

NHS RightCare scenario: **The variation between standard and optimal pathways**



Sarah's story: Parkinson's
Appendix 1: Summary slide pack

January 2018

Sarah's story

This is the story of Sarah's experience of a Parkinson's care pathway, and how it could be so much better.

In this scenario we examine a Parkinson's care pathway, comparing a sub-optimal but not atypical scenario against an ideal pathway.

1

At each stage we have modelled the costs of care, both financial to the commissioner, and also the impact on the person and their family's outcomes and experience.

2

It shows how the NHS RightCare methodology can help clinicians and commissioners improve the value and outcomes of the care pathway.

4

3

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.

Sarah and the sub-optimal pathway

- **Sarah**, a 70-year-old retired librarian, lives with her husband Ian. She is an **active volunteer** in the community
- Sarah first visited her GP in March of year one – she had noticed ‘slowing down’. At the third visit in July, her GP **started to suspect Parkinson’s** and organised investigations and treatment
- The **diagnosis of Parkinson’s** was confirmed by the neurologist almost a year later and her medication changed
- Sarah and Ian tried to come to terms with her diagnosis but her **social life was diminished** because of symptoms causing her embarrassment
- In year six, Sarah was admitted for surgery on her troublesome bunion. The **Parkinson’s medication was omitted pre-op** and not reinstated quickly enough post-op, causing significant physical regression and led to **prolonged hospital stay**
- In year seven, the caring situation at home was reaching **crisis point** and Sarah was admitted to a Community Intermediate Care bed for respite – where she started on an antidepressant
- There was a catalogue of primary and secondary care events which were distressing for both Sarah and Ian and **affected quality of life** for both of them
- By May of year nine, Sarah’s condition was **deteriorating relentlessly**. Her care package was increased but they still struggled to cope
- When she deteriorated acutely, she was **transferred to the acute medical unit** but died there 18 hours later; staff hadn’t had time to get to know or support her or Ian
- Ian was very distressed and became **depressed and mentally unwell** for over a year after Sarah’s death

Sarah and the sub-optimal pathway

No prevention

- Reactive
- No education
- No proactive third sector

No risk profiling and identification

Too long in acute care

- Traditional treatment
- Meds not well managed
- Too much time in bed

Inappropriate acute care

Not enough support

- Personal distress
- Too much reliance on acute care

Insufficient home care support

Questions for GPs and commissioners

In the local population, who has overall responsibility for:

1

Identifying individuals and their carers living with Parkinson's?

2

Planning care models to address key stages of diagnosis, maintenance, complex and palliative care?

3

Identifying and reporting on measurable positive and negative associated outcomes?

4

Quality assurance and value for money of Parkinson's care?

5

Has any engagement activity taken place with patients with regards to Parkinson's care?

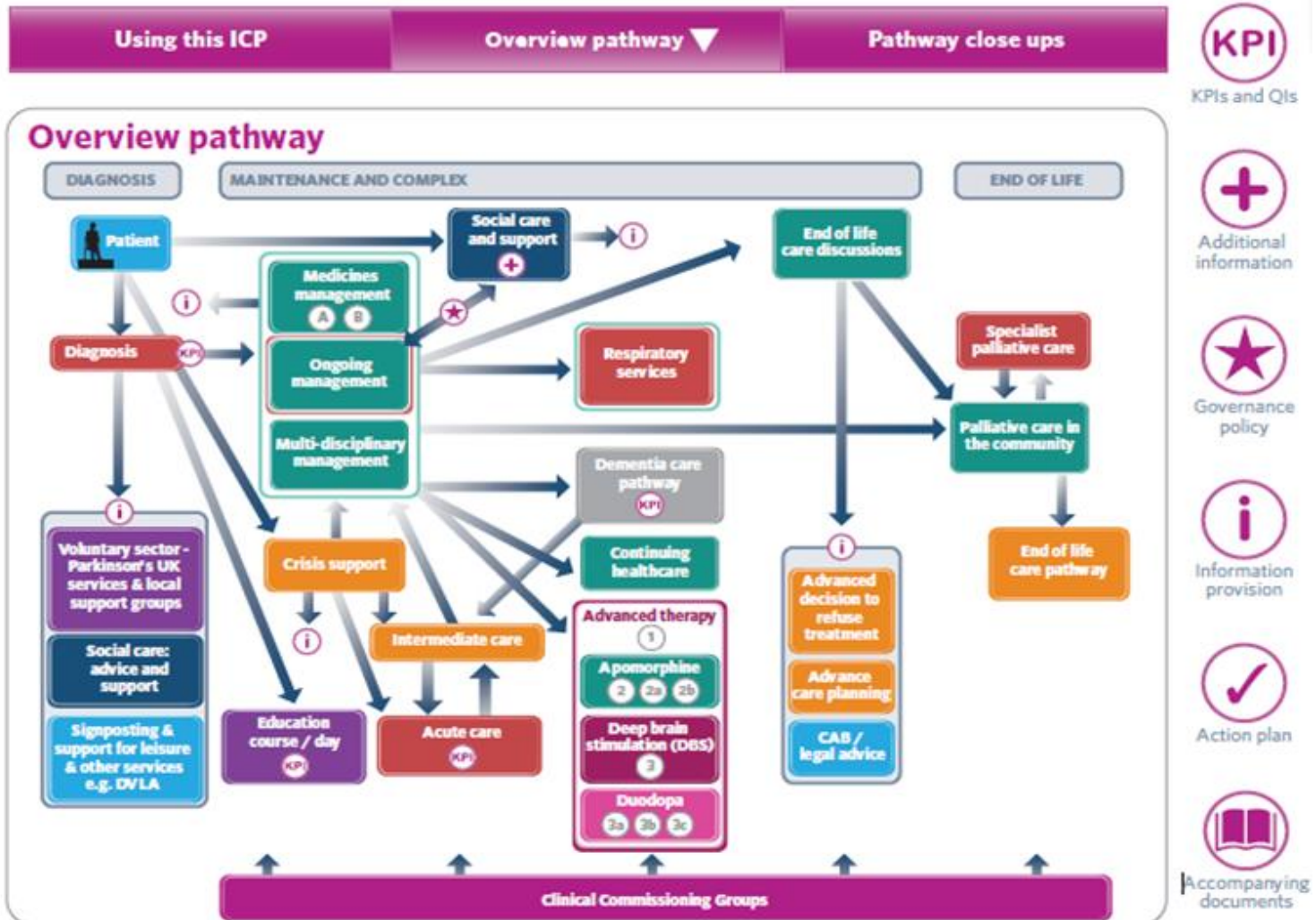
6

Do you already have local data around patient experience and outcomes for Parkinson's care in your area?

7

How could this valuable local data be used to identify and drive improvements?

An integrated Parkinson's pathway. Care needs can be made explicit and coordinated between team members



Sarah and the optimal pathway

- In April, Sarah saw her GP who suspected Parkinson's and **immediately referred her**, untreated, to the local neurology clinic. Treatment was initiated quickly using shared decision making
- The **Parkinson's nurse specialist** provided excellent support around medication, links to therapists, signposting to the Parkinson's UK website and introduced the idea of advance care planning
- Sarah had **structured reviews with her practice nurse** and GP in between annual reviews at the neurology clinic, with the Parkinson's nurse specialist available directly by phone at any time
- Sarah undertook exercise classes in the community and 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. This support was very valuable and continued for four years
- Sarah's hospital stay for her bunion surgery was minimal (four days) and uneventful because her **medication regime was tightly managed**
- There were a series of primary and secondary care interventions to support both Sarah and Ian as her condition began to deteriorate. The **specialist palliative care team**, primary care team and other specialists worked together to support her and Ian
- Sarah was regularly discussed at MDT meetings, her records updated on the Electronic Palliative Care Coordinating System and her **care package increased** to meet her needs
- In year 10 Sarah died peacefully at home **with Ian at her side**
- Three months after Sarah's death the Parkinson's nurse specialist visited Ian, who expressed his gratitude for **all the care they both received**

Sarah and the optimal pathway

Right first time focus

- Proactive
- Choice
- Education
- Shared decision making
- Third sector

GP awareness
and
identification

Fast

- Diagnosis
- Appropriate medication
- Greater understanding of need
- Minimal time in acute

Great acute
care /
knowledgeable

Appropriate

- Support mechanisms in place
- Trusted system
- Personalised care planning
- Happier and healthier experience

Great home
care support

Financial information

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%
Grand total	£68,004	£24,282	36%

Secondary care expenditure in the scenarios is radically different. The optimal case represents only 7% of the original sub-optimal case – 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, please note 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.

Financial information

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%
Grand total	£68,004	£24,282	36%

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.

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

NHS RightCare Approach



Further information

For more information about Sarah's journey, NHS RightCare or long term conditions you can:

Email

- rightcare@nhs.net
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Visit

- www.england.nhs.uk/rightcare

Tweet

- [@NHSRightCare](https://twitter.com/NHSRightCare)

You can watch the supporting video on the [NHS RightCare YouTube page](#)