

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



Katie's story: Advanced colorectal cancer

Appendix 2: Short summary slide pack

January 2018

Katie and the sub-optimal pathway (1)

- Katie is a 46-year-old retail worker. She lives with her husband, Isa and two young children
- Katie had **surgery and adjuvant chemotherapy** for colorectal cancer when she was 45. Scans clear at one year and the family moved county for husband's job
- Katie developed **right upper quadrant pain** – persisted and became more severe over a month
- Waited **two weeks for GP appointment** – saw GP twice and out of hours GP once over next two weeks
- Pain intensified – **ambulance took her to A&E** where enlarged liver noted
- Admitted to surgical ward – **inpatient for three weeks**. CT scan showed metastatic disease and she had liver biopsy. Katie was told the news on the ward whilst she was on her own, and **had to break the news to Isa herself**
- During this time, Isa took over childcare and was struggling, eventually **getting sacked from his job**
- Katie was referred to oncologist as outpatient: Palliative chemotherapy planned

Katie and the sub-optimal pathway (2)

- After first cycle of chemotherapy, **struggled with pain and constipation**: Visits to A&E and out of hours GP
- After further chemotherapy and inpatient acute care, follow up CT scan showed **no response to chemotherapy** and her liver function deteriorating: Chemotherapy discontinued
- The district nurse put in an application for the care package through continuing healthcare (CHC) but **Katie's clinical condition deteriorated** prior to this care being put in place
- Further admission to acute setting with bowel obstruction: Isa was told by the nurses that as Katie was '**terminally ill... nothing can be done.**' Isa was told he should 'take her home to die.'
- Katie said she did not want to die at home. Her preference was for a hospice if a side room was available. She did not want to discuss Advance Care Plans or decisions about Cardiopulmonary Resuscitation, or see the community palliative care team – **still struggling with situation**
- Katie **died at home** in the end and the family situation was stressful and distressing in the extreme

Katie and the optimal pathway (1)

- Katie and her family moved to their new home in January, having **finished her chemotherapy** for colorectal cancer a year earlier
- When registered, her new **GP promptly referred her** to a local nurse-led colorectal cancer follow-up clinic and forwarded her notes and images
- When she developed persistent abdominal pain a year later, Katie rang the **colorectal nurse specialist** directly – this triggered the locally agreed pathway and a CT scan and bloods were organised
- **MDT discussion** took place following results of CT scan and then of liver biopsy.
- On each occasion, Katie was **offered appointment at results clinic** and opportunity to bring somebody with her
- Katie was given a **double appointment in her GP surgery** to allow time for questions and discussion. A personalised care and support plan was documented using the enhanced section of summary care records

Katie and the optimal pathway (2)

- Katie was seen by the **enhanced supportive care service** in hospital and palliative nature of the treatment plan and symptom management discussed. Community palliative care team and local hospice family support team supported Katie and her family at home
- Katie's pain settled so she was **able to return to work** part-time, undergoing two cycles of chemotherapy
- Follow up **CT scan results** showed that her cancer was not responding - Katie decided to stop chemotherapy
- Katie was introduced to the concept of a **personal health budget** and later used it to pay her neighbour to help with her care
- Towards the end (two months later than the suboptimal scenario), although Katie's care was not perfect (as a hospice side room was not available when she needed it), she and her family were **well prepared and well supported**
- Katie was able to **die peacefully in hospital** (importantly not at home) and the whole process was well managed, including the provision of family bereavement support

Financial information

Analysis by provider	Sub-optimal	Optimal	Optimal %
Third sector	£0	£1,379	n/a
Acute	£18,467	£4,978	27%
Ambulance service	£536	£0	n/a
Carer	£0	£1,152	n/a
Community teams	£321	£3,732	1164%
Patient	£0	£10	n/a
Primary care	£302	£459	152%
Grand total	£19,626	£11,726	59.7%

- Secondary care expenditure in the two scenarios is radically different. Acute costs in the optimal case represent only 27% of the original sub-optimal case (90% reduction in bed days) – equating to a reduction of £13.5k.
- Community teams offer a great deal more support and a personal carer is also necessarily higher in the optimal scenario as the optimal case needs to invest in these areas to ensure Katie's care and support is as good as possible given this very difficult case. NB This also raises the importance of improved strategic budgeting across the wider health economy.

Financial information

Analysis by cost category	Sub-optimal	Optimal	Optimal %
Community care	£125	£2,907	2333%
Elective admissions	£0	£1,000	n/a
Palliative and End of Life	£156	£4,002	2558.1%
Prescribing and Meds Optimisation	£88	£491	559.5%
Primary care management	£117	£384	329.4%
Secondary care management	£17,719	£2,902	16.4%
Self care	£0	£20	n/a
Urgent and emergency care	£1,421	£20	1.4%
Grand total	£19,626	£11,726	59.7%

Not only is Katie's quality of care so much better in the optimal scenario, but the cost savings are also significant at £7.9k (40%). **NB** 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. Plus chemotherapy costs (including drug costs) are the same in both scenarios. This is not a distinguishing variable in this study.

NHS RightCare Approach



Further information

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

Email

- rightcare@nhs.net
- england.longtermconditions@nhs.net

Visit

- www.england.nhs.uk/rightcare

Tweet

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