

# NHS RightCare scenario: **The variation between sub-optimal and optimal pathways**



**Sarah's story:  
Parkinson's**

## NHS RightCare scenarios

This Parkinson's scenario is part of a [series](#) of NHS RightCare Long Term Conditions scenarios to support local health economies – including clinical, commissioning and finance colleagues – to think strategically about designing optimal care for people with long term conditions and their carers.

Each scenario is a discretionary resource that highlights potential improvement opportunities through a fictitious but representative patient story. They have been developed with experts in these areas and include prompts for commissioners to consider when using each product.

For this scenario on Parkinson's, commissioners, clinicians and providers responsible for the care of people with Parkinson's in their population should consider:

- Planning care models to address key stages of diagnosis, maintenance, complex and palliative care
- Systematically identifying individuals living with Parkinson's, offering personalised care and support planning with an emphasis on honest conversations and shared decision making, and tailoring care and support accordingly
- Ensuring the involvement of, and attention to care and support needs, of the carers of people with Parkinson's
- Seeking local data around patient experience and outcomes for Parkinson's care in the area to identify and drive quality improvements

Please contact your local [NHS RightCare Delivery Partner](#) if you would like to explore any of the scenarios further.

## The story of Sarah's experience of Parkinson's and how it could be so much better

In this scenario – using a fictional patient, Sarah, along with her husband, Ian - we examine a Parkinson's pathway from the initial first symptoms and diagnosis through to end of life care. This journey could span 20 to 30 years in total and **getting care wrong can have serious consequences**. We compare a sub-optimal but typical scenario against an ideal pathway. At each stage we have modelled the costs of care, both financial to the commissioner but also the impact on the person and their family's outcomes and experience.

This document is intended to help commissioners and providers to understand the implications – both in terms of quality of life and costs – of shifting the care pathway of people with Parkinson's from a reactive approach (primarily based on an acute response) to a proactive approach, e.g. providing an integrated primary care and community-based response, with support from the voluntary sector.

It shows how the NHS RightCare methodology can help clinicians and commissioners improve the value and outcomes of the care pathway as part of an overall approach to considering quality of care and commissioning.

Two summary slide packs and a [supporting video](#) are also included as appendices for optimal use by different audiences.

## Introduction

Parkinson's is a progressive neurological condition caused by an accumulation of a toxic protein (alpha-synuclein) that leads to damage to numerous brain regions, most notably those controlled by dopamine producing nerve cells. The cardinal motor symptoms that aid diagnosis are tremor (shaking), slowness of movement and rigidity (stiffness).

Approximately 110,000 people in the UK have Parkinson's and the incidence increases with age<sup>1</sup>. To put this more simply, one person in 100 over the age of 60, and one in 20 over the age of 85 years, will develop Parkinson's. Approximately 60% of people with Parkinson's (cumulative incidence at eight years) will also develop dementia in the later stages.

Whilst Parkinson's is incurable, it does not necessarily mean individuals with the condition will have a reduced life span. People can live for 20 to 30 years with Parkinson's (see Appendix 1 for more information about diagnosis and treatment). Each person is unique and although the motor symptoms are the ones most commonly recognised, falls, non-motor symptoms like bladder and bowel issues, speech and swallowing difficulties and pain are the ones that frequently cause the most problems<sup>2</sup>. Because they live with the condition for a long time, people with Parkinson's may not be monitored regularly. Problems that are developing may be unnoticed or disregarded by the people with Parkinson's because they don't realise these are related to the condition. Admission to hospital often results from a crisis occurring, with the response to management focussing on the shorter-term issue in a reactive way, and without addressing the underlying problems. This can lead to expensive, avoidable hospital admissions. Delayed discharges from hospital can also occur when the Parkinson's fails to be managed well in hospital. All these result in worse health and wellbeing outcomes, plus higher costs to health and care services.

What happens overall to Parkinson's patients? In the CamPaIGN study of Parkinson's, a 10 year outlook in an incident population-based cohort found that at 10 years:<sup>3</sup>

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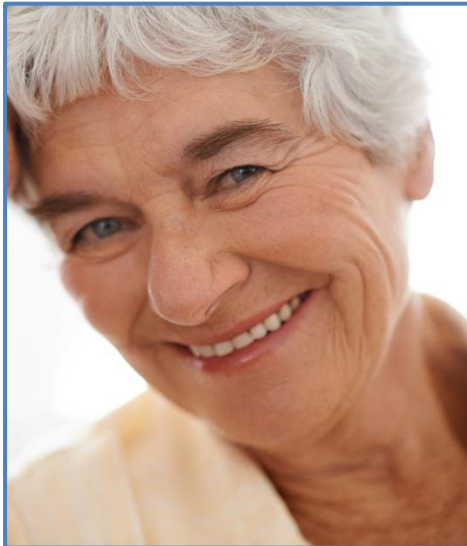
<sup>1</sup> Foltynie et al Brain (2004) The cognitive ability of an incident cohort of Parkinson's patients in the UK. The CamPaIGN study. Mar; 127 (Pt 3):550-60. Epub 2003 Dec 22.

<sup>2</sup> Chaudhuri K Ray et al (2015) Non-motor symptoms in Parkinson's disease 2<sup>nd</sup> Edition Oxford University Press Oxford

<sup>3</sup> Williams-Grey CH et al 2013 The Campaign Study of Parkinson's disease: 10 year outlook in an incident based population cohort J Neurol Neurosurg Psychiatry 2013

- 55% were dead
- 68% had postural instability during the course of Parkinson's
- 46% developed dementia
- 23% had a 'good outcome' (no dementia or postural instability during the course of Parkinson's)

## Introducing Sarah



Sarah is a 70 year old retired librarian living with her 75 year old husband Ian in a fourth floor, two bedroom council flat that they have purchased from the local authority.

Since retiring Sarah has been an active volunteer in the local church, flower-arranging and visiting older members of the congregation.

## Sarah's journey

Sarah's journey started in March when she became worried because she noticed that she was having problems turning over in bed at night. Her husband commented that he thought she wasn't walking as well, and Sarah herself thought she had slowed down recently. She also felt low in mood so she arranged an appointment with her GP. He didn't seem overly concerned, and advised her to return should she not improve or things changed any further. Three months later she made another appointment because she was still feeling low and her GP suggested some regular exercise.

Over the next few weeks Sarah started to notice that her right hand was shaking when she was in her armchair resting, so she returned to her GP who took some blood tests to check her blood count and thyroid function. He saw her with the results a couple of weeks later, and told her that he thought that she might have Parkinson's. He started her on medication for this and asked her to return in three months' time. She did so, and her prescription was renewed. In December she fell whilst in the garden and cut her head. Ian called an ambulance and her wound was sutured in the Accident & Emergency department. Her GP received a letter a couple of weeks later from the A&E doctor, suggesting that she should be referred to a neurologist.

The following February, Sarah went back to her GP remembering what the hospital doctor had said, and her GP agreed to refer her to the neurology clinic. She was seen three months later, where the neurologist explained to her and Ian that she did indeed have Parkinson's, and that he would change her medication to help with the symptoms. He also said he would write to her GP about it. The hospital did not have anyone with expertise in managing Parkinson's to refer to for support, but the neurologist suggested they might like to have a look at the website of the charity Parkinson's UK. Sarah and Ian were bewildered and upset. They had a look at the website and decided to go along to an evening talk at the local branch. But they left in the coffee break, shocked and upset by how ill everyone seemed. They agreed never to go again. The new medication started to have an effect, and the neurologist was pleased when he saw Sarah again in November. He arranged to see her annually before Christmas.

Over the next three years, Sarah and Ian tried to come to terms with her diagnosis. They told their children and some close friends. Her GP saw her each May and the neurologist each November. Her walking became more unsteady so she reduced how much activity she did. Other problems arose including excessive perspiration and drooling which she didn't realise might be part of the Parkinson's. This resulted in her not wanting to socialise with friends anymore because of embarrassment. She resigned from doing the flower arrangements and church befriending scheme she loved. Ian later said that her general apathy was a real problem at this time.



By the beginning of year six, Sarah was struggling because the benefits from her medication seemed to 'wear off' rather quickly. This made her very depressed because she found it increasingly difficult to do things. She visited her GP who increased her medication to six times a day with good effect.

Her GP checked the medication response in February that year when she also told him about the painful bunion on her foot which was affecting her mobility and causing pain. Her GP referred her to hospital for an orthopaedic opinion. In May, after being seen in the orthopaedic clinic, a date was fixed for admission for removal of the bunion. Now more or less housebound due to the pain of the bunion and her unsteady gait, Sarah was getting increasingly depressed.

In September Sarah was admitted for surgery. She stayed overnight prior to the surgery but her Parkinson's medication was omitted during routine fasting. Post-operatively the ward did not administer her medication at the times she needed it

and she quickly became rigid and unable to feed or dress herself. This breakdown in her medication regime rendered her totally helpless. In total she had an 11 week hospital admission, largely a result of the failure to get her medication on time. Intensive rehabilitation was then needed and it was not until December that Sarah was ready for discharge home with a care package until full independence could be achieved.

Even with the care package in place, Ian struggled to cope and Sarah was very depressed. They had a miserable Christmas that year.

*Sarah was admitted to hospital for an elective admission but the ward failed to give her medication on time. Medicines management is crucial when a person with Parkinson's is admitted to hospital electively or in an emergency. Missed doses or changes to timing can impair their swallowing, increase their risk of aspiration, render them immobile and prone to falls and fractures. Following a situation like this they may never fully regain their former mobility and independence. At worst, it can even lead to neuroleptic malignant-like syndrome, which can lead to coma and death.*

*Prescribing the correct drug preparation at the correct time is critical to preventing deterioration in Parkinson's. If a patient is unable to swallow or absorb their usual medication, an alternative dispersible or transdermal preparation must be given promptly. Parkinson's UK has a range of 'Get it on Time' material and training support available as well as a clinician-developed Optimal calculator which can assist when patients are unable to take medication orally:*

*<http://www.parkinsonscalculator.com/>.*

*A large part of the burden of caring for someone with Parkinson's are mental health issues such as depression, anxiety, apathy and Parkinson's dementia so it is important that these are recognised. 40% of people with Parkinson's will be depressed. Somatic symptoms, loss of sleep, deficits in concentration, tearfulness and loss of appetite should trigger alarm bells. Anxiety is often a co-existing feature.*

*Cognitive impairment can occur early in people with Parkinson's and clinicians need to look out for it. The chance of developing dementia<sup>4</sup> is high<sup>5</sup>. Unrecognised, this leaves vulnerable people without access to the right treatment and their families shouldering a heavy burden of care.*

## **Back to the story**

In January, at the start of year seven, Sarah was crying constantly and her husband was at his wit's end. He called the GP who asked a district nurse to see Sarah at

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<sup>4</sup> Please refer to the 'Tom and Barbara' NHS RightCare Dementia scenario at <https://www.england.nhs.uk/rightcare/intel/cfv/ltc/> for great dementia insights.

<sup>5</sup> Dag Aarsland (2009) Cognitive impairment in incident, untreated Parkinson's disease; the Norwegian Parkwest study Neurology 13 (72) 1121-1126

home. The district nurse spotted that the caring situation at home was at crisis point and suggested respite admission to a community intermediate care bed. In some localities, inpatient respite facilities may be provided in residential care homes or hospices: these have variable contributions from NHS funding.

Sarah was admitted for one week's respite care and started on an antidepressant. Her mobility was poor so she was reviewed by a physiotherapist. There was some slight improvement in her mobility by the time she returned home.



In March Sarah developed a high temperature, agitation and hallucinations. An ambulance was called and she was admitted into the medical assessment unit with a urinary tract infection and delirium. She returned home after seven days but was now very dependent.

In April Sarah became agitated and confused. Ian found himself unable to cope. Parkinson's severity<sup>6</sup> and carer age<sup>7</sup> can impact on the emotional wellbeing of the caregiver and their ability to cope. A social services assessment was undertaken and the 'hospital at home' team worked with Ian to try to stabilise care at home. Sarah started attending the day centre twice weekly. The local church, at which Sarah used to help, now reciprocated and offered a voluntary sitting service once a week to allow Ian to do the shopping and get out of the house.

In June Sarah was assessed for Continuing Health Care funding, but turned down. This is not unusual because a person with Parkinson's can have fluctuating symptoms, so on a good day when the medication is working optimally, the person may seem able to cope, but as the medication wears off there can be long periods where the person cannot manage even basic self-care without substantial help.

*People with Parkinson's have higher hospital admission rates than the general population and are also twice as likely to stay in hospital for more than three months. People were found to be admitted for four main reasons: pneumonia (13.5%), motor decline (9.4%), urinary tract infection (9.2%), and hip fractures (4.3%).*

*For more details please see Appendix 2.*

<sup>6</sup> Peters et al 2011 Parkinsonism Rel Disord 17

<sup>7</sup> Carter et al 2008 Mov Disord 25:6

By year eight, Sarah was in the complex phase of Parkinson's<sup>8</sup>. In February she fell at home, an ambulance was called and she was admitted to hospital for 10 days. Sarah was reassessed by allied health professionals whilst in hospital and returned home but was now too frail to attend the day centre.

In May she developed a high temperature and agitation. She was seen by the out of hours GP who diagnosed another urinary tract infection. An ambulance was called and she was admitted to hospital, remaining there for two weeks.

Sarah was too ill to attend the neurology clinic for her annual review in November, so a new appointment was requested. This meant that she did not get a specialist review of her symptoms and medication.

*The top symptoms that dominate people with advanced Parkinson's are immobility, pain, stiffness and insomnia - similar to the frequency of symptoms from cancer.*<sup>9 10</sup>

Early in year nine, Sarah failed again to make the new neurology appointment that was arranged after she had missed her November annual review, so her name was removed from the neurologist's list for the time being and she was told to request another appointment when she was ready.

In February she had significant weight loss and a tendency to cough when eating. She developed a productive cough. Her GP visited her at home and prescribed antibiotics for a chest infection.

Sarah started to struggle with her Parkinson's medication and became unable to swallow tablets. Her chest infection worsened and an ambulance was called. She was admitted to hospital for intravenous antibiotics. Whilst in hospital, she was reviewed by a neurologist and her Parkinson's medications changed. She returned home after two weeks and a twice daily care package was started.

Initially, they coped but then Ian started to struggle and developed a chest infection himself. Sarah was admitted for a two week respite stay to give him a chance to recover.

Sarah returned home with her care package increased to three times daily, but rapidly declined and very soon needed 24/7 support. Their GP was called and Ian expressed his view that she now needed full time nursing care. In the meantime, the GP prescribed more antibiotics. Because of Sarah's swallowing difficulties, a liquid formulation was prescribed, which she managed to take, though with some difficulty. They struggled on at home.

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<sup>8</sup> MacMahon DG, Thomas S (1998) Practical approach to quality of life in Parkinson's the nurses role J Neurol May 245 Suppl 1 S19-22

<sup>9</sup> Lee M et al (2007) Frequency of cancer symptoms in PD Parkinsonism RE. Dis 284-289

<sup>10</sup> Miyasaki JM, Long J, Mancini D, Moro E, Fox SH, Lang AE, et al. Palliative care for advanced Parkinson disease: an interdisciplinary clinic and new scale, the ESAS-PD. Parkinsonism Relat Disord. 2012;18 Suppl 3:S6-9.



By May Sarah had developed a pressure ulcer and the district nurse visited daily to dress this. Her GP asked for a specialist palliative care team assessment. They reviewed her at home but shortly after that, Sarah's condition deteriorated. Ian called for an ambulance and she was admitted to hospital via A&E. She was transferred to the acute medical unit but died there 18 hours later, before the staff had had time to get to know her and Ian. He was very distressed and became depressed and mentally unwell for over a year after her death.

Although there has not been long term follow up of the bereavement impact on carers of people who died with Parkinson's, there is ample evidence in the literature that unrelieved carer emotional burden and patient symptoms appear to be associated with negative bereavement outcomes.

### Questions for GPs and commissioners to consider

Approximately 110,000 people in the UK have Parkinson's and the incidence increases with age<sup>11</sup>. This means one person in 100 over the age of 60 and one in 20 over the age of 85 years will develop Parkinson's. Approximately 60% of them will develop dementia in the later stages.

In the local population, who has overall responsibility for:

- Identifying individuals and their carers living with Parkinson's?
- Planning care models to address key stages of diagnosis, maintenance, complex and palliative care?
- Risk stratifying those individuals most at risk?
- Ensuring appropriate care for people with Parkinson's who are admitted to hospital for other medical reasons?
- Quality assurance and value for money of Parkinson's care?
- Getting best value for money from the investment by caring agencies?
- Involving patients in planning improvements in the care provided for people with Parkinson's?
- Seeking local data around patient experience and outcomes for Parkinson's care in the area?
- Considering how this valuable local data could be used to identify and drive improvements?

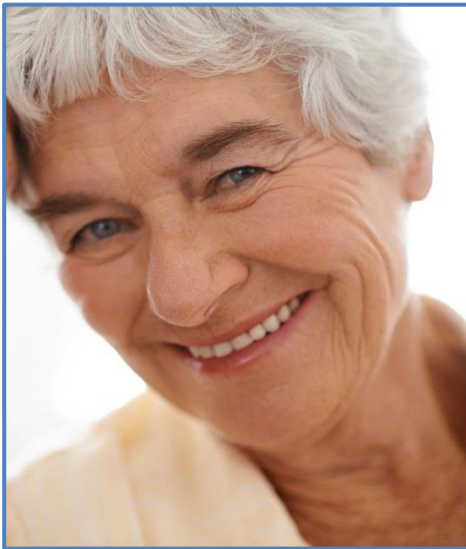
The above questions are vital in understanding who manages which components of a whole system. Most importantly, it is impossible to effect optimal improvement if the system is not even aware of the answers to these questions.

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<sup>11</sup> Foltynie et al Brain 2004 The cognitive ability of an incident cohort of Parkinson's patients in the UK. The CamPaIGN study. Mar; 127 (Pt 3):550-60. Epub 2003 Dec 22.

## What could have happened differently?

### Sarah's optimal journey



Sarah is a 70 year old retired librarian living with her 75 year old husband Ian in a fourth floor, two bedroom council flat that they have purchased from the local authority.

Since retiring Sarah has been an active volunteer in the local church, flower-arranging and visiting older members of the congregation.

As before, Sarah's journey started in March when she started to experience problems with turning in bed and generally feeling low. She noticed that she had slowed down generally. In April, she saw her GP who suspected Parkinson's and referred her, untreated, to the local neurology clinic. She attended the clinic in June where the diagnosis was confirmed. Treatment was initiated at the appointment using a shared decision making process about which medication would be the most suitable for her. A letter was sent to her GP to confirm the diagnosis and advise him of the treatment plan. The GP practice updated their coded records immediately.

The neurologist referred Sarah to the Parkinson's nurse specialist. She met with Sarah regularly to help adjust her medication until it was optimal. She told Sarah about the newly diagnosed Parkinson's meetings where she would have opportunity to meet other people who had also just been diagnosed, and allied health professionals who would be able to teach her how to live well with her Parkinson's. The Parkinson's nurse specialist gently introduced the idea of advance care planning and palliative care as part of longer term planning. Sarah and Ian agreed to think about this even though they weren't quite ready to make plans yet.<sup>12</sup>

Sarah felt really quite positive because the Parkinson's nurse specialist had given her a number to call should she have any concerns, as well as a leaflet about the whole Parkinson's team and the regular meetings that they hold. She also told her about the resources on the Parkinson UK website that might be useful. Sarah was focused on getting her symptoms under control whereas Ian needed more

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<sup>12</sup> Tuck KK BL, Nutt J, Fromme EK. Preferences of patients with Parkinson's disease for communication about advanced care planning. *Am J Hosp Palliat Care*. 2015;32(1):68-77.

information about Parkinson's itself, so he found it incredibly helpful to be able to dip into the website to help him come to terms with what was happening. By July, Sarah's medication had been optimised but the Parkinson's nurse specialist telephoned Sarah again a month later – just to check that all was well. This made Sarah feel supported and secure.

In September Sarah attended the newly diagnosed clinic where she met the allied health professionals who were part of the Parkinson's team. The local hospital had developed this service as part of the 'Diagnosis Year Best Practice Tariff'. Sarah was told about the benefit of exercise in Parkinson's and heard about local groups in the community that ran Tai Chi classes, which could help with her balance. She also heard about the Parkinson's UK resources for self-help material and was now more willing to look at this. Unlike Ian, she did not want lots of information about the condition itself but she did think that self-help materials would be something that she could use.

The Parkinson's nurse specialist phoned the practice nurse and GP to introduce herself and advised them about a risk assessment tool that could be used on routine appointments to monitor Sarah's Parkinson's in a structured way. This would ensure that Sarah was not experiencing adverse symptoms or problems or, if she was, this would be quickly picked up. The Parkinson's nurse specialist also supplied them with a [Non Motor Symptom questionnaire](#) that Sarah could complete prior to attending surgery appointments so they could monitor how she was doing. The Parkinson's nurse specialist told them that she would be 'only a call away' if they needed advice.

In December the practice nurse reviewed Sarah using the risk assessment tool prior to Sarah seeing her GP who reviewed the results and renewed her prescription. Sarah saw no reason to curtail her voluntary work so she continued as normal.

In June the following year, Sarah had her annual review with the neurologist at the Parkinson's clinic. She had remained well once her medications had been optimised, so she and her consultant agreed that the current care and treatment plan should continue unchanged, and the consultant wrote to her GP to confirm this.

In October, Sarah phoned the Parkinson's nurse specialist with a small concern about her medication and was easily reassured over the phone. This gave her further confidence that she could manage with the level of support she was getting. Again in December, her practice nurse reviewed and checked Sarah - particularly her bowels, continence and sleep. Her GP reviewed and issued her prescription.



Early the following year, Sarah undertook a 10 week course of exercise classes in the community. Ian joined a carer support group run by the local Parkinson's UK branch for social activities and mutual support, attending regularly over that year.

They settled down and this pattern followed over the next four years during which Sarah remained relatively well. She was seen annually by the neurologist or the Parkinson's nurse specialist and, in between, the practice nurse and GP reviewed Sarah using the risk assessment tool and Non Motor Symptom questionnaire. The areas that were likely to cause problems for Sarah were identified as bowel continence and sleep. So these were particularly carefully monitored.

In year six Sarah, having maintained contact with the exercise group, was told that she had a tendency to 'freeze' at times so she was referred to a 10 week falls prevention programme to help her deal with this. In the meantime her husband started meeting the local carers group again, which provided him with support.

In year seven Sarah found that a very painful bunion was making mobility more difficult. She consulted her GP who referred her to the orthopaedic consultant at the local hospital. Surgery was scheduled for two months hence. When Sarah attended her annual review at the neurology clinic in June, she told the Parkinson's nurse specialist about her pending operation.

The Parkinson's nurse specialist stressed the importance of not stopping her medication and gave Sarah some written information about this. The Parkinson's nurse then liaised with the ward to ensure that the medication was given at the times Sarah needed it. The ward had a self-administration policy that facilitated this. The Parkinson's nurse also checked that the ward had a stock of transdermal patches of Sarah's medication in place so that these could be commenced when she began to fast prior to her surgery. 'Get it on time' material was sent to the ward via Parkinson's UK and Sarah's stay was uneventful. This meant she was only in hospital for four days and had no untoward effects. She was reviewed in the orthopaedic clinic six weeks later and discharged from that service.

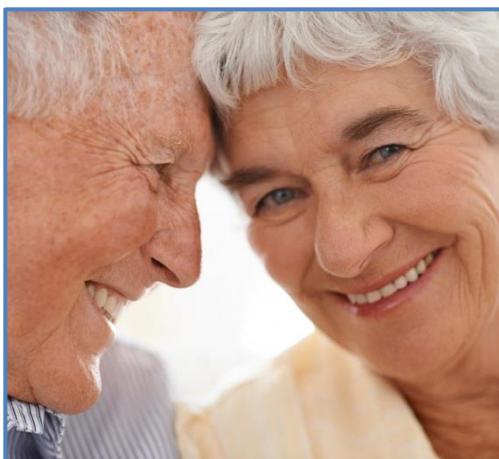
In December Sarah returned to her local surgery for her regular review, seeing both the practice nurse and GP who renewed her prescription.

In June of year eight, at Sarah's annual review, her Parkinson's nurse specialist noted that she was not getting as good an effect from her medication. She was

finding that her medication was wearing off earlier and that when she took her tablets, it seemed to be taking longer for them to work<sup>13</sup>; sometimes they didn't seem to work at all. She had also developed some dyskinesia (abnormal movements) and was experiencing visual hallucinations. The Parkinson's nurse specialist told Sarah that her medication needed to be adjusted. She was reviewed by the neurologist and her medication changed. Hallucinations are a potential predictor of cognitive decline and prognosis<sup>14</sup>, so discussions about advancing disease and prognosis were triggered. Sarah decided to make an advance care plan to preserve her autonomy and inform decision making if she lacked capacity to make her views known. Ian was involved in these discussions as this was what she wanted. With her permission, her GP documented and shared this information through their local electronic system with others likely to be involved in her care.

*This system, also known as an Electronic Palliative Care Coordinating System (EPaCCS), enables a core set of key information to be viewed by others involved in the person's care when necessary, with their consent or, if they are unable to give consent at the time, in their best interests. This includes ambulance services, out of hours GP services, urgent and emergency care clinical advisory hubs, accident and emergency departments, specialist services in the secondary sector, primary and community care, hospices and social services. There is an Information Standard (SCCI 1580) which determines what information must be included and local processes must be in place to ensure that information is kept up to date.*

At the surgery review in December the GP picked up signs of cognitive decline including some agitation, and signs of a urinary tract infection. He started her on a three day course of antibiotics and decided to seek a psycho-geriatrician assessment. She was assessed by the psycho-geriatrician who confirmed cognitive decline, suspecting this could be the start of Parkinson's dementia<sup>15</sup>.



Medication was started to improve cognition, leading to some reduction in her hallucinations. Sarah was appointed a Community Psychiatric Nurse although, at that stage, she felt that she could manage with the support of her husband and the Parkinson's team.

<sup>13</sup> Ahlskog E, Muentner MD (2001) Frequency of Levodopa related dyskinesia's and motor fluctuations as estimated from the cumulative literature Movement Disorders Vol 16:3 pp445-458

<sup>14</sup> Kempster PA, O'Sullivan SS, Holton JL, Revesz T, Lees AJ. Relationships between age and late progression of Parkinson's disease: a clinico-pathological study. Brain. 2010;133(Pt 6):1755-62.

<sup>15</sup> J Neurol Neurosurg Psychiatry 2011; 82: 1112- 1118

Sarah and Ian maintained their social life as far as possible despite Sarah's obviously worsening Parkinson's dementia. In March Sarah fell at home and the 'hospital at home' team visited to support her and Ian. A structured holistic assessment<sup>16</sup> of Sarah's medical, social and environmental needs was undertaken. It was noted that Sarah was becoming more dependent and, with the assistance of an electronic frailty index, the team judged her to be living with moderate frailty. This was logged on the practice computer system and the multidisciplinary team were made aware of her increasing needs. The team explained to Sarah and Ian that a few more assessments would need to be undertaken to get a fuller picture of her current condition and needs.

Over the following two months, the occupational therapist carried out a falls risk assessment in Sarah's own home, which also included an informed medication review by the local pharmacist targeted at people with Parkinson's. Sarah was offered a Personal Health Budget so that she could exert more control over her own care but she declined. She felt that the personalised care and support plan that she had discussed with her GP, and that they periodically updated, provided sufficient guidance for the professionals looking after her. She would prefer not to have to manage this herself though she appreciated the offer.

In May of that year, Sarah developed a chest infection and was treated with antibiotics. She also lost quite a bit of weight. Because of these significant changes in Sarah's condition, at her June annual review, both the practice nurse and Parkinson's nurse specialist did a joint assessment. Together, they discussed with her and Ian the implications of her diagnosis, including her moderate frailty and dementia, and the obvious need for increasing support. A speech and language therapist was asked to see her at this point. Nutritional supplements were started. The speech and language therapist advised on safe swallow techniques. The therapist noted that Sarah had some dental decay, so a dental appointment was arranged for her before this caused any problems. Over the course of two appointments, she was assessed, treated and given advice about optimising her mouth and dental care.

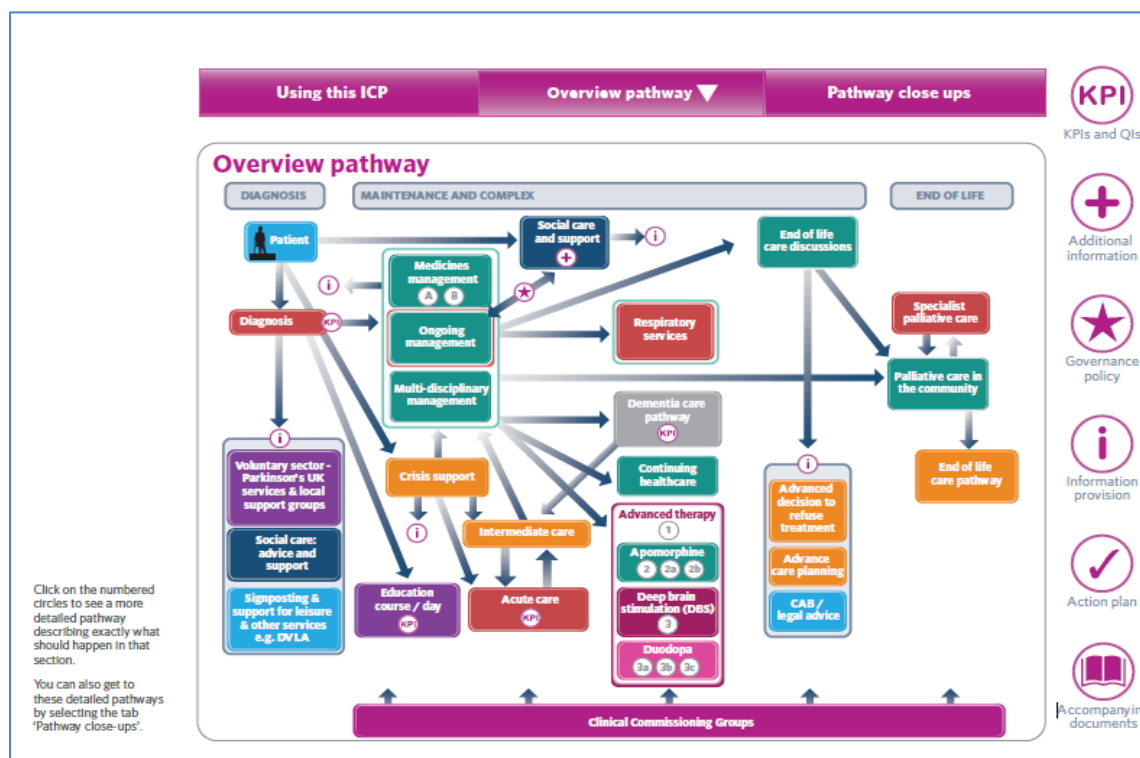
*By using an Integrated Parkinson's pathway<sup>17</sup> (see diagram on the following page) care needs can be made explicit and coordinated between team members.*

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<sup>16</sup> Richfield E AD, Jones E, Johnson M, Campbell C. A palliative care service for Parkinson's disease: Patient characteristics and service interventions [abstract]. *Movement Disorders*. 2012;27(Suppl. 1):551.

<sup>17</sup> Peel C, Thomas S, Worth P (2013) Developing an integrated care pathway: the process and its application to neurological conditions *BJNN Vol9 6 pp292-300*

Figure 1: Integrated Parkinson's Pathway<sup>18</sup>



Sarah's care plan identified her support needs, reflected her goals and aspirations and outlined actions, including what to do in case of a serious event. Regular gait assessments and reviews at the exercise group were put in place until she stabilised. Sarah and Ian were invited to attend the Memory Café run by the local charity to reduce the impact of her memory problems and to provide them both with support. They continued with the Parkinson's branch meetings. Her local district nurse popped in to introduce herself so that she would not be entirely unknown to them if she was needed. Sarah was also referred to the specialist palliative care team at this point to provide more support for Ian, optimise her symptom management and help her review and update her advance care plan. She started to attend the hospice day centre weekly, where she received physiotherapy and group support. Ian found this really helpful as it gave him a regular break. Things stabilised and for the next while, the specialist palliative care team agreed to stop visiting so that Sarah and Ian could spend their time on other things.

Following a review at home in December, Sarah's GP asked the community matron to step in as the key worker, liaising as needed with the Parkinson's nurse specialist. This was important because people with Parkinson's are twice as likely as the general population to be admitted to hospital and to stay for a period of over three months<sup>18</sup>. With their community support Sarah and Ian maintained a reasonable life at home. They maintained their social networks for a while but Sarah was obviously

<sup>18</sup> Low V, Ben-Shlomo Y, Coward E, Fletcher S, Walker R, Clarke CE. Measuring the burden and mortality of hospitalisation in Parkinson's disease: A cross-sectional analysis of the English Hospital Episodes Statistics database 2009-2013. *Parkinsonism Relat Disord*. 2015 May;21(5):449-54. doi: 10.1016/j.parkreldis.2015.01.017. Epub 2015 Feb 17.

reaching the advanced stages of Parkinson's. Following a home visit, with her consent, her GP asked the community matron to facilitate an enhanced package of care at home. The matron visited Sarah and Ian at home three times over the following two weeks to discuss her symptoms, her wishes for the future, and her preferred place of care and of death. With her consent these wishes were updated on the Practice Palliative Care Register, and the EPaCC system. She was also discussed in the monthly Multidisciplinary Palliative Care meeting. Ian admitted that the most difficult thing for him to manage were the disturbed nights, so after some discussion, they agreed to accept twice weekly night sitters.

In May of year 10, the out of hours GP was called to see Sarah at home because she had become agitated and psychotic. Liquid antibiotics were prescribed for a urinary tract infection. The following day, her own GP reviewed her at home, and phoned the neurologist to ensure that her treatment was not exacerbating this and to optimise treatment. They did not want to withdraw treatment that might cause undue pain or discomfort through the Parkinson's medications being withheld. Pain is one of the most dominant features in Parkinson's<sup>19</sup>.

The GP asked the specialist palliative care consultant to review Sarah at home. The consultant discussed with Sarah and Ian the impact of her symptoms, their wishes and the practical aspects of care at home towards the end of life. Sarah agreed to a respite admission in the local community hospital to allow Ian to visit their daughter and to have a break. They both benefited from this change in routine. When Sarah returned home, their local community group offered a twice weekly sitting service which enabled Ian to get out to the shops and to have a regular walk with a close friend. The community matron, specialist palliative care nurse and district nurse coordinated a weekly visiting rota between them. Equipment was delivered to the house to support her independence and ease the provision of care.

Sarah's condition continued to decline. One night she suddenly became feverish, agitated and psychotic. Ian called NHS 111 as he had been advised previously. Her record had been flagged so he was directly put through to the clinical advisory hub. Information about Sarah's wishes to stay at home and her care plan were available to the clinician at the hub, so an out of hours GP was despatched to review her at home. Oral liquid antibiotics were started, and although the rest of the night was tricky, Ian managed to cope. The following day, the specialist palliative care team increased the care package to twice daily, starting immediately, which enabled Sarah to remain at home.

As she began to recover from this episode, Sarah's GP visited her at home and discussed the situation with them both. Ian described the gradual cognitive decline that he had noticed in Sarah over recent months and her worsening mobility. The GP rang the neurologist for advice about optimising Sarah's Parkinson's medication. Following discussion with Sarah and Ian, the community matron stopped visiting,

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<sup>19</sup> Lee M et al (2007) Frequency of cancer symptoms in PD Parkinsonism RE. Dis 284-289



and the specialist palliative care nurse and district nurse continued providing weekly visits between them to rationalise the number of different people visiting.

A month later, Sarah became unwell again, this time with a chest infection which responded to oral liquid antibiotics. She was found to have a small pressure sore. She was discussed at a complex case review involving the Parkinson's nurse specialist, the specialist palliative care team and the primary care team. Thereafter, recognising that Sarah was now entering the last weeks of her life, her GP visited fortnightly, the palliative care nurse specialist weekly and the district nurse daily. Her care package was increased to three times a day. Swallowing became difficult and she was sometimes agitated. The team liaised with the Parkinson's nurse specialist to continue some dopaminergic therapy aimed at keeping her comfortable. Anticipatory medications were arranged and a syringe driver was set up with low doses of medications to address pain and agitation. Care was taken to avoid drugs such as haloperidol, metoclopramide, levomepromazine, cyclizine and olanzapine because of their interaction with Parkinson's drugs.

In October Sarah died peacefully at home with Ian at her side. The specialist palliative care nurse and Parkinson's nurse specialist both phoned, and then visited after the funeral. Ian received good support from his friends and neighbours, and expressed his relief that Sarah was able to stay at home, and to die so peacefully.

Three months after Sarah's death the Parkinson's nurse specialist also visited Ian, who expressed his gratitude for all the care they had received.

## **What was the cost of Sarah's journey to the NHS and the wider social and economic impacts?**

For the financial evaluation we performed detailed analysis through mapping the lifecycle of the pathways. Through this process we were able to identify the cost drivers that would be incurred in primary, community and hospital care, using NHS reference costs and, where there is a hospital stay, average cost per bed day<sup>20</sup>. We have included the wider social and economic impacts but we have not attempted to cost financially outside of the health remit or the social, emotional, physical and financial costs to Sarah and Ian.

This scenario is using a fictional patient, Sarah. It is intended to help commissioners and providers understand the implications (both in terms of quality of life and

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<sup>20</sup> £400 has been used as a proxy measure to calculate the approximate costs of a single day's treatment in a ward in a hospital setting. This value has been derived from 2015/16 SUS data using the weighted bed-day cost with Market Forces Factor applied for age ranges between 40-74. This age range is typical for the suite of Long Term Conditions scenarios produced.

Edbrooke and colleagues estimated the average cost per patient day in 11 ICUs was £1,000 [www.ics.ac.uk/EasySiteWeb/GatewayLink.aspx?allId=441](http://www.ics.ac.uk/EasySiteWeb/GatewayLink.aspx?allId=441) (please note that you will need to become a member to view the link). Reference costs applied are at 2015/16 prices. The excel spreadsheet designed to cost these scenarios includes full details of cost data sources and is available upon request. Please contact NHS RightCare at [rightcare@nhs.net](mailto:rightcare@nhs.net) if you would like further details about the methodology.

financial costs) of shifting the care pathway of older people living with Parkinson’s from a reactive to a proactive approach. The financial costs are indicative and calculated on a cost per patient basis. Local decisions to transform care pathways would need to take a population view of costs and improvement.

**Table 1: Analysis by provider**

Analysis by provider	Sub-optimal	Optimal	Optimal %
Third Sector	£2,880	£1,219	42%
Acute	£50,757	£3,542	7%
Ambulance service	£2,330	£0	0%
Community hospital	£3,843	£2,404	63%
Community teams	£3,025	£7,351	243%
Primary care	£702	£1,552	221%
Social services	£4,466	£8,214	184%
<b>Grand total</b>	<b>£68,004</b>	<b>£24,282</b>	<b>36%</b>

**Secondary care** expenditure in the two scenarios is radically different. Acute costs in the optimal case represent only 7% of the original sub-optimal case – equating to a reduction of £47k.

**Primary care and social care** expenditure are necessarily higher in the optimal scenario as the optimal case invests in early intervention, community teams, practice-level support and social services (which raises the importance of improved strategic budgeting across the wider health economy). This is more than offset by the secondary care savings, however as stated above, the financial costs are calculated on a cost per patient basis and local decisions would need to take a population view of costs and improvement.

Not only is Sarah’s health and quality of life much better in the optimal scenario, the cost savings are significant.

**Table 2: Analysis by cost category**

Analysis by cost category	Sub-optimal	Optimal	Optimal %
Community care	£8,732	£10,718	123%
Elective admissions	£800	£1,600	200%
Intermediate care	£3,607	£2,404	67%
Non-elective admissions	£13,600	£0	0%
Palliative and end of life care	£480	£2,958	617%
Prescribing and meds optimisation	£313	£2,015	644%
Prevention and public health	£0	£457	n/a
Primary care management	£360	£879	245%
Rehabilitation	£5,768	£1,362	24%
Secondary care management	£32,692	£1,609	5%
Self care	£0	£155	n/a
Urgent and emergency care	£1,654	£125	8%
<b>Grand total</b>	<b>£68,004</b>	<b>£24,282</b>	<b>36%</b>

This is a scenario that clearly highlights that proactive planning and correct signposting to well trained (and equipped) teams is important - there is a significant impact on patient outcomes, quality and finance. Care can be improved by investigating the root cause of sub-optimal care and working with clinicians to design an improved evidence-based pathway.

In the sub-optimal pathway Sarah received no support during the early years of her Parkinson's. No significant health costs arose at that point but the time bomb was starting to tick loudly. Strategically, these years were the most important to Sarah's long-term health. If preventative and enabling care had begun to impact here, then the later complications may have been delayed and/or been more manageable as highlighted in the optimal pathway. Also, because her care was less than ideal, the toll on her husband was significant and he continued to suffer physical and mental ill-health after her death.

Not only were Sarah's and Ian's health, experience and quality of life significantly better in the optimal scenario, there was also a £44k saving to the health economy, even though Sarah lived for the same amount of time.

## Acknowledgements

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## Think change, Think NHS RightCare

This optimal pathway was understood, tested and created using the proven NHS RightCare approach.

NHS RightCare is a methodology that focuses relentlessly on increasing value in healthcare and tackling unwarranted variation. It is underpinned by intelligence and robust evidence, showing commissioners and local health economies 'Where to Look' i.e. where variation and low value exists. The approach then goes on to support health economies through 'what to change' and 'how to change'. The diagram showing all three key phases is shown below.

NHS RightCare offers facilitation and support to all CCGs and their health economies in implementing the RightCare approach and the developmental thinking, tools and data that enhance population healthcare improvement.

NHS RightCare is a proven approach that delivers better outcomes and frees up funds for further innovation. Please explore our latest [publications](#) and for more details about our programme visit [www.england.nhs.uk/rightcare](http://www.england.nhs.uk/rightcare).

You can also contact the NHS RightCare team via email at [rightcare@nhs.net](mailto:rightcare@nhs.net).



To watch the supporting video please visit the NHS RightCare YouTube page at <https://youtu.be/lCzkoQ2MtQI>.

For more information about the Long Term Conditions work at NHS England please contact [england.longtermconditions@nhs.net](mailto:england.longtermconditions@nhs.net).

## **Appendix 1: Additional information about diagnosis and treatment of Parkinson's**

Treatment of Parkinson's can be complex and at the onset of symptoms GPs should refer patients untreated to a neurologist or movement disorders specialist<sup>21</sup> NICE highlights first choice therapy for symptom control but each case is individual and patients may need titration of drugs to ensure best effect.

At this stage involvement of a Parkinson's nurse specialist can assist with titration of drug therapy and allaying fears related to initial diagnosis. Introduction to the wider multidisciplinary team of physiotherapists, occupational therapists and speech and language therapists can also do much to alert patients to problems they need to be aware of, so that if they occur, early help can be sought. Most Parkinson's Nurse Specialists have a telephone helpline facility. Close liaison with the GP and practice nurse so they are aware of problems that might develop can help prevent and defuse problems as these arise. This can also be facilitated through newly diagnosed courses where people at a similar stage in the illness can meet and develop self-care techniques.

The Diagnostic Year Parkinson's Best Practice Tariff<sup>22</sup> includes referral to Parkinson's UK<sup>23</sup> for information and this can be a valuable source of support to provide self- help courses and social functions.

Taking medication regularly is important. It is widely assumed that patients with Parkinson's are excellent at taking medication but there is significant medication non-compliance, varying between 10 and 67 %. Medication adherence is related to health costs and to the quality of life of people affected by Parkinson's, and, indirectly, their carers. If medication is not taken correctly this can limit function and independence.<sup>24,25</sup>

Routine use of a self-completed non-motor symptom (NMS) questionnaire<sup>26</sup> can assist in identifying problems prior to GP or neurology appointments and save busy consultation time.

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<sup>21</sup> Nice Parkinson's disease diagnosis and management in primary and secondary care Quick reference guide June 2006 NICE London

<sup>22</sup> Parkinson's Best Practice Tariff <https://www.parkinsons.org.uk/professionals/news/5-march-2013/new-best-practice-tariff-announced-government-parkinsons>

<sup>23</sup> <https://www.parkinsons.org.uk/>

<sup>24</sup> Malek, N. & Grosset, D.G. (2015) Medication adherence in patients with Parkinson's disease CNS Drugs (2015) 29: 47. doi:10.1007/s40263-014-0220-0

<sup>25</sup> [https://www.parkinsons.org.uk/sites/default/files/publications/download/english/nms\\_questionnaire.pdf](https://www.parkinsons.org.uk/sites/default/files/publications/download/english/nms_questionnaire.pdf)

<sup>26</sup> Chaudhuri K Ray et al (2015) Non-motor symptoms in Parkinson's disease 2<sup>nd</sup> Edition Oxford University Press Oxford

## Appendix 2: Hospital admission rates and outcomes for people with Parkinson's<sup>27</sup>

**BACKGROUND:** Patients with Parkinson's condition have higher hospital admission rates than the general population. We examined the reasons for admission, length of stay, costs, and in-hospital mortality in a national sample of Parkinson's condition patients.

**METHODS:** We used hospital admission data from the English Hospital Episodes Statistics database (2009-2013). Patients with Parkinson's condition or Parkinson's dementia and aged over 35 years were compared to all other admissions, excluding the above, with the same age criteria. We examined reasons for admissions (ICD-10), length of stay and in-hospital mortality. We used indirect standardization and Poisson modelling to derive proportional ratios adjusting for age group and sex.

**RESULTS:** There were 324,055 Parkinson's condition admissions in 182,859 patients over 4 years which included 232,905 non-elective admissions (72%). This resulted in expenditure of £907 million (£777 million for non-elective admissions). The main reasons for admission were pneumonia (13.5%), motor decline (9.4%), urinary tract infection (9.2%), and hip fractures (4.3%). These conditions occurred 1.5 to 2.6 times more frequently in patients than controls. Patients with Parkinson's condition were almost twice as likely to stay in hospital for more than 3 months (ratio 1.90, 95% CI 1.83, 1.97) and even more likely die in hospital (ratio 2.46, 95% CI 2.42, 2.49).

**CONCLUSIONS:** Parkinson's condition patients in England have higher rates of emergency admissions with longer hospital stays, higher costs and in-hospital mortality. Urgent attention should be given to developing cost-effective interventions to reduce the burden of hospitalisation for patients, carers and healthcare systems.

This information can be made available in alternative formats, such as easy read or large print, and may be available in alternative languages, upon request. Please contact 0300 311 22 33 or email [england.contactus@nhs.net](mailto:england.contactus@nhs.net)

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<sup>27</sup> Low et al. Measuring the burden and mortality of hospitalisation in Parkinson's disease: A cross-sectional analysis of the English Hospital Episodes Statistics database 2009–2013. *Parkinsonism and Related Disorders* May 2015; 21(5): 449-54.