Can death and dying be made to balance with birth and living?

A personal blog by: Paul W Jennings, Chair of Hospice UK and, until the end of September, the CCG CEO and system lead for Birmingham and Solihull ICS

Since its foundation in 1948 the NHS has essentially been a rescue service, albeit a world-leading and ethical one that treats all comers on the basis of need and provides care free at the point of use. It was one of a series of measures linked to the foundation of the welfare state, which gave to post-war Britain an unprecedented sense of security and a safety net, especially around income and health.

However, one thing the NHS has always struggled with is death and its immediate precursor: dying. If your role is to pluck out the victims of illness as they float past on the river of life and restore them to health and wellbeing, it's hardly surprising if you struggle with those whom you cannot cure, those who are flowing inexorably towards the sea of eternity.

It was the absence of a thoughtful, proactive approach to dying and death that gave rise to the hospice movement. Often driven by the vision, passion and commitment of individuals, hospices have flourished over the years. There are now more than 200 in the United Kingdom, including a number that are wholly managed by the NHS.

However, the tapestry is still too multi-patterned. There are some great examples of integrated work. There are many supportive GPs who have been trained in advance care planning, working alongside colleagues in community services, the voluntary sector, independent hospices, Marie Curie and Sue Ryder, and those in care homes and retirement villages. But there are also too many examples of poorly coordinated and badly planned care.

The range of NHS commissioner investment in hospices is unacceptably variable, from those who contribute 80% of running costs to those who contribute less than 10%. The range of commissioning approaches is also too wide, from those who specify services and standards to those who give out (usually small) grants for generalist poorly defined purposes.

During the COVID pandemic hospices have received unprecedented support from central government through an arrangement negotiated by the Hospice UK executive team. There's no question that this has stabilised the sector in the face of real concerns about the collapse of charitable income and therefore the potential bankruptcy of many services. Importantly, it has also demonstrated that the sector can deliver in a measured and organised way within a monitored agreement. This is crucial for the future survival of the hospice movement with the impending move to integrated care systems (ICSs).

The ICS approach is really welcome if we are to see improved support and management of end-of-life services because it will shift commissioners to a different style of engineering improvement, through collaboration rather than competition.

Transactional commissioning and contracting will be replaced by something more strategic, focused on delivering outcomes against quality standards through a population or care pathway approach.

For end-of-life services we would hope to see a well-defined pathway of care involving the contributions of the acute, community, primary care and voluntary sectors alongside local government, with a coordinated approach to investment and a core offer to those in need of palliative support and care. Commissioning in this way would remove some of the massive variation in the experience of patients and the equally massive postcode lottery in investment.

A number of hospices across the UK are already working up partnership examples of what an integrated end-of-life pathway might look like; between themselves as charities and with statutory partners from the NHS and local government.

The collaborative approach underpinning integrated care systems offers the best opportunity in decades to achieve what has long been the goal of the end-of-life movement: a parity of practice and investment in palliative care that matches that given to birth and addressing illness.

Hospice UK will continue to work hard with partners to achieve that aspiration.