and it doesn't seem to happen. It's left too much to chance, and I feel it shouldn't be left to chance. Now I mean the unfortunate thing is at the time they diagnose it most people don't really need anything, you know, and if you're very lucky it'll be many years before you do. But there ought to be flag in there, there ought to be something to tell those organisations there's a*

*potential problem here. It may not be today, it may not be tomorrow, but it will be there."*  
(Carer of person with Parkinson's - case study 1)

However it was also highlighted that the time of diagnosis can be overwhelming and some individuals do not want to engage at that moment in time.

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. Furthermore, very few people appeared to engage with planning ahead in terms of anticipating their changing needs for the future:

*"I've tried to engage the kind of care I need before I really need it...like I don't think I really needed care in [city 2] when I first got it, but within 6 months I really had it...**Researcher: So you were ahead of the game or ahead of yourself?** Yeah because if I'd have been in that situation 6 months down the line and was having difficulty getting up and my medication was all wrong...I would have found it really difficult to kind of prevent it" (Person with Parkinson's - case study 4)*

*"It's so easy to kind of hide in the moment and not think about the future...It's really easy to go along with that, and you just need to, because I'm on my own I've had to do it myself. And I think other people just need to rise up to what's happening to them"*  
(Person with Parkinson's - case study 4)

Awareness was therefore essential amongst both individuals with Parkinson's and their carers, but it was also highlighted that it was important for professionals (e.g. GPs, social workers, ISWs) to keep up-to-date about what was available. However, this was seen as very difficult and challenging because services were not stable, but constantly changing.

### *Influencing factors*

The important factors that influenced the process of finding out and accessing what's available in terms of social care are presented below under the following three groups: personal factors, champions and supporters, and service/system logistics.

#### Personal factors

The main personal issue centred on how ready the person themselves and where relevant also their main family carer were to accept the need for social care.

For many individuals with Parkinson's there was a strong desire and pride around keeping going and managing on their own, without social care or help, in order to maintain their independence. For example case study 3 was still determined to live independently with very little help even though it was clear he was struggling, and he viewed the provision of DLA as a means to remain in control and somewhat independent:

*"DLA and the support you get with DLA helps you with your independence, because you can afford things that you otherwise wouldn't be able to afford. So you don't want to*

*claim for services or the services you can use, you can pay for them, you can pay for them out of your DLA." (Person with Parkinson's - case study 3)*

Similarly for the husband of case study 1 direct payments opened the door to asking and importantly being able to pay friends to provide ad-hoc informal support for his wife when he wanted or needed a break. Without be able to offer payment for this support, he would not have felt comfortable to ask.

To some degree the process of finding out and accessing social care involved the individual, and also the main family carers, accepting that they have reached a point where help was required. At times the fact that Parkinson's was a fluctuating condition made this decision more difficult because on some days they may be able to manage tasks (and if they could they wanted to do these tasks for themselves) when on other days they really struggled with the same tasks.

In addition this issue around personal acceptance might involve the need for individuals to change their values in terms of their desire for independence and instead potentially accept financial benefits and help with personal care such as washing and dressing.

*"I mean delaying accessing things is good...I really felt I was crossing a bit of a personal Rubicon when I started letting people in my house to do stuff for me who I didn't know.... I don't really like it really, because your privacy's gone out the window" (Person with Parkinson's – case study 4)*

In the case of family carers, being labelled as a 'carer' in order to receive carer's benefit often felt uncomfortable and inappropriate:

*"The problem is that many, many carers, like I was a few years ago, didn't believe you were a carer. [NAME] my wife, I love her, and it's something that you give without question. Many, many people are the same, and only in more recent years have you realised that it is a specialist role really, specialist in as much as I know exactly what [NAME] requires, someone else coming in isn't aware of those things." (Carer to person with Parkinson's - case study 1)*

Furthermore, case study 2 illustrated the reluctance to ask for more help and articulated how earlier experiences of trying to access support might influence future attempts:

*"with my Mum and Dad wanting an early call, and then they asked for this, it was a case of oh well, the carers are busy, we can't give everyone an early call – and it's very much like being scolded like you're a naughty child because you've asked for it. And so then there's a reluctance to ask for further things because you've been treated that way once...it's very hard for them to ask for something in the first place, so when they're knocked back it becomes even more difficult to ask for things" (Daughter of person with Parkinson's – case study 2)*

At times there was also evidence that some individuals with Parkinson's avoided getting involved with peer support networks (e.g. the Parkinson's UK local branch), a source of

information, because they feared seeing what their future might hold when meeting others with more advanced Parkinson's:

*"I had that in hospital actually...I got moved to another bed and they brought in this guy who had really advanced Parkinson's...I thought I'm going to end up like that, and I ended up on the bathroom floor wailing and moaning because I felt so desperate"* (Person with Parkinson's – case study 4)

While those individuals who did access the Parkinson's UK branch were often provided with useful information about what help is available, reluctance to be exposed to some of the potential realities of a deteriorating condition could be a factor in why some individuals did not find out or access help and support in a timely fashion.

### Champions and supporters

Across the four case studies there were differences in terms of who helped the person with Parkinson's find out about and access what's available in terms of social care. Although often people were in touch and found out about things through a variety of means (e.g. family/friends, Parkinson's UK branch meetings, Parkinson's UK ISWs, social services contacts), for most of the people with Parkinson's they had an initial advocate or supporter who helped them to navigate the process of finding out and accessing what was available. In case study 1 and 2 this was a family member (spouse and daughter respectively). In case study 4 this role was primarily undertaken by the person with Parkinson's themselves, who individually initiated the social care services and adaptations required, with some support from family and friends. Case study 3 had only used very limited services which had mainly been accessed through his minister contacting social services and a Parkinson's UK ISW contact who was instrumental to him receiving the support he now accessed. These differences reflect the lack of a central advocate in some cases (e.g. where people are single or living alone) but also relate to the strong individual desire in some cases to maintain their independence and potentially not wanting to engage with some of the avenues (e.g. Parkinson's UK support group) where they might find out what is available. A Parkinson's UK ISW reflected on how, given the high numbers of cases she had on her books, she had to make judgements on who to prioritise based on individuals social circumstances and needs:

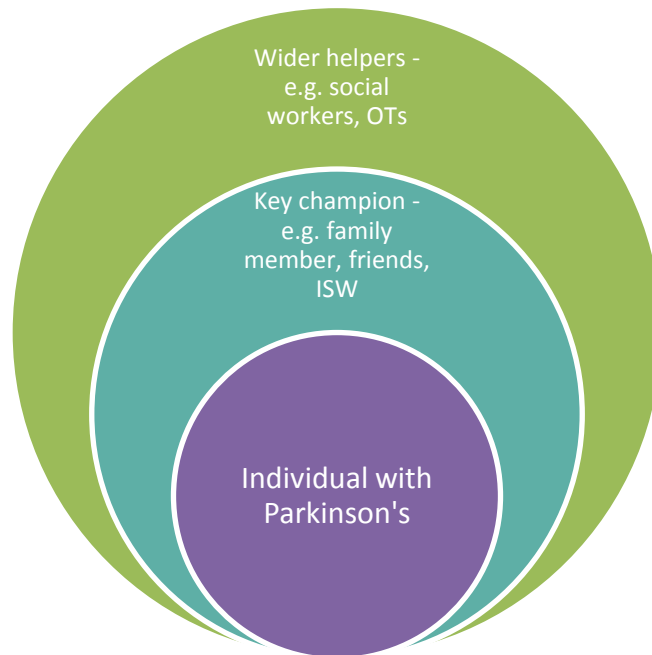
*"...the reason I've not been as involved is their daughter is very on the ball. I'm not sure what job she does but when you speak to her you can tell she knows probably loads more than me about services, and she's very active in supporting them"* (Information and Support Worker)

It was also evident that in order to get services/support in place the person doing the negotiating needed to be very persistent and often fight to get what they or the person with Parkinson's needed:

*"They put every barrier that they can find in your way...you ring up and it's passing you round a bit - this is in the early days. You then have to just keep at it until such time as you get hold of the right person"* (Carer of person with Parkinson's - focus group)

*"I think one of the things is it has been difficult to access the care, equipment, adaptations, and it seems to be every single thing has been difficult. But when things have eventually happened then there has been a big improvement. And I think a lot of people won't keep asking and keep asking and keep asking" (Daughter of person with Parkinson's - case study 2)*

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



Following the work done by the key champion, a variety of additional people then often helped to provide further information or actually access services including social workers and occupational therapists who reviewed what aids, adaptations and support might be helpful or set up a package of care. The experience of this process therefore often also depended on the quality of the services provided by these individuals, for example some people reported having been in contact with very helpful professionals (e.g. social worker or community neurology matron), but unfortunately not everyone reported such positive experiences.

#### Service/system logistics

A variety of logistical and organisational issues relating to services or systems that provide social care were discussed. These were particularly highlighted in the service provider/professional focus group and interviews with health and social care professionals where it was reported how services were being squeezed, social care packages scrutinised more closely and cuts occurring across services. These were already seen as having an impact or would result in the future in it being more difficult for people to access social care. For example in adult social care in some areas, there was a move away from condition specific social workers to generic social workers and a move towards a single assessment of needs

rather than repeat assessments. In a condition such as Parkinson's where the person's needs and abilities fluctuate on a day to day basis and social care provision needs to be tailored towards the condition specific needs of the individual, this was not seen as conducive to ensuring that people were able to access either adequate or the most appropriate social care services.

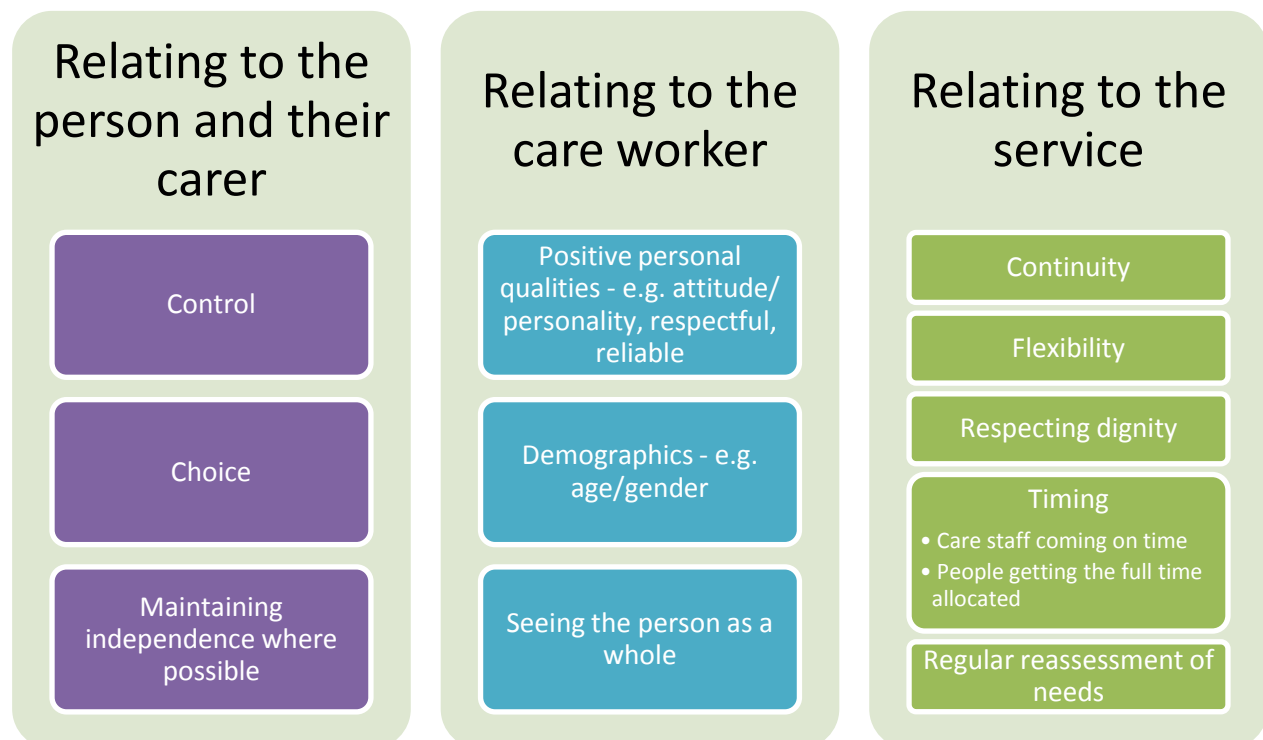
Importantly regular reassessment was considered essential in terms of ensuring that individuals were receiving the most appropriate information and access to what was available and potentially helpful to them at that moment in time.

The lack of integration between health and social care services was also raised both by professionals and some service users as not helping to facilitate the timely receipt of information and support to access social care services.

### What's important about social care in general

In terms of what was valued about social care in general, aspects related to three key groups in terms of relevance for the person and carer themselves, care workers or the service. These aspects were considered general because although they were highlighted as important for individuals with Parkinson's and their carer, it was considered that they were not specifically related to Parkinson's (i.e. likely to be important for other patient groups too).

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



### *Relating to the person and their carer*

It was evident that the person with Parkinson's valued social care that gave them some choice and control and enabled them to maintain their independence where possible. In case study 1 this choice and control was realised through using a direct payment which ensured that the couple remained in control of who was providing them support:

*"They wouldn't want me to say use your direct payment to get in this local agency that could provide seven hours; they actually do want to do what they're doing. They want to have the control of who they have in their home really. You know that is important to them." (Social worker - case study 1)*

This was in contrast to some of the individuals who received care from a formal care agency where there was often less choice and control about who attended, at what time, etc.

These findings indicate higher levels of satisfaction where people were able to manage their own services. However, not everyone was able to do this or felt comfortable with this approach. Everyone expressed the need to have some level of control of the services they received. This could take a number of forms. In some case this involved directly employing care workers and managing the employment obligations. In other cases this simply meant choosing not to have the responsibility for organising care but being able to define the nature of the care received including what kind of care workers came to the home and at what time.

Maintaining independence was also crucially important – individuals with Parkinson's wanted to do what they could when their condition allowed it.

### *Relating to the care workers*

It was highlighted how all the care workers who provided help and support to people with Parkinson's should have positive personal qualities (e.g. reliable, respectful, positive attitude). Furthermore, it was important that they were an appropriate demographic in relation to the person receiving the care:

*"when I needed to eventually need them for personal care in the morning they kept sending girls of 17 and, I said 'do you think I've got no dignity?' I don't want somebody like that helping me to shower." (Person with Parkinson's - focus group)*

It was also important for all care workers to see the person as a whole, and treat them as a person in their own right, rather than just a person with Parkinson's.

### *Relating to the service*

Continuity in the social care interventions provided to individuals was seen as important in terms of providing a consistent service and ideally the same care workers that the individual is familiar



with. It was also important that care workers came on time and that people received the full time allocated to them. Unfortunately there were many stories of care workers only staying for five minutes when they were allocated a longer slot. It was also important for the service to respect individual's dignity in terms of providing care workers that were matched appropriately (e.g. age and gender), particularly when providing personal care. Furthermore, it was highlighted that a degree of flexibility of services was particularly valued – for example case study 2 received a 30 minute visit from a formal care worker employed by a home care agency, and her experiences of the difference in how different care workers work was very significant in terms of the flexibility that could be achieved:

*“some carers probably might go in and just do what is actually on the care plan, but then what you’ve got to realise is, with [NAME] being very independent, you know, it probably says personal care, but [NAME] has actually got herself ready, has actually washed herself before I’ve got there. So that time that I’m allocated for that I can be doing other things to help her.” (Care worker – case study 2)*

*“I think they [PARENTS] could do with more help...I think it's more around some sort of extra care but the thing is enabling them to do things as well, and maybe looking at care in terms of they still want to do some things, so why, instead of having a care package that says oh we do this that and the other, be a bit more changeable in well, you know, I think I could manage to do this this week, but could you do this for me instead. So it's a bit, I don't know, a bit more rounded and a bit less regimented I suppose.” (Daughter of person with Parkinson's – case study 2)*

Being able to provide a degree of flexibility was seen as particularly important in a condition such as Parkinson's where symptoms and the person's abilities can fluctuate on a day to day basis. It also highlighted that this was why informal ad-hoc family support was so beneficial.

Finally it was also considered important for social care provision to include regular reassessment of the people's needs to ensure that they were receiving the most appropriate help and support.

### **What's important about social care relating to Parkinson's specifically**

A variety of aspects were highlighted as important to consider when considering social care for individuals with Parkinson's specifically. 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



#### *Understanding Parkinson's*

It was emphasised that it was important for all those involved in social care (e.g. care workers / care providers / other professionals) to understand the symptoms of Parkinson's. There was a general consensus that there was a lack of public awareness about the condition and the range of symptoms that included not only the physical symptoms but also psychological and cognitive elements:

*"I think it's having that kind of perspective about him as a person in that very sort of holistic way, and recognising if you like all the different layers that Parkinson's presents, not just the kind of physical stuff that most people know about, like tremors and rigidity, but the psychological stuff, sort of the anxiety and depression, the kind of cognitive stuff*

*about sometimes lacking organising executive functions.” (Friend of person with Parkinson’s – case study 4)*

There was some indication that employing carers directly through a direct payment scheme might be preferential in terms of being able to ensure that carers had some understanding of the condition - this would ensure that continuity of care could be built into care packages but also it gave the person/family control to choose who they employed and potentially also provide them with training or information about the condition.

In addition it was emphasised that the condition could fluctuate quite dramatically and therefore it was important for people to understand that a person with Parkinson's could present very differently on different days or at different times of day, which could have an impact on their ability and mood. This fluctuating and unpredictable nature of the condition could cause difficulties when setting up or defending the level of care required in formal care packages. Furthermore, because people with Parkinson's often strove to maintain their independence they wanted to do the things they could when they were able to, which might mean that setting a rigid care plan was difficult.

#### *Understanding medication (especially timing)*

Understanding the nature and importance of the medication that individuals with Parkinson's were taking was emphasised as crucial. This included the potential side effects of the medication (e.g. hallucinations, dyskinesia) and the importance of taking the medication at rigidly set times each day. This was especially important if individuals relied on others to help them take their medication, for example in case study 1 this was a major concern for Mrs Brown's husband should anything happen to him in the future:

*“Carer: Well immediately it would be family, but in the event of, because they wouldn't be able to permanently care for [NAME], carers coming in. And the thing that concerned us most of all was the immediate drug regime. If a carer came in they'd need to understand what it was that she needed when she needed it...**Researcher: What happens for you [NAME], if you don't get your medication on time, what are the implications?** Person with Parkinson's: I go off, bad enough in the morning to start going, but I start to freeze and can't get on very well at all.” (Care workers and person with Parkinson's – case study 1)*

Even if individuals were taking their own medication, it was important for carers to be aware that the medication had to be taken a set times and that this had an impact on the symptoms and ability of the person with Parkinson's. Being armed with knowledge about the importance of synchronising care delivery with medication times could potentially yield benefits for care services as well as the person with Parkinson's in terms of resource provision and costs of care:

*“you say to them if you do it this way as opposed to this way, medication's always a simple example. You know, it's not necessary to have two carers to get someone up to give them their breakfast and then give them their medication. If you gave them their*

*medication as soon as they put their feet on the floor they can reduce the carers to one carer, you know, and that sounds simple, but I see it so many times. You see it in the care homes, you see people being wheeled to the breakfast table in a wheelchair when they walk back following their breakfast, following their medication.” (Lead Parkinson’s specialist nurse – Focus Group)*

#### *Allowing the person with Parkinson’s time*

In addition to the general aspects relating to timing (see previous section), it was highlighted that people with Parkinson’s might require more time to answer a question or complete a task and it was important to allow them this time and not to over-stimulate them:

*“there are two things that I try and press home with informal and formal carers is calmness and time, even if you’ve only got 15 minutes to do it, don’t fire questions at people...so you’d go in and you’d say Jack how are you feeling today? Give him a chance to answer, what would you like for your breakfast? Give him a chance to answer...even just by being calm and giving them time to respond that could actually set the person up so that when you do get them walking you’re not trying to take them this way, because if a carer’s had time and the person’s had time to just really absorb and get going really. **I agree, because it actually does cognitively set you in gear and that’s what you need when you have PD. You need to get into gear with each task especially as you progress down it, multitasking no, it’s task after task, you need time to process.**” (OTs – Focus group)*

At times the fluctuating nature of the condition made issues around timing more pronounced, for example if a carer only had 15 minutes allocated and the person with Parkinson’s had frozen:

*“it’s very frustrating too if you are on the clock and you’re thinking well I’ve got 15 minutes. I’ll give you 1,000 examples, I went to see a lady yesterday...She’d actually she’d come downstairs that morning and she’d forgot to bring her dispersible Madopar with her, which she needs as a rescue dose and she realised this too late and by the time she got back up to the bedroom she was rigid, she was absolutely solid and everything was going off, you know, breakfast and everything and this lady couldn’t do anything, she couldn’t even speak. For myself and the occupational therapist that understood that it wasn’t an issue, but for other people around, carers, they really, really struggled with the fact that this person could be faking this, could be putting this on, you know, it’s a case well one minute she’s running up and down the stairs, the next minute she’s like this and it’s very very challenging, because if you are on a 15 minute clock and you do turn up someone’s home and they are switched off you’re looking at at least 30 minutes.” (Lead Parkinson’s specialist nurse – Focus Group)*

### *Understanding the person with Parkinson's is the expert*

It was highlighted by some interviewees that it was important to understand that the person with Parkinson's, and in some situations the family carer, is the expert because they live with their condition on a day-to-day basis, know exactly what to expect and often how best to handle things. Both formal and informal carers and professionals highlighted that they learnt a lot about the condition from their experiences with individuals with Parkinson's:

*"They are the expert, I've seen people come and go with Parkinson's and I've seen the pitfalls and I've seen the successes, and the people with Parkinson's have got all the answers" (Lead Parkinson's specialist nurse – Focus Group)*

### *Social inclusion*

People with Parkinson's could quite easily become isolated from society because they relied on others to get out and do things. It was emphasised in case study 4 that the person with Parkinson's aimed to live as normal a life as possible and the informal support received enabled him to do this and take part in society:

*"He's a fabulous musician and comes to the pub that we all play in...and I think that's a really good example of a sort of social model of care, and someone being welcomed into a community on their terms, because their contribution's valued, so therefore the fact that he has to lie on, well he doesn't anymore, but he used to have to lie on the floor in the middle of the pub sometimes because he'd frozen up and you'd see an entire pub just coping with that quite happily" (Friend of person with Parkinson's - case study 4)*

### *Regular reassessment of needs relating to Parkinson's symptoms and treatment*

In addition to the general importance of the regular reassessment of needs (see previous section) it was highlighted that this was especially important in terms of Parkinson's because it was a condition that could deteriorate quite rapidly over time and was highly dependent on the effectiveness of medication. It was emphasised that as people with Parkinson's often don't require any social care at the point of diagnosis and that treatments may be altered over time, it was important for their needs to be reviewed on a periodic basis:

*"Maybe when somebody's diagnosed let them know the support that's available briefly and then follow up in six month's time and then in a year, like follow up at a regular thing for every person to see what they need" (Information and Support Worker - case study 2 & 3)*

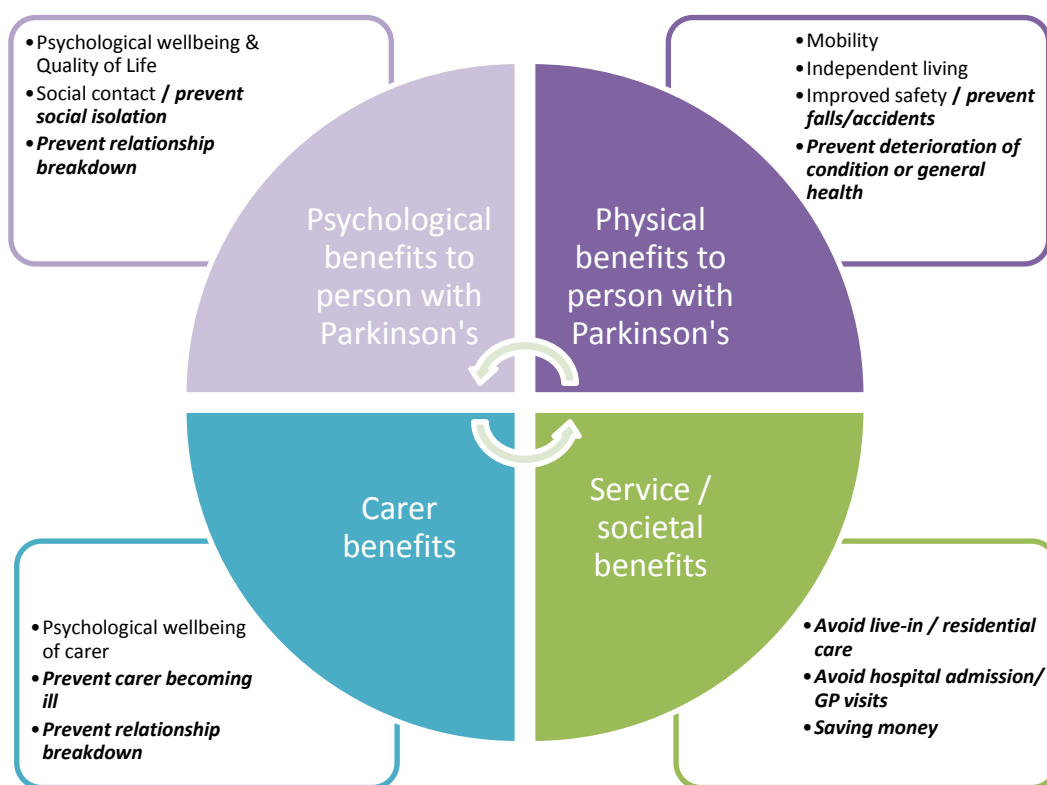
*"I don't think he needs the amount of contact hours that he's getting now, and this is again to do with the change in his treatment regime, but I think it's the quality...perhaps fewer hours but with someone who's better trained and more able to kind of deal with the*

*psychosocial aspects, alongside the practical stuff" (Friend of person with Parkinson's - case study 4)*

## Benefits of social care

A variety of benefits of social care were highlighted. As the diagram below indicates these benefits 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**)



## Psychological benefits

### Psychological wellbeing & quality of life (QoL)

Clearly for some of the individuals with Parkinson's the social care they received had a major impact on their psychological wellbeing and QoL. In many ways this was as a result of the emotional support and social contact (see next section) that, in particular, family and friends provided:

*“My sister lives nearby and she’s very important as well, in terms of emotional support...sometimes it’s just topping you up, just make sure you don’t go under and sometimes it can just be a quick visit” (Person with Parkinson’s – case study 4)*

*“Paid care enables [case 4] to live his life and social care makes it worth living. **Researcher: That’s really good way of putting it actually and if that wasn’t there?** Well I think he’d sink into a really grim depression frankly. I mean he does sometimes anyway...Sometimes I just can’t imagine what’s it’s like at like four o’clock in the morning for him” (Friend of person with Parkinson’s - case study 4)*

### Social contact

Linked to the psychological impact, some of the social care interventions provided the person with Parkinson’s with social contact with other people. On a basic level this could simply be some company for the person with Parkinson’s – for example a formal carer who attended each day for 30 minutes, sitters/befrienders to talk to at home, or the means to get out and about to different environments such as wheelchairs or community transport. This reduced the isolation that the person could feel when they did not get out and about very often.

Some of the people with Parkinson’s also attended activities organised by their local Parkinson’s UK branch. However, some reflected on how they needed more support to get out and about socially. Not having somebody to physically attend events/meetings with them or push their wheelchair, restricted their ability to regular attend such activities. For case study 4 the support provided by family and friends was really key in enabling him to have “as normal a life as possible”, engage socially with the things he liked doing, which had a great impact on his psychological wellbeing:

*“If people like myself weren’t around in his life, who are friends with him and would be going to pub sessions anyway, he would need a lot more of that kind of stuff...from formal care providers, but that’s unlikely to come from more community care budgets because it would be a low priority, taking someone to the pub to play the guitar...despite the gigantic plus impact it has on his quality of life” (Friend of person with Parkinson’s - case study 4)*

In the focus group with service users the important benefit of social contact on quality of life was also emphasised:

*“I think it’s important to go out whether you’re a carer or a person with Parkinson’s. Most people that know me in this room would say I’m a very positive person and bouncy and things. If I’m in the house on my own there’s a black cloud that follows me around, and I think it’s to do with the condition and the chemicals in my brain, you know, and in my head I know that, but in the heart I get so miserable...Coming out and meeting and being in a group of people where you don’t have to explain why, why you’ve got a tremor or why you can’t get through a door or something is very helpful, both emotionally, physically and mentally and I think, you know, I’m in a group in [City 1] that does that.” (Person with Parkinson’s - focus group)*

*"I mean one of the things which they'd been good with me, I like to go to pub quizzes and things like that, and they have given me two hours once a fortnight for someone to take me. Although I was told the other week that probably the Council would take that off me. **Researcher: Who's providing that at the moment then [NAME]?** My social care worker, and one of them does that, and they had two hours to help me shop and two hours to go with me for pub quiz." (Person with Parkinson's - focus group)*

## **Physical benefits**

### Mobility

The social care provided to people with Parkinson's also enabled them to maintain their mobility or become more mobile. This could be through the Motability scheme (accessed through eligibility for DLA) that enabled them to lease a car, providing a motorised scooter or powered wheelchair, or through the provision of a Blue Badge or the use of Community Transport schemes. This allowed people to get out and about, attend events or just be sociable. There were instances of people with Parkinson's attending exercise classes, physiotherapy or groups that aimed to promote mobility, for example Case study 1 attended a Conductive Education session and the impact on her ability to walk had been quite profound.

### Independent living

Many of the people with Parkinson's interviewed strived to keep their independence as much as they could. The social care they received meant they could remain more independent for longer and avoided residential care. For example, due to the care provided to case study 1 and 2 by their spouses and family both of these people were able to stay in their own homes, something that without this informal support would be highly unlikely. It seemed that informal/family support allowed more flexibility in terms of aiding independent living at home and potentially slowed down the trajectory of deterioration which was associated with good management of symptoms and complications:

*"And he [husband/main carer] can go with the good days and the bad days, and he knows when she's more mobile, and when she has, you know, she's faced a lot of what she was saying dyskinesia. It can go on for hours where she's rolling around on the floor, and he can ignore that, knowing, and they know how she will be when she's gone through that. You know, it's that bond really and that relationship that is holding them together. Whereas when you see people in the community who haven't got that kind of support you know that the deterioration is much more rapid." (Social worker – case study 1)*

Case study 2 and 4 received formal care from provider agencies to help them on a daily basis, and without this it was considered that residential care might have to be considered. Case study 3 was only in receipt of minimal social care interventions and had strived to keep his independence – at first he refused all support and care offered but he had gradually started to accept more. He reflected that now he wouldn't be able to manage without the support he gets. Aids and adaptations to the home, Telecare devices, the provision of benefits and schemes like Blue Badges also allowed the individuals to continue living with some independence:



***“Researcher: If all that care [informal care] wasn’t there how would life be? Crap! In a word, crap! Because if I wasn’t there she’d be in a home, and that would be her life!” (Carer - focus group)***

Most of the social care received impacted on the basic functions of day-to-day life (e.g. getting around, getting dressed, keeping self and home clean, shopping), but there was also a few examples of benefits on wider independent living and quality of life. For example the informal care provided by family and friends enabled case study 4 to actively engage with society and attend the music pub gigs he enjoys. Within the focus group one person with Parkinson's was also provided with support from a formal care organisation to attend a local pub quiz. However, having to leave sometimes before the results of the quiz came in due to the time-restricted nature of the support was a source of frustration.

#### Improved safety – e.g. reduced falls & accidents

For some of the people with Parkinson's the interventions were essential in terms of improving safety and in particular preventing falls or accidents. For case study 1 who was at significant risk of falling, this involved having around the clock support from her husband and having friends/carers to sit with her if her husband had to go out. Most of the cases had also had adaptations around their homes such as grab rails, bath seats or wetrooms, which made getting around and engaging with day-to-day activities possible and safer. Telecare including personal alarms was also vital for people who lived alone and had frequent falls. Without such devices the likelihood of lying on the floor unable to get up for long periods of time were all too real.

#### ***Carer benefits***

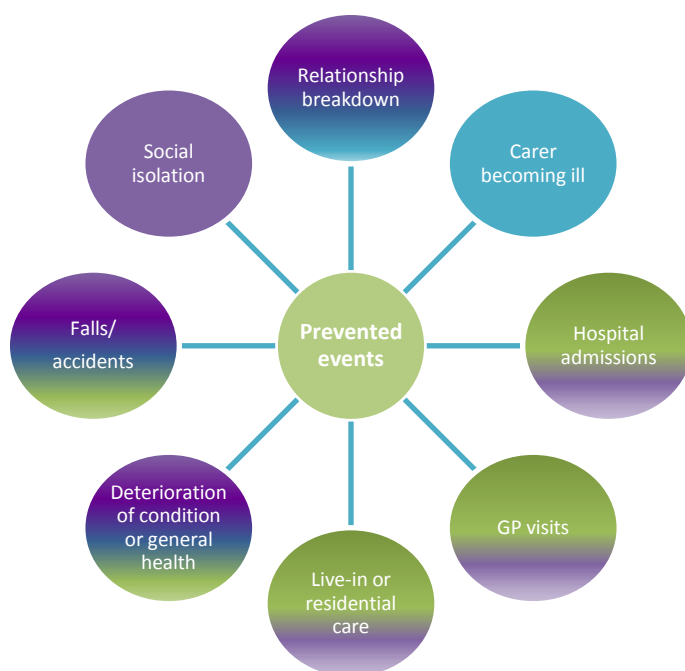
##### Psychological wellbeing of carer

Importantly for family members who often played a big part in the day-to-day care, the social care interventions could provide them with a break, which had a significant impact on the psychological wellbeing of the carer, reduced the isolation they could feel and importantly enabled the carer to continue to provide the support they did on a long-term basis. This was also beneficial for the person with Parkinson's who was pleased that their partner got a break and also provided them with a change in terms of perhaps a new or different environment. The danger of carers burning out or becoming unable to cope with the day to day demands of caring were very real. However, it was highlighted in the focus groups that individuals were often only accessing this type of support at crisis point, rather than receiving some respite that might mean that crises were averted.

#### ***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 the text and figure overleaf.

Figure 6: Prevented events



One of the most frequently prevented events reflected upon was the need for live-in or residential care, which was considered to be the likely outcome if the social care received was not present in a number of cases. Other benefits included reductions in service use, such as hospital admission and GP visits – although some people felt that service use would be similar regardless because of the complexity of the condition. Furthermore, it was considered that the social care provided could prevent falls, accidents and the deterioration of condition or general health – for example, a formal care worker reflected that she alerted case study 2 to various physical complaints including a weeping area on her leg and an eye problem and prompted her to seek help before they got more serious and became long term complications.

*"like this with her leg, I mean that could flare up to anything, whereas the district nurse came in and we caught it before it did get any worse. She's been having problem with her eye. And we've had a doctor out a couple of times, you know what I mean, but I brought that to her attention from the start. If it was left up to [NAME] she'd probably push that to one side a bit". (Carer, case study 2)*

It was also considered that the social care received could help to prevent informal carers becoming ill or relationship breakdown. In summary the impact of prevented events could be characterised in two ways - a reduction in the number of 'crisis events' for the person or their carers and a slowing down of the trajectory of deterioration associated with good management of symptoms and complications. The long term sequelae of these could be rapid deterioration and the need for residential care. Overall, it was also considered that the provision of often small, low-cost packages of care prevented the need for larger expensive packages, thus reducing the cost to society.

## KEY MESSAGES ON COMMISSIONING

A number of key messages on issues related to commissioning social care for people with Parkinson's emerged from focus groups and an interview with a former commissioner. These are outlined briefly below.

- There is now a window of opportunity to improve social care provision and tailor it more to people's health needs due to the current integration agenda (NHS England 2013).
- There is increasing recognition that commissioners need to move away from reacting to extreme need, and to acknowledge that early recognition is much more cost-effective than intervening in a crisis.
- Commissioners commission services for populations and take a needs-based approach not a condition specific approach. Given that people with Parkinson's have very similar needs to people with other degenerative long term conditions, for example MS and dementia, these could be clustered into bundles of care needs and enhanced services that could be commissioned.
- These enhanced services may need to be commissioned at a more expensive rate than standard services underpinned by robust economic arguments about costs offsets that would result.
- Commissioners might develop an approved list of preferred suppliers and build this into contracts in the way that some care homes are 'dementia specific.'
- Commissioners might build in criteria that staff are trained in a particular way or by particular approved organisations.
- The best way for Parkinson's UK to influence the debate may be to form alliances with other large organisations with whom commissioners tend to consult when developing services for people with needs associated with degenerative long term conditions e.g. Age UK, Alzheimer's.
- Messages that commissioners may respond to include:
  - economic arguments about saving money later down the line
  - case studies that show how preventive care early on at the right time saves money later
  - case studies that illustrate the difference that "Parkinson's aware" social care makes compared to 'standard' social care
  - a big agenda for commissioners is the cost of residential care. Commissioners may be more likely to respond to arguments which focus on this, rather than arguments which focus on hospital admissions per se.

## PEN PORTRAITS AND THE IMPACT GAP

### Pen portraits

In order to bring the research to life and help gain a deeper understanding of the factors that influence the outcomes for people with Parkinson's; we have developed a set of 'pen portraits' (Appendix 2). These are not real stories or people. They are built using the research findings and real life observations to depict a 'portrait' of possible scenarios created using a descriptive narrative.

Each of the pen portraits aims to describe the findings of the research. They illustrate how significant benefits are experienced from timely and appropriate care being put in place for people whose circumstances may differ. Benefits accrue for the individual concerned and the commissioners of care. The possible outcomes relate to the domains in the Adult Social Care Outcomes Framework (DH 2013) and the measures outlined in the 'Better Care Fund' which aims to facilitate delivery of the 'vision' for future adult social care. These centre on reducing the need for hospital or residential care by allowing people to remain independent in their own homes for as long as possible.

The pen portraits also aim to build an understanding within those who commission and develop plans and policy around care (be that on a local or national level), the everyday challenges faced by people with Parkinson's. They aim to describe how they feel, the drivers to attitudes and behaviour as well as the difference timely and appropriate care will make to them.

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 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.

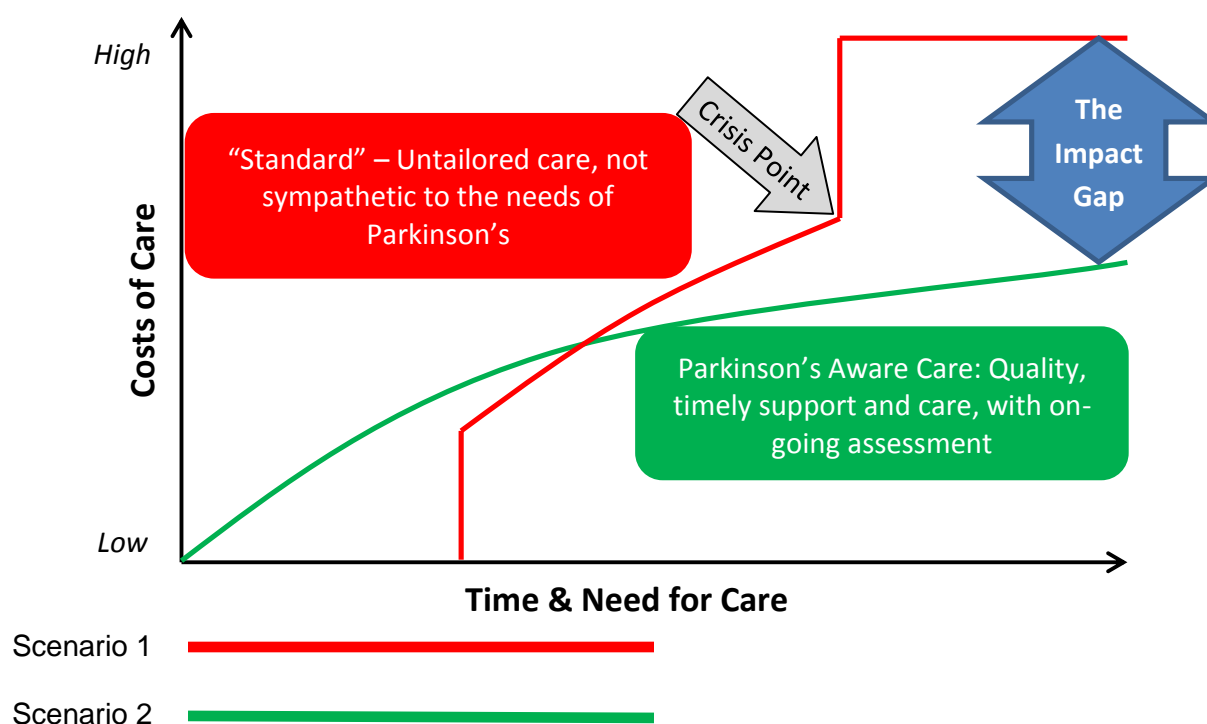
Within scenario 1, a standard care package of domiciliary visits is in place. There is no care for the carer and the package does not take into account the timing of medication and the needs of someone with a neurological disorder such as Parkinson's.

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 require 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.

We have called this the '**Impact Gap**'.



The pen portraits are outlined in full in Appendix 2.

## ECONOMIC IMPLICATIONS

As stated in the methods section the economics of "Parkinson's aware" care versus standard care are based upon logic, intuition and assumptions at this stage. This is because it has yet to be tested. Using the findings from the case studies we developed a simple logic chain approach. This reflects that although "Parkinson's aware" care does not affect the disease it can impact positively on the trajectory of deterioration associated with good management of symptoms and complications. The underlying hypothesis for this is as follows:

If care is "Parkinson's aware" (i.e. personalised, delivered in a timely fashion, delivered by care workers who are experienced and trained to recognise the complications and limitations that Parkinson's placed on individuals, and synchronised with medication and the functioning of the person with Parkinson's) it could:

1. Maximise the ability of the person with Parkinson's to assist in their care.
2. Minimise distress / frustration to the person with Parkinson's and their carer.
3. Minimise the time it takes to complete care tasks appropriately.
4. If accompanied with appropriate respite opportunities, maximise the time a person with Parkinson's can be cared for at home.
5. Minimise the number of adverse events including trips and falls.
6. Minimise the number of medical complications from inadequate fluids, diet, bowel care etc.
7. Reduce the risk of premature death

The model makes assumptions about the extent to which:

1. "Parkinson's aware" care would allow care to be delivered more quickly and efficiently.
2. "Parkinson's aware" care coupled with suitable respite would allow many individuals and their carers to manage at home thus delaying or preventing admission to a residential facility.
3. More effective care delivered at the time that the individual is best able to benefit from it can reduce accidents, falls, problems with inadequate nutrition, fluid intake, constipation etc. and the medical conditions that can arise from them
4. Minimising complications of inadequate care can impact positively on death rates.

NB At present the assumptions are populated with numbers based upon the 'best guess' of the author for demonstration purposes. Ideally the assumptions will be replaced by evidence based numbers from a pilot of a bespoke care service evaluated against a control group. As an interim more robust assumptions could be generated from a small study including a focus group or consensus conference of experts in the field.

The key cost vectors identified in the model are as follows:

1. The number of hours of care a person needs each day to help with their daily needs and the hourly cost of the care
2. The cost of appropriate respite care to help a person and their carer to continue living at home sustainably
3. The cost of A&E attendances, GP visits, Hospital Admissions which might arise as a result of falls, accidents or inability to provide adequate care due to the person with Parkinson's condition or insufficient time
4. The annual cost of residential or nursing home care
5. The cost of end of life care

Assumptions are made about the likelihood of these costs being incurred if the person with Parkinson's received bespoke care rather than generic care. These assumptions are as follows:

Assumptions	Current Care	Bespoke Care
Probability of needing residential care	40%	20%
Probability of an acute episode	60%	20%
Probability of Death	16%	14%
Average daily home care hours	4	3
Hourly cost of a carer	£9	£12
Average cost of respite care per annum	0	4000
Average cost of an A&E attendance	£120	£120
Average cost of a GP visit	£70	£70
Average cost of an admission	£1,040	£1,040
Average cost of a nursing home per annum	£44,200	£44,200
Average cost of a residential home per annum	£31,200	£31,200
Proportion of Residential Care in Nursing Homes	40%	20%
Proportion of Residential Care in Residential Homes	60%	80%
End of life care costs	£3,000	£3,000
Death costs	£1,000	£1,000

**NB These assumptions reflect the author's estimates for the purpose of demonstration only and need to be adjusted through further research**

The logic underpinning the model is that "Parkinson's aware" care from staff who are experienced and trained to recognise the complications and limitations Parkinson's placed on the individual's ability to help with their own care, that is delivered in a timely fashion, tailored to

individual needs and synchronised with the person's medication times could provide more efficient and effective care. Also that more efficient and effective care is likely to help the person with Parkinson's and carer to cope with the strain of living with this level of disability and delay or prevent the need for residential care.

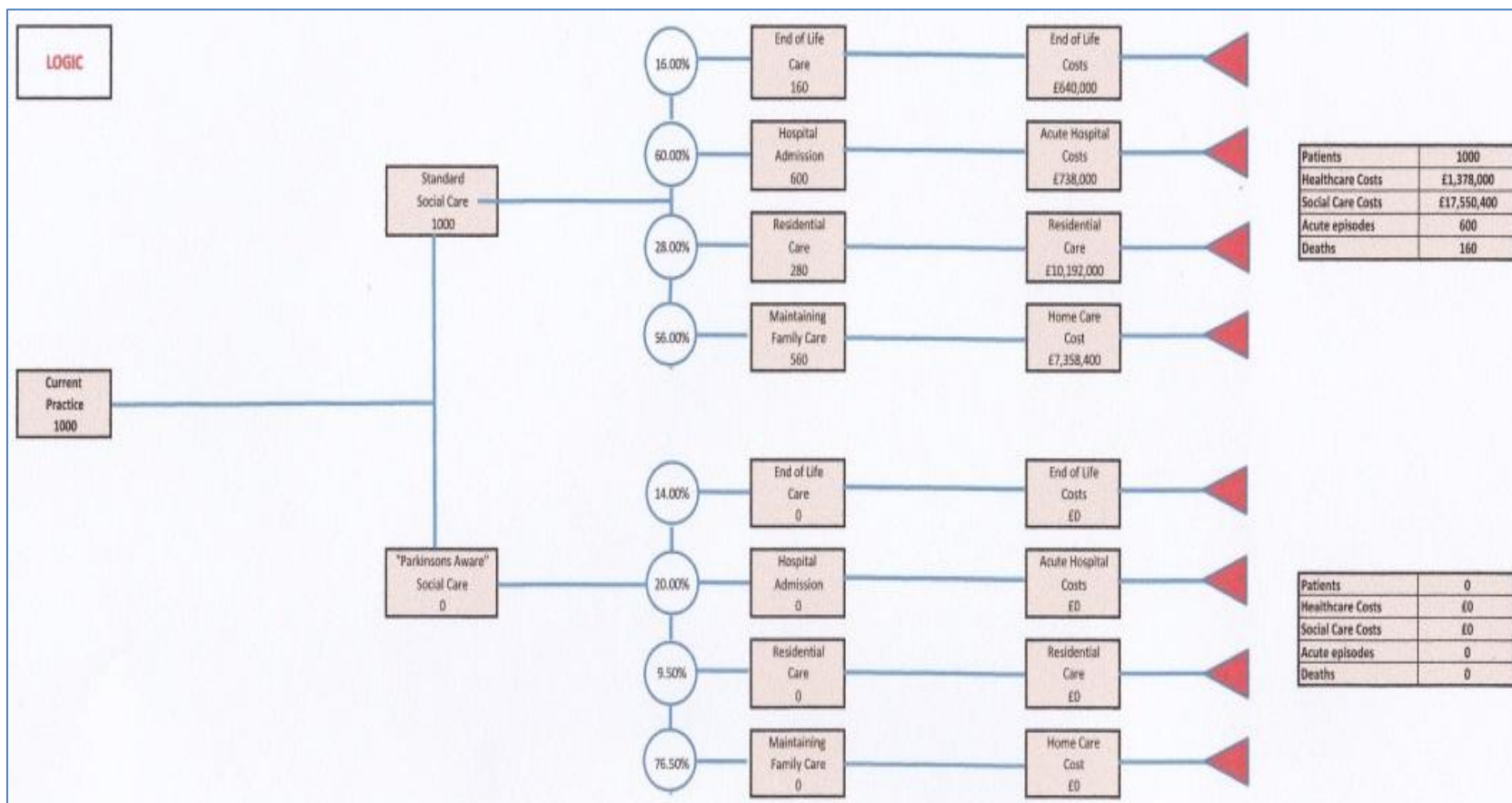
The model allows the user to model the cost of two scenarios.

Scenario 1: The current position in terms of the proportion of people with Parkinson's receiving standard care v "Parkinson's aware" care. The diagram below shows a scenario where current care includes 0% of people with Parkinson's receiving "Parkinson's aware" care.

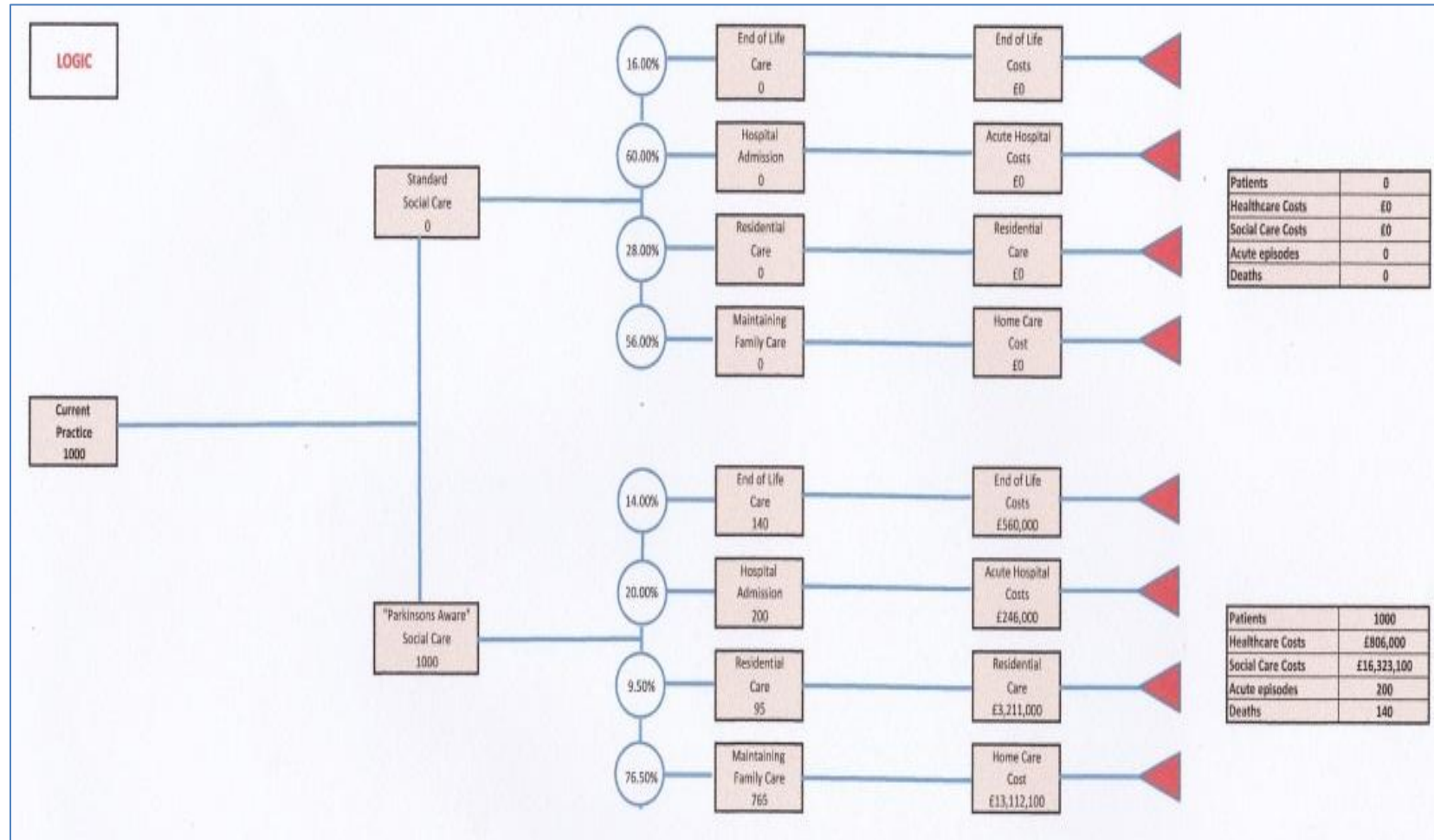
Scenario 2: The target position in terms of the proportion of people with Parkinson's receiving standard care v "Parkinson's aware" care.



**Scenario 1. NB These assumptions reflect the author's estimates for the purpose of demonstration only and need to be adjusted through further research**

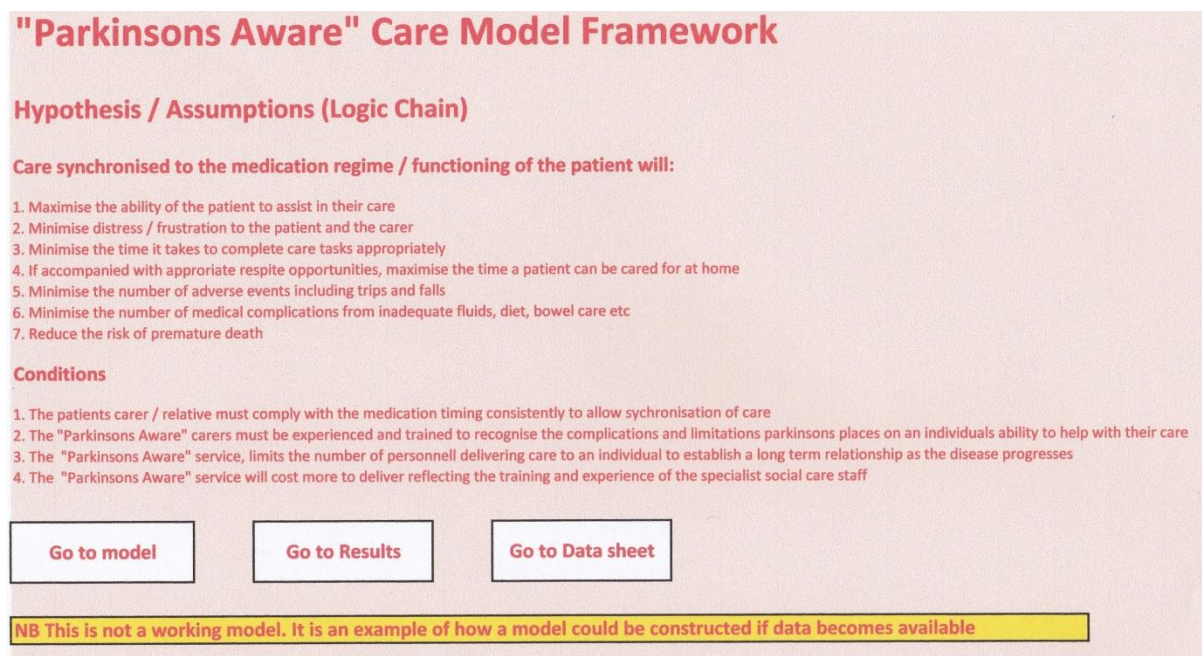


**Scenario 2. NB These assumptions reflect the author's estimates for the purpose of demonstration only and need to be adjusted through further research**



Based upon the current assumptions in the model, moving to scenario 2 would lead to a reduction in acute episodes of around 400, avoidance of 20 deaths and an annual saving of over £500,000 in healthcare costs and £1.2m in social care costs in 1000 person with Parkinson's. **NB These assumptions reflect the author's estimates for the purpose of demonstration only and need to be adjusted through further research**

The model allows the user to define the number of person with Parkinson's, the current level of "Parkinson's aware" care, the target level of "Parkinson's aware" care and all assumptions about cost and probabilities. This allows extensive testing of 'what if' scenarios. The diagram below shows the model user interface.



This includes an assumption that "Parkinson's aware" care would cost more than standard care. (£12 / hour rather than £9 / hour). This would cover the additional cost of training and more experienced carers. **Again the costs in the current model are only estimates and can be adjusted to reflect validated costs if this information is made available.**

## KEY MESSAGES AND RECOMMENDATIONS

Key recommendations are provided here drawn from the project findings. To enhance their application the recommendations are presented linked to the relevant domains of the Adult Social Care Outcomes Framework (Department of Health 2013).

### 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 that 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 person 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 people with Parkinson's with Parkinson's and similar neurological conditions.***

#### **Implications for commissioners**

- Commissioners should only contract with organisations to provide care for people 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.

#### **Considerations and recommendations for Parkinson's UK**

- Parkinson's UK should build on strategic alliances<sup>1</sup> with influential national and local organisations that represent populations with care needs similar to those of people with Parkinson's.
- This alliance should collaboratively facilitate and influence commissioners through the communication of key messages about the common care need of this population. These messages should shape joint commissioning strategies and operational plans
- Parkinson's UK should work with allied organisations at a national and local level to generate robust and relevant criteria to underpin the collection of evidence around service user experience of social care. Parkinson's UK could facilitate the collection of this evidence. At national level this might include surveys of service users and at a local level this might include branches working with service providers to develop user involvement consultations.

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<sup>1</sup> NB. At the time of writing the report Parkinson's UK were already working collaboratively with relevant organisations.

- This alliance should work with the provider organisations to ensure that their service offer is ready to meet the common care needs of people with neurological conditions including Parkinson's including specialist training.
- This could include a formal accreditation process to identify which organisations are able to provide this enhanced level of care for people with neurological conditions. This would provide commissioners with the assurances they need that they are contracting for quality services.
- Parkinson's UK and allied organisations should work with provider organisations to ensure that their services offer include initial assessment and regular reassessment of care needs of people with neurological conditions including Parkinson's.
- Parkinson's UK should review existing provision of care and support roles including clinical nurse specialists and Information and Support Workers in order to help local branches, people with Parkinson's and their carers find out about and access social care in a timely manner
- Parkinson's UK should consider whether the role of the Information and Support Worker should be further developed to enable them to act as advocates to better help people with Parkinson's to access and navigate good quality social care. This may require the provision of further training as well as standardisation of job descriptions, roles and responsibilities.
- Parkinson's UK should consider whether the development of formal referral mechanisms and communications pathways between clinical nurse specialist and Information and Support Workers would enhance the provision of good quality social care.
- Parkinson's UK should explore the development of strategic alliances with organisations such as Skills for Care to develop accredited training programmes in order to build competence within their workforce to enhance control and choice for service users

## **Recommendations for future research and evaluation**

The prototype model developed for this project indicates that bespoke care for people with Parkinson's could be more efficient and effective as well as improve the quality of life for people with Parkinson's and carers. The additional cost of higher quality care could potentially be offset by reductions in complications arising from inadequate care.

This is theoretical hypothesis. In many cases such theoretical conclusions are not borne out when put into practice. This is often because little thought is then put into how to re-design the service to achieve the required cost offsets. Services may be only slightly adjusted and standard care is priced and badged as "Parkinson's aware" care.

In order to rigorously investigate the true impact of correct bespoke care, a great deal of thought needs to be put into what "Parkinson's aware" care would actually look like. This thinking then needs to be underpinned with research evidence showing best practice in each component. For example:

1. How would "Parkinson's aware" care be assessed and planned?

2. What would the care plan look like? It is likely that "Parkinson's aware" care from care staff would only add benefit if it dovetailed with the care provided by the family
3. Synchronising care with a medication regime can only work if the medication regime is adhered to faithfully. How can this be achieved?
4. What would be the best way to arrange the respite component? What communication system needs to be in place to adjust care if the person with Parkinson's condition or routines change?
5. Would a rapid response helpline avert crisis when certain problems arise?
6. Should the care staff use a case management model whereby a team of staff look after a defined group of people with Parkinson's?

If a "Parkinson's aware" approach to care can be developed in line with the findings in this report further research would be required. In order to evaluate the "Parkinson's aware" care model it would first need to be piloted to test, tweak and validate it. Ideally, the model of "Parkinson's aware" care would then require evaluation against current practice to examine the impact of the care model on service user outcomes and refine the assumptions in the economic model.

In the absence of such an evaluation it would be useful to do a small study, maybe a survey of people with Parkinson's and carers backed up by a consensus conference or expert focus group to build the robustness of the assumptions. Confidence is required in the validity of the economic assumptions before making the case to commissioners for this approach. If one assumption is seen to be way off the mark it detracts from the credibility of the whole model, even though in itself that assumption may make little difference to the results. If the model were to be developed we could build in a sensitivity analysis around each assumption.



## **TURNING INSIGHT INTO ACTION**

### **Findings**

The aim of this research project was 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.

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.

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

### **The context of the engagement and communication recommendations**

In order to achieve the sustainable behaviour change required from all stakeholders, it is important to note that these recommendations need to sit alongside wider strategic plans and interventions within Parkinson's UK and partners. These recommendations below support the initial engagement and communication aspects that will be required in relation to achieving the overall goals and original rationale for commissioning this report. They do not cover the future steps required in terms of informing, assisting and ensuring that systems and processes are in place to support sustained change once the initial engagement and communication has taken place. This will require on-going plans in line with over-arching organisational strategy.

### **Aims**

The engagement and communication recommendations aim to:

- Build an understanding of what good social care for people with Parkinson's looks like within all stakeholders.
- Build an understanding of the Impact Gap within those who develop policy or commission social care and demonstrate what timely and quality care can mean in reducing the need for residential or high cost care packages.

- Build an understanding within stakeholders of the challenges and needs of those living with Parkinson's and their carers.
- Aid joint working and partnerships.
- Develop advocates and influencers.
- Aid behaviour change at individual and organisational level.
- Engage with existing partners and stakeholders by giving thanks for their support thus maintaining established relationships.
- Provide an opportunity to celebrate success.
- Provide an example of success for senior managers, elected members and Council/NHS leaders to build upon.

## Objectives

That by a specific date in the future (TBA), in line with overall Parkinson's UK strategies, all internal and external stakeholders will be aware of:

- The nature research, the findings and recommendations.
- What is their role/responsibility in improving outcomes for people with Parkinson's?
- How they can improve the health and wellbeing of those with Parkinson's.
- What the benefits will be for them for example, as illustrated by the Impact Gap.

### *In order to achieve these objectives we must:*

- Accurately map and segment the stakeholders.
- Identify the most appropriate channel of communication for each stakeholder group – this must consider access to media and technology, language and tone of voice and literacy skills where applicable.
- Develop the most appropriate 'messages' for each stakeholder group.
- Ensure co-branding and reciprocal promotion from partners involved in the work.
- Ensure potential advocates are informed and able to promote the work.
- Ensure that the messages are clear, constant and **integrated** into all we do - Spoken, written, broadcast and printed.

## Audiences

The stakeholders should be mapped and divided into four groups according to the interest in and influence over the project. See example below:

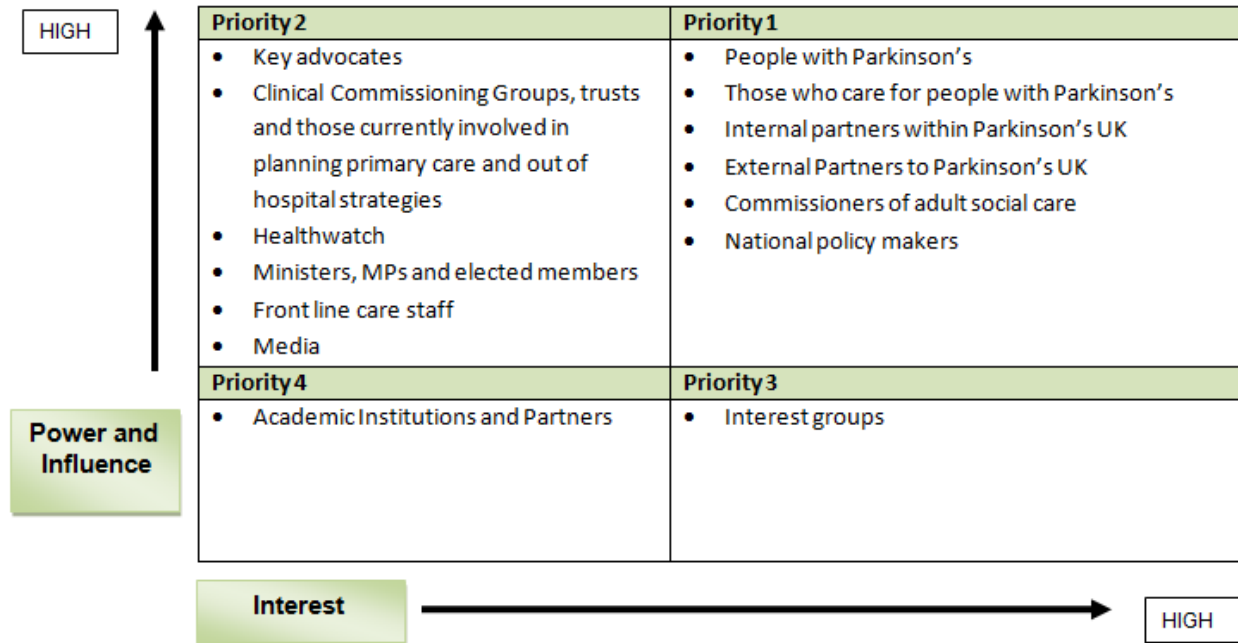
**Priority 1** – Powerful and interested parties, key to success.

**Priority 2** – Possibly powerful but maybe not as immediately interested. Need to be brought on board.

**Priority 3** – May be interested but not so powerful. Need to be kept interested and informed as may move to more powerful position.

**Priority 4** – Wider stakeholders – Informed to build wider positive PR and share learning.

### Stakeholder mapping example



### Strategy

The emphasis should be delivering a mix of communications that are appropriate to the audience. In order to achieve this it is important to understand the needs, opinions and circumstances of the target audience.

The communications should concentrate on the management and engagement of the Key and Priority stakeholders and should utilise a variety of tools and tactics in order to reach these target audiences.

### Key messages

'Strap-lines' and copy should be built around a key set of messages. These should be split into 'primary messages' and 'secondary messages' to build advocacy and keep key stakeholders informed. The significance of these primary and secondary messages should be adjusted depending on the target audience.

## **Engaging and communication with the key stakeholders – recommendations for messages, channels of communication and tactics**

Below are suggestions and recommendations. This list is not exhaustive and would be refined and prioritised in the light of considerations around funding, staff capacity and skills and support/alignment with over-arching organisational strategy

## Priority 1 stakeholders

<i>Target audience</i>	<b>National/local policy makers and the commissioners of adult social care</b>
<i>Aims of engagement and communications</i>	To promote understanding and behaviour that will lead to quality, timely care and better outcomes for those with Parkinson's
<i>Key messages</i>	<p><b>1. The Impact Gap</b></p> <ul style="list-style-type: none"> <li>Timely and quality care which is sympathetic to those with neurological conditions such as Parkinson's results in: <ul style="list-style-type: none"> <li>Increased health and well being</li> <li>Avoids 'crisis points' and this reduced need for primary and secondary care interventions</li> <li>Slowing down or alleviating the need for residential or high cost care packages</li> <li>Meets requirements around 'Adult Social Care Outcome Framework' and 'Better care Fund' outcome measures</li> </ul> </li> </ul> <p><b>2. 'Care for carers'</b></p> <ul style="list-style-type: none"> <li>They need support too!</li> <li>They are a vital channel of communication and monitor of care needs</li> <li>They are critical – if something happens to them, you will have to fill the gap</li> </ul> <p><b>3. To open communications channels with front line care staff</b></p> <p>Detail in line with report findings and recommendations</p>
<i>Channels of communication</i>	<ul style="list-style-type: none"> <li>Presentations and F2F meetings</li> <li>High level briefing papers</li> <li>Links to web-based information</li> <li>Media</li> <li>Social media</li> <li>Professional publications and networks</li> <li>Building advocates and spokespeople</li> </ul>
<i>Tactics and resources required</i>	<ul style="list-style-type: none"> <li>An executive summary of the report</li> <li>Pen portraits, case studies and models scenarios possible visual media – videos, interviews with case studies etc.</li> <li>Social media copy/feeds</li> <li>Presentation materials</li> <li>Briefing papers</li> <li>Website copy and links</li> <li>Press releases – pro-active</li> </ul>

	<ul style="list-style-type: none"> <li>• Journal articles</li> </ul>
<i>Considerations</i>	<ul style="list-style-type: none"> <li>• Resources required, internal capacity and skills</li> <li>• Willingness of people to engage with media or be spokespeople</li> <li>• Ability to get on the agenda at key meetings</li> </ul>

<i>Target audience</i>	<b>People with Parkinson's and those who care for them</b>
<i>Aims of engagement and communications</i>	To help: <ol style="list-style-type: none"> <li>1. Understand the impact of planning ahead</li> <li>2. Be aware of the support and entitlement to do so</li> <li>3. Be able to access support and information and to feel confident in doing so</li> </ol>
<i>Key messages</i>	<p>For both the messages should be around:</p> <ul style="list-style-type: none"> <li>• Alleviating <b>worry and fear</b></li> <li>• <b>Positive outcomes</b></li> <li>• <b>Plan ahead</b> and access support now</li> <li>• Rights, entitlements and in the light of recent and forthcoming policy change</li> <li>• Who can provide support</li> <li>• Who to contact</li> </ul> <p>For carers messages should centre around the 'I'm not a carer, I'm his wife' attitude. Focusing on:</p> <ul style="list-style-type: none"> <li>• <b>You matter too</b></li> <li>• <b>You are important and valued</b></li> <li>• There is help and support for you</li> <li>• How and what they can access</li> <li>• Who to contact</li> </ul>
<i>Channels of communication</i>	<ul style="list-style-type: none"> <li>• Friends and family</li> <li>• Media</li> <li>• Front line professionals</li> <li>• Primary Care</li> <li>• Support Groups</li> </ul>
<i>Tactics and resources required</i>	<ul style="list-style-type: none"> <li>• Press releases</li> <li>• Social media copy/feeds</li> <li>• Website materials</li> <li>• Presentation materials for support groups</li> <li>• Printed information and links to web-based information for care professionals</li> <li>• Printed information and links to web-based information for primary care professionals</li> </ul>
<i>Considerations</i>	<ul style="list-style-type: none"> <li>• Resources required, internal capacity and skills</li> </ul>

<i>Target audience</i>	<b>Internal Stakeholders within Parkinson's UK – including senior managers and front-line staff</b>
<i>Aims of engagement and communications</i>	<ol style="list-style-type: none"> <li>1. To raise awareness throughout the organisation of the work in relation to: <ul style="list-style-type: none"> <li>• <b>Purpose</b></li> <li>• <b>Findings</b></li> <li>• <b>Recommendations</b></li> <li>• <b>How the work will be used</b></li> </ul> </li> <li>2. Ensure that the findings are fed into planning and <b>strategy development</b></li> </ol>
<i>Key messages</i>	<p>We now have a qualitative evidence base and models that can be used to:</p> <ul style="list-style-type: none"> <li>• Demonstrate the need to form alliances with other stakeholders</li> <li>• Demonstrate the impact of quality care</li> <li>• The benefits for individuals and care providers/commissioners in providing care that is tailored to neurological conditions such as Parkinson's</li> </ul>
<i>Channels of communication</i>	<ul style="list-style-type: none"> <li>• Staff briefings</li> <li>• Staff newsletters</li> <li>• F2F meetings and presentations</li> <li>• Intranet, Yammer or SharePoint</li> </ul>
<i>Tactics and resources required</i>	<ul style="list-style-type: none"> <li>• An executive summary of the report</li> <li>• Briefing papers</li> <li>• Newsletter/web copy</li> <li>• Presentation materials</li> <li>• Copies of report</li> <li>• Corporate screen savers</li> </ul>
<i>Considerations</i>	<ul style="list-style-type: none"> <li>• Resources required, internal capacity and skills</li> <li>• Competing organisational priorities</li> </ul>



<i>Target audience</i>	<b>Possible external partners who would be required in delivering recommendations from report</b>
<i>Aims of engagement and communications</i>	<ol style="list-style-type: none"> <li>1. To build alliances and partnerships</li> <li>2. To understand possible roles and expectations</li> </ol>
<i>Key messages</i>	<p>Key messages should be around:</p> <ul style="list-style-type: none"> <li>• <b>More powerful together</b></li> <li>• Able to act together for people with similar care needs despite condition</li> <li>• Able to make efficiencies and be more effective in partnership</li> <li>• Have more clout together</li> <li>• <b>Be more credible as one</b></li> </ul>
<i>Channels of communication</i>	<ul style="list-style-type: none"> <li>• F2F meetings</li> <li>• Conferences</li> <li>• Professional journals</li> <li>• Briefing packs</li> </ul>
<i>Tactics and resources required</i>	<ul style="list-style-type: none"> <li>• An executive summary of the report</li> <li>• Template contact letters</li> <li>• Presentation materials</li> <li>• Journal articles</li> <li>• Briefing materials</li> <li>• Pen portraits, case studies and models scenarios</li> </ul>
<i>Considerations</i>	<ul style="list-style-type: none"> <li>• Resources required, internal capacity and skills</li> <li>• Competing organisational priorities both internally and externally</li> </ul>

## Priority 2 stakeholders

<i>Target audience</i>	<b>The Media</b>
<i>Aims of engagement and communications</i>	<ol style="list-style-type: none"> <li>1. To build advocacy</li> <li>2. Wider public understand</li> <li>3. And, if required, some political clout!</li> </ol>
<i>Key messages</i>	<p>Messages should centre around:</p> <ul style="list-style-type: none"> <li>• <b>Real people</b> – what this means to them</li> <li>• <b>Positive outcomes</b> and benefits</li> <li>• What happens now, what could happen and the benefit to society</li> </ul>
<i>Channels of communication</i>	<ul style="list-style-type: none"> <li>• Press releases</li> <li>• Pen portraits/case studies</li> <li>• Spokespeople</li> </ul>
<i>Tactics and resources required</i>	<ul style="list-style-type: none"> <li>• Copy for press pro-active releases (positive outcomes based)</li> <li>• An executive summary of the report/Press pack</li> <li>• Re-active and pro-active lines for media</li> <li>• Any stock photography appropriate</li> <li>• Pen portrait/case study material</li> <li>• Individuals and professionals willing to be spokespeople</li> </ul>
<i>Considerations</i>	<ul style="list-style-type: none"> <li>• Resources required, internal capacity and skills</li> <li>• Willingness of people to engage with media or be spokespeople</li> <li>• Media – not within our control – reputational risk</li> <li>• Possible negative impact on partners – for example policy makers if criticised by media</li> </ul>

<i>Target audience</i>	<b>Possible advocates – Those within CCGs, Healthwatch, Strategic Clinical networks, Primary Care and Out of Hospital Strategy development</b>
<i>Aims of engagement and communications</i>	<ol style="list-style-type: none"> <li><b>To build understanding of:</b> <ul style="list-style-type: none"> <li>Need for <b>quality, timely and appropriate care</b> for these with neurological disorders such as Parkinson's</li> <li>The <b>benefits and contribution to targets and outcome measures</b> in relation to current policy AND regional and local strategy development</li> <li>How it <b>support regional, local priorities</b> – JSNA etc.</li> </ul> </li> <li><b>Build advocacy</b></li> <li><b>To open communications channels with front line care staff</b></li> </ol> <p>Detail in line with report findings and recommendations</p>
<i>Key messages</i>	<p>Key messages should be built around:</p> <ul style="list-style-type: none"> <li>Benefits to commissioner and planners – cost etc.</li> <li>Outcomes for individuals and people with Parkinson's</li> <li>Outcomes for commissioners in relation to policy and targets</li> </ul>
<i>Channels of communication</i>	<ul style="list-style-type: none"> <li>F2F meetings</li> <li>Conferences and seminars</li> <li>Professional Journals</li> <li>Briefings</li> <li>Web- based and social media</li> </ul>
<i>Tactics and resources required</i>	<ul style="list-style-type: none"> <li>An executive summary of the report</li> <li>Pen portraits, case studies and models scenarios possible visual media – videos, interviews with case studies etc.</li> <li>Presentation materials</li> <li>Briefing packs</li> <li>Journal articles</li> <li>Web and social media copy</li> </ul>
<i>Considerations</i>	<ul style="list-style-type: none"> <li>Resources required, internal capacity and skills</li> <li>Competing priorities</li> </ul>

<i>Target audience</i>	<b>MPs and elected members</b>
<i>Aims of engagement and communications</i>	<ol style="list-style-type: none"> <li>1. To raise awareness</li> <li>2. To build understanding</li> <li>3. To build advocacy and support</li> </ol>
<i>Key messages</i>	<ul style="list-style-type: none"> <li>• <b>Real people</b> – what this means to them</li> <li>• <b>Positive outcomes</b> and benefits</li> <li>• What happens now, what could happen and the benefit to society and their constituents/local areas</li> </ul>
<i>Channels of communication</i>	<ul style="list-style-type: none"> <li>• F2F and meetings</li> <li>• Letters and briefings</li> <li>• Web</li> </ul>
<i>Tactics and resources required</i>	<ul style="list-style-type: none"> <li>• Template letters</li> <li>• Briefing papers</li> <li>• Presentation materials</li> <li>• Web-based information</li> <li>• Copies of reports</li> <li>• Pen portraits, case studies and models scenarios</li> </ul>
<i>Considerations</i>	<ul style="list-style-type: none"> <li>• Resources required, internal capacity and skills</li> <li>• Competing priorities</li> </ul>

### **Priority 3 stakeholders**

<i>Target audience</i>	<b>Interest Groups</b>
<i>Aims of engagement and communications</i>	<ol style="list-style-type: none"> <li>1. To raise awareness</li> <li>2. To build understanding</li> <li>3. To build advocacy and support</li> </ol>
<i>Key messages</i>	<ul style="list-style-type: none"> <li>• <b>Real people</b> – what this means to them</li> <li>• <b>Positive outcomes</b> and benefits</li> <li>• <b>How they can help and feed into the next steps</b></li> </ul>
<i>Channels of communication</i>	<ul style="list-style-type: none"> <li>• F2F and meetings</li> <li>• Web</li> <li>• Newsletters</li> </ul>
<i>Tactics and resources required</i>	<ul style="list-style-type: none"> <li>• Presentation materials</li> <li>• Web-based information</li> <li>• Executive summary and copies of reports</li> <li>• Pen portraits, case studies and models scenarios</li> <li>• Web and social media copy</li> </ul>
<i>Considerations</i>	<ul style="list-style-type: none"> <li>• Resources required, internal capacity and skills</li> <li>• Competing priorities</li> </ul>

#### **Priority 4 stakeholders**

<i>Target audience</i>	<b>Academic institutions and partners – professional networks</b>
<i>Aims of engagement and communications</i>	To share the learning and develop advocacy
<i>Key messages</i>	Messages should centre around: <ul style="list-style-type: none"><li>• The focus of the <b>research</b></li><li>• <b>Findings</b> and recommendations</li><li>• <b>Application</b> to policy and practice</li><li>• Recommendations for further work</li></ul>
<i>Channels of communication</i>	<ul style="list-style-type: none"><li>• The report - copies sent to key academics and professional groups</li><li>• Journal articles</li><li>• Conferences</li><li>• Websites</li><li>• Social media</li></ul>
<i>Tactics and resources required</i>	<ul style="list-style-type: none"><li>• Copies of report</li><li>• Articles</li><li>• Conference presentation and speakers</li><li>• Web based information</li><li>• Promotion of links providing access to web-based resources and report</li><li>• Copy for ‘tweets’ to academic and professional networks</li></ul>
<i>Considerations</i>	<ul style="list-style-type: none"><li>• Costs and resource</li><li>• Priority in terms of overall aims</li></ul>

#### **Next steps for Parkinson’s UK**

- Refine:
  - Stakeholder mapping
  - Refine primary messages and develop secondary messages
- Develop a communication and engagement implementation proposal plan and schedule
- Align plan with organisational strategy and aims, resource requirements and availability
- Refine plan and prioritise if required
- Produce supporting project plan including roles and responsibilities
- Sign off and roll out

## 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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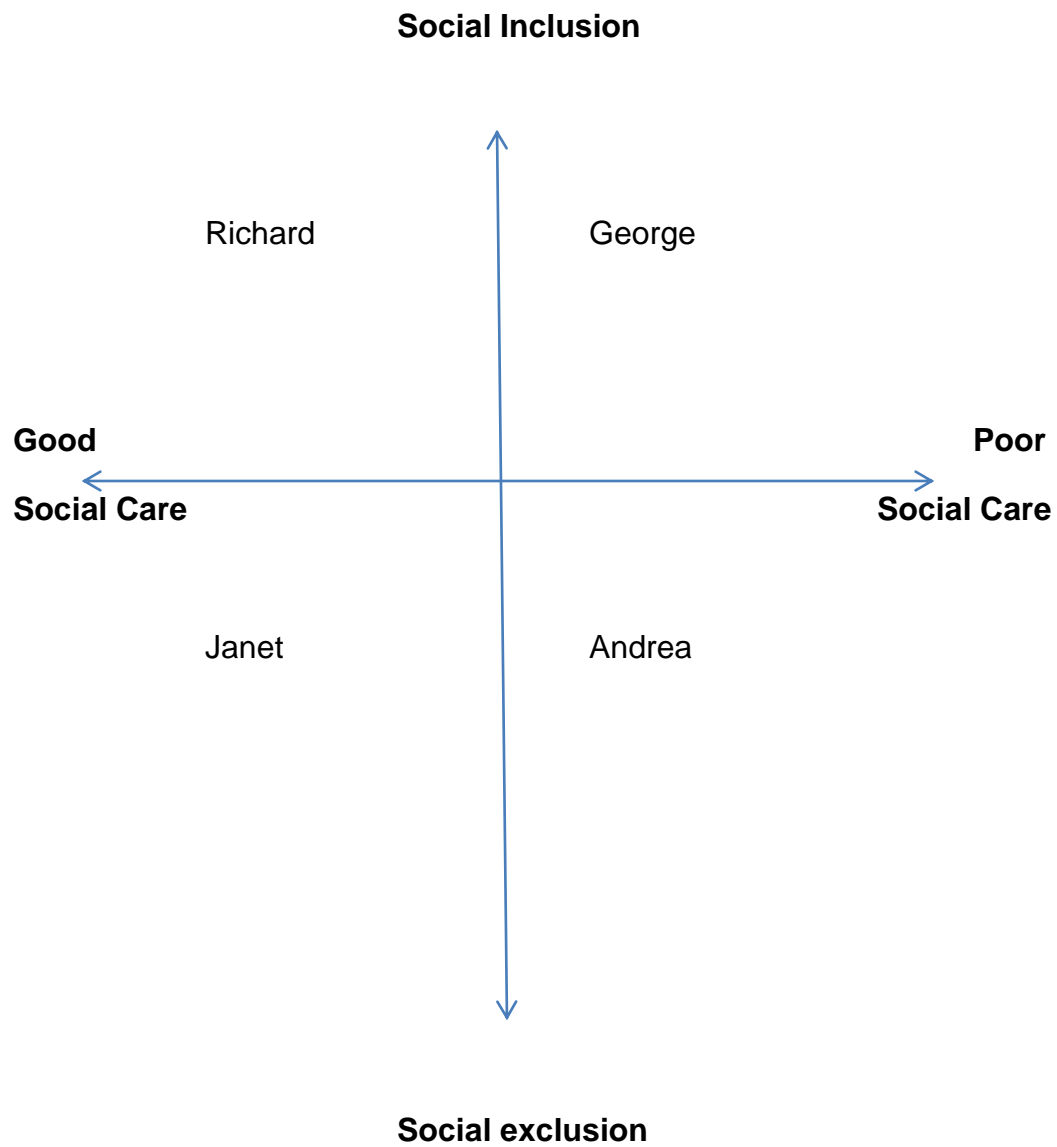
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## Appendix 1.

### Segmentation criteria: Factors influencing good quality social care

Context	Health	Attitudes and values	Social care
<ul style="list-style-type: none"> <li>• Age</li> <li>• Gender</li> <li>• Living alone</li> <li>• Social connections</li> <li>• Hobbies and activities</li> <li>• Socio economic status               <ul style="list-style-type: none"> <li>• income</li> <li>• housing</li> <li>• education</li> </ul> </li> </ul>	<ul style="list-style-type: none"> <li>• General health               <ul style="list-style-type: none"> <li>○ age</li> <li>○ co-morbidity</li> <li>○ other disability</li> </ul> </li> <li>• Parkinson's               <ul style="list-style-type: none"> <li>○ Stage</li> <li>○ symptoms</li> </ul> </li> </ul>	<ul style="list-style-type: none"> <li>• Pride</li> <li>• Protecting independence</li> <li>• Stoicism</li> <li>• Liking to be sociable</li> <li>• Valuing privacy</li> <li>• Valuing control</li> <li>• Coping</li> <li>• Fear and denial</li> </ul>	<p><b><i>Parkinson's specific</i></b></p> <ul style="list-style-type: none"> <li>• Timing               <ul style="list-style-type: none"> <li>○ anticipatory / early</li> <li>○ allowing time</li> </ul> </li> <li>• Understanding               <ul style="list-style-type: none"> <li>○ Parkinson's (symptoms and fluctuations)</li> <li>○ Meds</li> </ul> </li> <li>• Regular reassessment of needs</li> <li>• Social inclusion</li> <li>• Person with Parkinson's as expert</li> </ul> <p><b><i>Parkinson's important but not specific</i></b></p> <ul style="list-style-type: none"> <li>• Continuity</li> <li>• Consistency</li> <li>• Control</li> <li>• Choice</li> <li>• Maintaining independence</li> <li>• Flexibility</li> <li>• Respecting dignity</li> </ul>



## Appendix 2. Pen Portraits

In order to bring the research to life and help gain a deeper understanding of the factors that influence the outcomes for people with Parkinson's; we have developed a set of 'pen portraits'. These are not real stories or people. They are however built using the research findings and real life observations to depict a 'portrait' of possible scenarios created using a descriptive narrative.

Each of the pen portraits aims to describe the findings of the research. They illustrate how significant benefits are experienced from timely and appropriate care being put in place for people whose circumstances may differ. Benefits accrue for the individual concerned and the commissioners of care. The possible outcomes relate to the domains in the Adult Social Care Outcomes Framework (DH 2013) and the measures outlined in the 'Better Care Fund' which aims to facilitate delivery of the 'vision' for future adult social care. These centre on reducing the need for hospital or residential care by allowing people to remain independent in their own homes for as long as possible.

The pen portraits also aim to build an understanding within those who commission and develop plans and policy around care (be that on a local or national level), the everyday challenges faced by people with Parkinson's. They aim to describe how they feel, the drivers to attitudes and behaviour as well as the difference timely and appropriate care will make to them.

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 tailored to the needs of someone with Parkinson's is received. We have called this the '**Impact Gap**'

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

The diagram below 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.

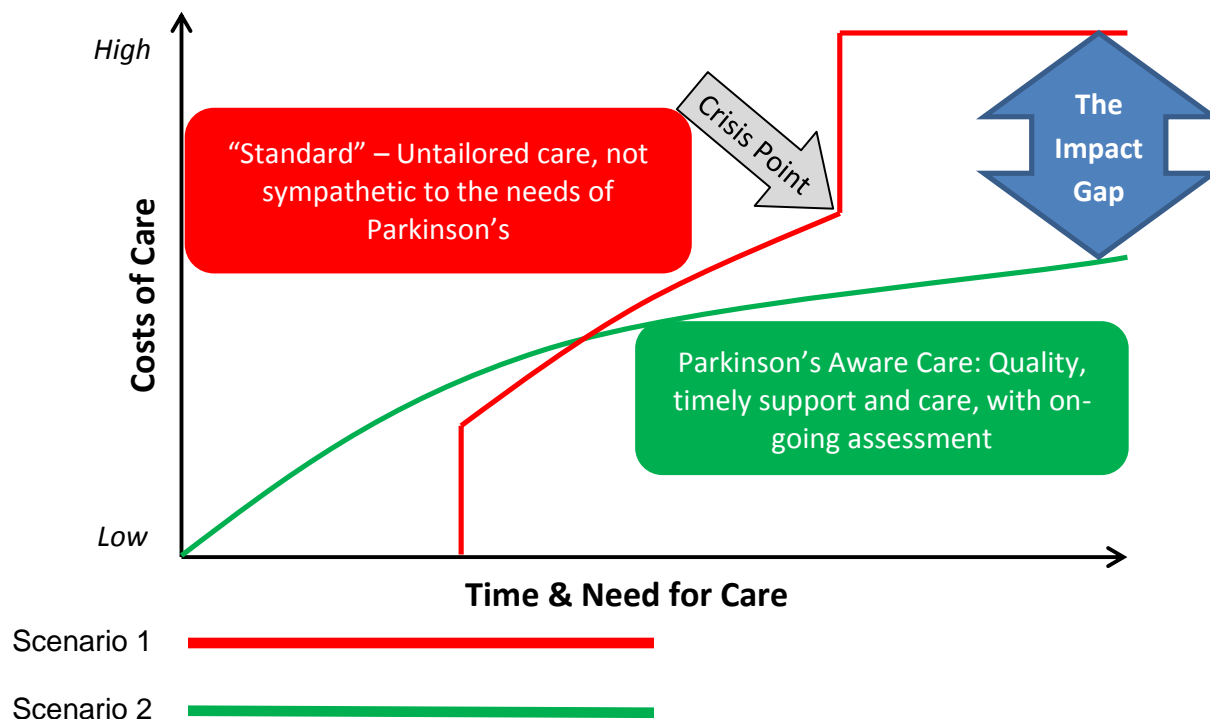
Within scenario 1, a standard care package of domiciliary visits is in place. There is no care for the carer and the package does not take into account the timing of medication and the needs of someone with a neurological disorder such as Parkinson's.

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.

We have called this the **'Impact Gap'**.



The case studies overleaf illustrate some of the different outcomes and possible Impact Gaps.

## ***Andrea (Socially Excluded, Poor Social Care)***

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### ***Andrea's world***

Andrea is in her early 60s, is single and lives alone. She has some family but they don't live close by and she has no children of her own. Andrea used to work as a cook in a school but had to retire early due to ill health.

She has to watch her finances but her state pension is topped up by a small occupational pension and she does get disabled living allowance (DLA).

Prior to her diagnosis Andrea had a reasonable social life and kept herself fit by going to the public baths to swim three times a week. When she was working she had more money coming in and now and again, she would treat herself to a shopping trip and she loved to hunt for bargains in the sales.

Andrea was always very house proud and kept things spick and span but now struggles with housework because of Parkinson's. She finds it hard to keep up with things because of the physical effects of the Parkinson's but sometimes she just feels so low. She has noticed that her home is getting a bit cluttered and is not as tidy as it used to be. Keeping up to her appearance in terms of keeping her clothes clean and hair neat is harder too. All this makes her low mood even worse.

She is however, determined to be independent and keep living in her own home. This means that she is reluctant to ask for help in case it jeopardises her independence and choice. Not having family near, or being able to get out like she used to, means that she is becoming increasingly socially isolated.

### ***Andrea's health***

Andrea was diagnosed with Parkinson's 10 years ago. There is an established trajectory for the condition, Andrea has complex Parkinson's.

Andrea has angina, is unsteady on her feet with a history of falls, limited mobility and needs her mobility scooter to leave the house. She has also had frequent urinary tract infections. She has periods of severe involuntary movements; trying to manage daily tasks during these periods can leave her feeling exhausted.

In addition she is starting to have problems swallowing and additional quietening of her voice; often this makes her speech unintelligible to others.

Andrea does have some help and she is paying for her care with DLA. She has some help with cleaning and gardening but it is only an hour a week. The meals on wheels she gets really helps and there have also been adaptations to her home such as hand rails, a bath hoist and an alarm. She has a personal alarm too but does not always remember to wear it, or where she has left it.

Andrea doesn't often go to Parkinson's UK branch meetings because she doesn't like to see people whose Parkinson's is further advanced than hers. However, Andrea has been visited at home by the Parkinson's UK Information and Support Worker who has been invaluable in helping her to access DLA and the aids and adaptations.

### ***The social care Andrea receives now***

Although Andrea was receiving sufficient social care to enable her to remain at home, her quality of life could be considered poor. She rarely sees people and finds it difficult to leave the house on many days in spite of having access to a scooter.

The lack of social contact creates additional safety risks as Andrea is at high risk of falling and often forgets to wear her personal alarm. Her social isolation means that no-one is keeping an eye on Andrea on a regular basis. No one has an overview of how she is coping on a day to day basis or could pick up that she is struggling to manage and needs more input. On some occasions she had fallen down and lay on the floor for hours unable to get up.

She had high standards in terms of her home, but is not able to maintain these standards to her satisfaction with only 1 hour a week of cleaning. The cleaners she employed are neighbours and have no specialised knowledge of her condition. Although the meals on wheels are welcome, they are expensive and still mean that Andrea has to prepare 2 meals a day for herself.

### **What does the future hold: The possible 'Impact Gap'?**

#### ***If things carry on as they are?***

If things stay the same for Andrea in terms of the care and assistance she receives, it is likely that:

- She will find it increasingly difficult to leave the house as symptoms worsen and will decline into a vicious circle of social isolation and worsening symptoms
- Her social isolation will also lead to lower mood, depression and less people around to notice if she deteriorates.

She will be at increased risk of falling, leading in time to injurious or fear-related consequences. She has already lain on the floor for hours after a fall.

- Her health will deteriorate leading to a greater likelihood of illnesses such as:
  - chest infections
  - urinary tract infections (UTIs) - linked to general health and mental confusion

Symptoms of these illnesses may go unnoticed so are likely to get worse before treatment or care is introduced. This means more visits to hospital and when care is introduced Andrea will need a bigger care package for longer.

It is also likely that the need for permanent residential care will be required earlier.

### ***What if things change and social care improves?***

Andrea's quality of life could potentially be improved considerably by not only increasing the amount of social care she receives, but tailoring it more specifically to her Parkinson's. This could include carers to help with her personal care including bathing and dressing. However, these visits would need timing carefully to fit in with her medication to minimise the level of assistance she needed and ensure that she could be supported by a single carer going in. Increased support with food preparation would also ensure that Andrea drank enough to reduce the likelihood of UTIs.

Social inclusion for Andrea would mean being helped to go swimming and to visit the shops - this would make her feel part of the world again. As well as needing transport, she would also need someone to go with her and assist. Andrea would need to feel in control and to manage this assistance as her abilities fluctuate on almost a daily basis. Regular exercise would also improve or maintain her balance and mobility and reduce the risk of falls.

Increased support in the home which was provided by the same carers on a regular basis would ensure that someone was 'keeping an eye' on Andrea and could spot deterioration in her condition and changes in her needs. This would have the potential to reduce the risk of falls, reduce the risk of UTIs and chest infections, improve her mental health and overall quality of life, reduce visits to the GP, reduce hospital admissions, allow her to remain in her own home and delay the need for residential care.

### **Things to consider**

However, accessing any increase or improvement in social care for Andrea would require a detailed assessment of her health and social care needs. Andrea's pride makes her reluctant to ask for an assessment. Everything she has accessed to date, she has had to fight for and overcome lots of barriers. This has made her feel that she is somehow not entitled to help and that she shouldn't ask. Well signposted access to a Social Worker who understood some of the realities of living with Parkinson's could transform Andrea's life.

## *Richard (Socially Included, Good Social Care)*

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### ***Richard's world***

Richard is in his late 60s and lives with his wife Linda. They have 3 children and 6 grandchildren that live nearby and visit regularly. Richard is a retired accountant who had to retire in his early 50s due to ill health. Linda had been a teacher but retired at 55 to look after Richard. They have lived in the same house for 30 years which they now own. They have always enjoyed a good social life and have a wide network of friends. They had good jobs with good occupational pensions which on top of their state pensions and savings, means they are not too badly off financially.

The home is immaculate and they make an effort to keep the home tidy for Richard to move around safely. They have always liked to be organised and plan ahead so, knowing Richard's mobility will decline, they have recently installed a wet room.

Richard had been a keen golfer and liked physical activity before his illness and Linda loves going to yoga. They both enjoy reading and Linda is a member of a book club. They have a car, so Linda can take Richard to visit friends and family and maintain social contact.

Since Richard's Parkinson's diagnosis they had been stalwart members of the local Parkinson's UK branch.

### ***Richard's health***

Before his diagnosis of Parkinson's, Richard had no other health problems and seemed fit and well for his age. He was diagnosed over 20 years ago and is now in the advanced stages of the condition.

Richard has severe dyskinesia which means he has involuntary muscle movements including movements similar to tics or chorea and diminished voluntary movements. Dyskinesia can be anything from a slight tremor of the hands to an uncontrollable movement of the upper body or lower extremities. This means he is at high risk of falls, has very poor mobility within the house and needs help to move around his home. He is unable to wash or dress himself or prepare his own meals.

Richard also has problems with speech which makes communication difficult, but Linda can understand his needs very well. She often interprets for him in unfamiliar situations.

Both Richard and Linda are in good spirits. They are very cheerful and feel in control and organised. They still enjoy life and are a good and loving team. Linda manages nearly all his care needs, including cooking, cleaning and hygiene. The only thing she struggles with is helping him have a shower because of his size and poor mobility.



### ***The social care Richard receives now***

Richard has been assessed by a social worker and has been in receipt of direct payments for some time. Some of this is spent on domiciliary care to help shower him three times a week. They have also made adaptations to their home including hand rails, a hoist and an alarm. Richard also spends some of his direct payments on a carer to come in one evening a month so that Linda can go to her book group. Richard also attends a day centre once a week where they have a range of activities including exercise.

They have chosen the carer they employ via an agency who helped them to recruit a Personal Assistant. This has meant consistency in terms of the carer who attends and the time that they attend. The carer who comes to shower him and sit with him is the same person each time who completely understands the need to arrive at the time Richard has booked him for in order that Richard needs minimal assistance.

They have an organised approach to social care provision. The blend of care from family and paid carer enables them to enjoy a full social life which they value. The good quality of care enables them to maintain Richard's independence at home.

Richard receives high quality social care which is tailored specifically to meet his needs. He is able to employ someone whom he has chosen, to offer him support when he needs it. Because he is in receipt of direct payments Richard and Linda are in complete charge of the social care he receives. Both Richard and Linda can get out and about and see people. Richard is able to maintain a good standard of personal hygiene and always look smart and well dressed. This increases his confidence to get out and about. Richard values highly the bath hoist and handrails which reduce his risk of falls and enable him to be more independent in his own home.

Richard is a big chap and caring for him fulltime often means Linda doesn't get enough sleep and she is tired out some days.

Having a day each week when Richard goes to the Day Centre and being able to go to her Book Group makes her feel human. Without this kind of respite, Linda isn't sure that she could cope indefinitely.

### **What does the future hold: The possible 'Impact Gap'?**

#### ***If things carry on as they are?***

People are involved in caring for Richard on a consistent basis so change is likely to be picked up quickly and in a timely way. Richard and Linda are well informed and are able to plan ahead to anticipate and meet future care needs. This means that:

- There are minimal costs in terms of carer intervention
- Reduced need for emergency health and social care: e.g. hospital admissions, reablement packages
- They are delaying the need for residential or intensive domiciliary care package

- Richard and Linda are maintaining a good quality of life and service user experience.
- There are reduced NHS costs in terms of primary care use and prescription e.g. antibiotics.

### ***What if things change?***

Richard and Linda love each other and are desperate to stay together and get the most out of life. However, if anything happens to Linda, Richard does not know what he would do. They both dread the thought that he may one day need residential care.

As time goes on and Linda ages, she may develop a chronic health problem that impacts on her ability to co-ordinate and care for Richards needs.

### **Things to consider**

Helping Richard and Linda with advice and support regarding timely transfer to extra-care housing for example, will lessen the potential Impact Gap and ensure they are prepared for additional care when this is required.

They will both develop additional care needs. The implications of this are that they will need to use the personal budget in different ways and will need to employ carers with a different set of skills. They could be supported to achieve this.

## ***George (Socially Included, Poor Social Care)***

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### ***George's world***

George is in his mid 70s and lives with his wife Sue. They have a large family with 4 children and 8 grand-children. Although their children work full time and have their own children to care for, they live nearby and manage to visit regularly.

George was a bricklayer and had already retired at 65 prior to his Parkinson's diagnosis. Sue had worked in a local café, part-time. They have lived in the same social housing property since they were married. Their home is comfortable, and full of family photographs; it is a warm, "lived-in" family home.

They had always liked to keep themselves to themselves and only really socialised within the family. Both George and Sue came from large families themselves and had large extended families.

They have lived in this house for a long time but the local neighbourhood has changed and they don't know the neighbours any more. However, someone from a local church group calls in regularly to check on them and take them to a lunch club so they do get out a little.

George and Sue rely on a state pension and various benefits including attendance allowance, carer's allowance, and housing and council tax credit. They do not have any savings.

When they can organise community transport they attend the local Parkinson's UK branch meetings. This is becoming more difficult because they are both becoming increasingly frail.

Sue used to love to bake but struggles to cook now and relies on ready meals that she heats in the microwave. They muddle through together, helping one another. George used to be a keen gardener with an allotment, and hates looking out at the unkempt garden. George used to like going down to the pub to watch the football but hasn't been able to do this for some years now.

### ***George's health***

Both George and Sue are now very frail. As well as Parkinson's, George has heart failure and a lung disease referred to as chronic obstructive pulmonary disease (COPD). Sue has osteoporosis and is unsteady on her legs. They are both at high risk of falling. George was only diagnosed in the last five years but had deteriorated rapidly and is advancing to the later stages of the condition.

George has a bradykinetic or rigid type of Parkinson's which means he is at high risk of falls, with very poor mobility. He struggles to get around within the house and needs help to move around. George has severe "on-off" syndrome and for large parts of the day becomes almost immobile. The effect of his medication wears off between doses and he has episodes of feeling his feet are stuck to the ground and he is unable to move. He struggles to speak and can't move at this time. During these 'off' periods, George feels anxious and frustrated at his loss of

control and dependency on help. It's really very important for George that he has his medication on time.

George and Sue are just about managing day to day. In reality they are really starting to struggle but they are the type of people who don't like to complain.

### ***The social care George receives now***

George has a carer coming in each morning to help get him up, washed and dressed. The carers vary day-to-day and he never knows who is going to turn up. Sometimes they send young women. On these occasions he sends them away as he feels embarrassed. He thinks this is inappropriate and doesn't want to be seen undressed by "young girls".

The carers are supposed to come at 7.30 each morning, in line with his medication. However, they tend to turn up at any time between 7 and 10 which means that sometimes George is rigid and can't be dressed by one carer. George often feels rushed by the carers. They don't seem to understand that some days it takes him much longer to do things than others. He wishes they wouldn't keep chatting away to him and asking him questions but let him just focus on the task in hand.

George often suffers from faints. He was assessed for care as a result of a hospital admission following a fall. George had a fractured neck of femur and was in hospital for two months. After this he received an enablement package, following which a number of adaptations were made to the home. This included grab rails, a raised toilet seat and a bath hoist which carers use to bath him twice a week. Although the aids and adaptation to his home are really useful, overall George experiences poor social care, which isn't tailored in any way to his Parkinson's.

Their eldest son has argued on their behalf to have their care needs reassessed, as he felt they have deteriorated recently. This has involved repeated phone calls to adult social care. Often his calls were not returned, and on one occasion he was told no-one had any record of previous contact.

They haven't been offered direct payments but if they were, they wouldn't want them. They would rather have their care organised by someone else and don't think they could cope with the responsibility of organising their own care package.

George would like it to be much easier to access social care. He doesn't feel he can do it for himself and even his son who is articulate and assertive seems to get fobbed off and passed from pillar to post whenever he contacts Adult Social Care Services. He knows his care isn't ideal, but feels there's no point complaining - what difference would it make?

He feels trapped in his own home and hates being dependent on Sue. George would like to go to the pub and watch the football as he used to do.

## **What does the future hold: The possible 'Impact Gap'?**

### ***If things carry on as they are?***

George and Sue are just about hanging on at home. They are not sure what the future will bring. There is a real probability that Sue will become too ill or exhausted to cope and the family feel that residential care will be needed very soon.

There is a real danger that:

- For both of them, their health will decline rapidly and they will need increased care. They are likely to need two carers rather than one and longer and more frequent care visits
- Crisis situations and accidents will happen needing hospital admission
- Quality of life increasingly is impaired as they get more social isolated and they are not able to do the things they like to do. This will have a detrimental impact on mental health.
- Self-help and management regarding diet, hygiene and housework gets harder

The outcome is likely to be residential care. In addition, if one goes into care, the impact on the other is likely to result in high domiciliary care needs or residential care also.

### ***If things change and social care improves?***

George would like the same person or a small team of carers coming in each day who get to know him well and arrive within 30 – 60 minutes after he has taken his medication so that he is not 'off' and rigid when they arrive to get him up and dressed.

His carers would need to understand more about Parkinson's and the importance of allowing him to do things in his own time and not to distract his attention while he is trying to concentrate on a task.

He would like to be able to shape his care without having too much responsibility or forms to fill in. He would benefit from regular reassessment to ensure his needs are met as his condition deteriorates and he enters the advanced stages of Parkinson's

Improving the social care would mean that they are less likely to be admitted to hospital as a result of some sort of crisis e.g. a fall at home or Sue becoming too exhausted to cope. This may not necessarily mean increasing the input in terms of cost, but simply ensuring it better meets the Parkinson's-specific needs. The improved outcomes would mean:

- A better quality of life for George and Sue
- They could remain in their own home and maintain independence
- Better service user experience because they are in their own home, where they have lived for year and have their family memories

- Less social exclusion
- Reduced care costs
- Reduced preventable events
- Delaying the need for residential or high cost care packages

### **Things to Consider**

The person assessing their care needs take a person-centred approach to meeting his needs. The assessor could help George access care through a local service provider and helps him maintain social contact. He could have a buddy from a voluntary sector agency who helps him get to the pub to watch a game of football. This means he has the outcome he requires without what he sees as the burden of direct payments.

## *Janet (Socially Excluded Good Social Care)*

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### **Janet's world**

Janet finished work as a nurse 2 years ago because her Parkinson's affects the speed in which she had to make clinical decisions, and she was concerned about her own competency and safe practice.

She is in her late 40s and recently divorced so lives alone in her ground floor flat. She doesn't really have any family close by and her two children have moved away.

She manages OK with her money and owns her flat outright now. She also has an occupational pension and receives direct payments following adult social care assessment.

Her home is well looked after. She does what she can but increasingly relies on someone to do her cleaning for her. Prior to her Parkinson's Janet used to sing in a choir and was a member of a walking group. She's unable to do either of these now due to the Parkinson's symptoms. She relied on work for her social network. After her divorce, and early retirement, she doesn't have many friends and has few visitors.

### **Janet's health**

Janet always enjoyed good health and there is no recorded family history of Parkinson's. Janet struggles to understand why Parkinson's has happened to her; it seems unfair. She gets frightened when she thinks of the future and is becoming increasingly anxious about what this means for her.

Janet was diagnosed about eight years ago. We might say she is in the maintenance stage of Parkinson's

Janet is having problems with mobility and her voice and she feels her medication isn't working as well as it used to. She has also noticed other problems with her body and has begun to suffer from digestive problems and quite bad constipation which makes her feel sluggish and generally low in mood. She has recently started taking antidepressant medication. She is noticing the onset of dyskinesia which means she has involuntary muscle movements including movements similar to tics or chorea and diminished voluntary movements. Dyskinesia can be anything from a slight tremor of the hands to an uncontrollable movement of the upper body or lower extremities.

Janet fears the embarrassment this might cause when she is out, fearing that others would think her drunk. She feels depressed which on some days is made worse by her fear about what will happen to her. Janet's symptoms of low mood and anxiety are also exacerbated by increasing impairment of her cognitive abilities due to the Parkinson's. Things that she used to do easily, she now finds hard or impossible to do, for example understanding her bank statements or motivation to sit and do the crossword.

### ***The social care Janet receives now***

As soon as she was diagnosed a friend who was a clinical nurse specialist in Parkinson's recommended she contacted the Parkinson's UK branch. They were very helpful and referred her straight away to the Parkinson's UK Information and Support Worker (ISW). Although she didn't have any social care needs at that time, the ISW kept in regular, but not frequent, contact.

When her symptoms started to deteriorate, Janet's ISW helped her access an assessment by Adult Social Care. She is now in receipt of Direct Payments and has employed her own personal assistant (PA) to help. The PA currently takes her out shopping, helps with the cleaning and ironing, and has started to help with personal hygiene, especially washing her hair. Janet feels the benefit of knowing she has a 'companion' to help her manage with things she struggles to find motivation to do on her own.

The PA has received some basic training and information about Parkinson's via the local Parkinson's UK branch. She is confident and knowledgeable and is able to work alongside people and help keep them going and maximise their independence.

Because her PA has been picked by Janet and has had some training, they get on well and her PA has got to know Janet over time and is familiar with her condition and the impact this has on her mood. She has learned how to work round this and helps motivate Janet rather than just accept it at face value when Janet says she isn't up to doing anything that day. This has made a huge difference to Janet's psychological wellbeing. She really looks forward to seeing her PA and without this input is likely to need medication to cope with her low mood. Janet trusts her PA implicitly. This is especially important to her after the horror stories she has heard in the papers about carers stealing from people, abusing their trust and not staying for as long as they were contracted to do, but still charging for the full amount.

Whilst she can manage her Direct Payments at the moment, she is starting to find this difficult because of the cognitive impacts and fatigue associated with Parkinson's. With support from the ISW she has already identified an organisation that can help her manage this in the future.

Whilst she is currently socially isolated, she is hopeful that she will be able to engage in activities outside the home that will increase her quality of life. She is using her personal budget to pay for some counselling, which she is starting to feel the benefit of. As a result she is starting to feel like she can face people again socially.

Even though she can't sing any more she has enquired about helping to run the choir. She has also heard about a group that organise walking for the disabled, which she thinks she will join as her condition progresses.

Janet has never been to Parkinson's UK branch meeting because she didn't like to see people whose Parkinson's was worse than her own, and because she feels younger than most other members. However, the help Janet has had from the ISW has opened doors to social care.



## **What does the future hold: The possible 'Impact Gap'?**

### ***If things carry on as they are?***

While she still feels isolated socially, Janet is feeling the benefit of social care which is tailored specifically towards her Parkinson's. She enjoys getting out and would like to do this more often. However, her personal budget doesn't stretch far enough to pay her PA to come on more than a few occasions. She currently uses her to do the 'essentials' like the supermarket shop but would love to expand this a bit and do more choir related activities to help her socialise and expand her social circle.

The fact that Janet has received Parkinson's aware care at an early stage in her condition trajectory means that she has got good quality of life and is able to manage her mental health symptoms more effectively which has averted the need for multiple GP visits.

She is banking on the fact that the ISW will come through for her as she has in the past. However, on she knows that the ISW has hundreds of people on her books and is conscious that she can't do as much for everyone as she would like to do.

As her condition worsens, Janet is aware that she will need more help at home and this is adding to her anxiety. She will need regular reassessment by Adult Social Care Services but is unsure when this will take place and how it will be instigated. This could lead to care not meeting Janet's needs as her condition worsens and the risk of a crisis or escalation of care package requirements will be heightened. This could also mean:

- Serious deterioration in her physical condition and mental wellbeing
- Increased care package requirement and NHS use.
- Needs support to access a replacement and responsive contingency plans need to be in place for this event.
- Increased risk of preventable events and associated care needs

Increased risk of early need for an intensive community support package

### ***What if things change and social care improves?***

Additional input from her PA and ISW as her condition worsens will mean a number of things for Janet including:

- Increased social inclusion in a way meaningful for Janet
- Mental health improves and reduced visits to GP
- Parkinson's trajectory remains steady and is less likely to have crisis or rapid deterioration
- Reduced costs from prevented events and lower prescription costs

- Improved service experience and quality of life

### **Things to consider**

The biggest risk is that the PA leaves which leaves a huge gap in Janet's confidence to cope as well with her care needs.



# Sheffield Hallam University

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