Strategic thinking: end of life care

This year presents a unique opportunity to improve services for children with life-limiting illnesses

Major announcements were made in all four parts of the UK at the end of last year. All have the potential to improve the way seriously ill children are looked after.

In December, the National Institute for Health and Care Excellence (NICE) unveiled its final guidance for end of life care for infants, children and young people in England and Wales. This came a month after Northern Ireland published its own plans, which set out a ten-year vision for services. In October, the Scottish Government announced a £30 million five-year funding package for Scottish hospices.

Content of the guidelines across the UK

**England and Wales**

National Institute for Health and Care Excellence (NICE) recommendations published in December set out details of symptom management and calls for:

- Children to be cared for by multidisciplinary teams, provided with 24/7 access to end of life nursing care and supported by specialist paediatric palliative care teams.
- Children and parents to have central roles in decision making and consideration of the needs of siblings.
- Age-appropriate communication involving play, music, pictures and digital media.
- All patients to get advanced care plans that cover life-threatening events and preferred places to die.
- Consideration of practical support, such as schooling, and emotional and psychological support.

**Northern Ireland**

The Strategy for Children’s Palliative and End-of-Life Care was published in November. It makes a number of similar recommendations to NICE, including access to multidisciplinary teams, rapid transfer arrangements, and putting children and parents at the centre of decision making. It also calls for the establishment of a network for children’s palliative care to help ensure standards are met.

**Scotland**

In October, the Scottish Government announced a £30 million five-year investment in the Children’s Hospice Association Scotland, which provides short breaks, end of life care, bereavement services and home care support. The charity will receive the funds, about half of what it needs, from April.

People with life-limiting and life-threatening illnesses, but they are due to more than 300 different conditions.

Some of these conditions are rare so there is a huge range of issues for clinical staff to manage. We have a shortage of paediatric palliative care consultants coming through, and of specialist nurses with the right skills and experience.’

Ms McNamara says the managed clinical networks recommended in England and Wales, and the version put forward for Northern Ireland, will be crucial to implementing the new standards.

As well as getting these areas to think strategically about staffing and skill mix, she says they will also provide a crucial opportunity to improve the coordination of care, as similar networks have done for diabetes and neonatal care.

Informal networks

‘There are informal networks in most areas in the UK, but nothing like this. However, you need to invest in them and free people up to run them. People cannot carry out network roles on top of their day jobs.’
Case study

Haven House Children's Hospice has been praised for how it has made sure families' needs are put first. A Care Quality Commission report published last year states that the London-based hospice delivers care with 'compassion and warmth'.

The hospice is said to involve families in the design of services, and to hold regular parent forums in which families can meet trustees, raise issues and lead on service development. It also provides families with electronic surveys to rate its performance and provide feedback.

The report states that the hospice is always looking for ways to improve the care it provides. For example, at the request of families, the hospice has started to provide outreach play, music and respite services as well as end of life care.

So what will success look like? Ms McNamara says that two of the big goals are ensuring palliative care starts at diagnosis – something that is stressed explicitly in the final NICE guidance – and putting children and families at the heart of planning care through ‘open, honest communication’.

This involves thinking about the wider family, she says. ‘Sometimes the system is not always good at this. For example, are there sufficient space and facilities in hospitals for siblings to be at the bedsides of sick children?’

Director of care at London’s Haven House Children’s Hospice Eileen White says there should be a measure of progress made in ensuring children and young people receive end of life care in the places of their choosing. ‘A lot of babies and children die in hospital, but some want to be at home or in a hospice.’

She says there should be more collaboration between hospices and health and social care to enable effective advance care planning, something that the Scottish Government has highlighted as a priority in its funding package.

She says ensuring each family gets a key worker to coordinate care will help. ‘The key worker can be anyone really: a palliative care doctor, community children’s nurse, a clinical nurse specialist. You just need someone to help coordinate and guide families through the system.’

Rachel Hollis, lead nurse for children’s cancer at Leeds Teaching Hospitals NHS Trust and member of the Royal College of Nursing’s children and young people specialist care forum, agrees.

Access to training

She says the guidelines fill a ‘big gap’. ‘We have had guidelines for palliative and end of life care for adults, but not for children.’

She has concerns, however: ‘Many children receive excellent care at the end of life, but provision of services is variable across the country.’

Ms Hollis cites the scarcity of paediatric palliative care teams and access to children’s nurses ‘day-and-night’ as specific problems.

She says these problems arise because of the ‘critical issue of the training of children’s nurses able to work across acute and community care.’

‘We also need to look at specific education, training and support for nurses providing palliative and end of life care. ‘There are courses out there, but lack of access to training is a real issue given that so many different types of nurses have contact with children who have such complex needs.’

Alamy

£30M

Scottish Government package over five years for hospices


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Fast facts

300+
Life-limiting conditions affect children and young people

50,000
Children and young people have life-limiting illnesses in the UK

£30M
Scottish Government package over five years for hospices