



20 April 2021

End-of-life care in the age of integrated systems

The UK hospice sector already does its difficult and hugely important job very well. How can we improve the efficiency and effectiveness of end-of-life care in the era of ICSs?

Death, that ultimate rite of passage, is one of life's few stone-cold certainties. Each death is, of course, deeply personal and each has hugely significant implications for other people's lives.

The final days of any life should be among the most precious of all and we should do whatever is humanly possible to ensure that is the case.

That's the focus of the UK's hospice care sector, which does a wonderful job of supporting around 225,000 people with terminal and life-limiting conditions each year, as well as providing bereavement support to tens of thousands more.

But half of us die in a hospital bed – in fact, one third of the people in hospital beds are in the final year of their lives – and a third of them have no real medical need to be there and would prefer to die at home.

Around one fifth of NHS spend is on palliative care and three quarters of the people who die have some sort of palliative care need. But a quarter of those needs aren't currently being met.

Better coordination of care

These statistics were shared by Tracey Bleakley, CEO of Hospice UK, during last week's GGI ICS webinar about the future of end-of-life care, to illustrate the need for better coordination of care. Tracey described end-of-life care as taking a 'cast of hundreds'; in too many cases it's not being organised well enough.

The best way to understand the problem, said Tracey, would be to accompany a hospice nurse on their round. At each home visit you will probably find expensive medication that's no longer needed – perhaps because it's designed to prevent conditions that have been rendered sadly irrelevant by more pressing illnesses, or can't be used with other medicines.

Then, during your visit, a district nurse might appear, ready to perform some of the same tasks the hospice nurse has just completed. Your patient might tell you about an impending hospital appointment for an electrocardiogram, despite having just weeks left to live. And of course that hospital visit will be risky and costly as well as unnecessary.



Sadly, the issue doesn't even disappear when the patient dies, because many appointments will remain needlessly open and prescriptions still pointlessly catered for. It all costs time and money and as a system, we must do better.

Integrated care improvements

Our event served to highlight some of the ways hospices can use the shift to the integrated care model to make some of the necessary improvements.

Kate Tompkins, chair of the board of trustees at Dorothy House Hospice Care, highlighted how her organisation has engaged with the complexities of the Bath and North East Somerset, Swindon and Wiltshire (BSW) integrated care system, which comprises three local authorities, three foundation trusts, 94 GP practices and numerous other health and care providers serving nearly 950,000 people.

Top of the agenda was developing a shared vision and unified voice for the 25 organisations offering end-of-life and palliative care services on the BSW ICS board. These organisations aligned to produce a shared vision document that set out eight key recommendations, which were duly accepted by the board.

Reaching that shared vision required new relationships to be built. And it required a willingness to establish a shared understanding of the population health challenges facing the ICS.

Common success factors

Kate's experience in the west country echoes some of the themes we have noticed in the areas where the relationship between hospices and the NHS is working well.

In those areas, hospices felt part of broader team and valued. They had learned to pitch themselves as helping the NHS with its agenda. They had found champions within the ICS leadership and built relationships with them. They usually had former NHS senior leaders on their boards. And they were ambitious and outward looking, keen to influence the whole end-of-life pathway and not just the bit they were responsible for.

The sector should be proud of what it has achieved but it must also be honest about the challenges ahead. One of those challenges will be to find a way to ensure the sector's voice is heard equally across the three component parts of integrated care systems: at the overall system level; at the still rather loosely defined level of place, where most of the integrated working will take place; and within provider collaboratives.

Illuminations

- The hospice care sector is already a success story. Hospices already deliver twice as much as NHS England asks of them and yet hospice medical staff still score incredibly highly on treating patients with dignity and respect.
- In order to thrive in the world of integrated care, hospices must understand the three component parts of integrated care systems and ensure their voices are heard at all three levels.
- End-of-life care is one area where integrated care systems have looked outside the NHS to benefit from the skills and expertise of another sector. Let us all hope the same can happen with other sectors, especially social care.

If you have any questions or comments about this briefing, please call us on 07732 681120 or email advice@good-governance.org.uk.