Personalised palliative care: making it a reality

The NHS wants palliative care to be better coordinated and more person-centred – but nurses and services are not always equipped to address individuals’ needs.

Not everyone gets the care and support they need to die with dignity and in as much comfort as possible. For years, nurses have led improvement in palliative and end of life care. We take a look at some recent developments – and what role nurses can play in the continuing improvements.

Although they are sometimes used interchangeably, the two terms are distinct. End of life care is treatment and support for people who are near the end of their lives. That is normally defined as those expected to die within 12 months and includes those whose death is imminent.

While palliative care can involve end of life care, it is much broader and can last a lot longer. The aim is to improve the person’s quality of life by preventing or relieving suffering, whether physical, mental or spiritual, and providing practical support. Offering palliative care does not necessarily mean the person is expected to die soon – some people can receive palliative care for years.

Nurses are of course, central to the provision of palliative care, along with multidisciplinary colleagues. District nurses play a key role alongside GPs and some patients need specialist support.

According to the Association of Palliative Medicine and Marie Curie an estimated 90% of people who die in the UK...
would benefit from palliative care – a figure based on the numbers dying with progressive conditions such as cancer, heart disease and dementia.

Lack of palliation, the charity says, causes distress and pain, not just to the person but their families too. In addition, gaps in provision are inefficient for the health service too, leading to unnecessary and expensive hospital admissions.

Office for Health Improvement and Disparities data show around 15% of emergency admissions are of people in the final year of life, with two-thirds experiencing at least one emergency admission in the final three months.

Yet there are significant gaps in the provision. The 2022-23 National Audit of End of Life Care for England and Wales highlights areas requiring improvement, including:

» Communication
» Use of advance care plans
» Access to specialist support seven days a week

Access to palliative care

There are some people, though, who do not even have access to any palliative care. The Marie Curie research estimates as many as one in four people who need palliative care do not receive it. And the charity warned demand for care was only going to increase, thanks to an ageing population and growth in complex conditions.

Marie Curie chief executive Matthew Reed says: ‘The UK has an end of life problem. To put it bluntly, you only die once – and the last chapter of life has not been right for many, many people.’

‘What is needed is more – much more – support for people in their own homes. That care is often better, and cheaper, than what is available in hospital.’

Barry Quinn, senior lecturer in the school of nursing and midwifery at Queen’s University Belfast, and an expert in palliative care, agrees. ‘Until we recognise that dying is a natural part of life, we will end up over-medicalising a natural process. Yes medicine is important, but it needs complemented by care.’

He believes there has been an over-specialisation in palliative care.

‘Most good end of life care is delivered by community and ward-based nurses and doctors,’ Dr Quinn says. ‘It should be about collaboration and support – and more focus on moving resources from the acute sector to the place where people want to die. But people are not willing to let go of precious funding.’

Across the UK, work to improve palliative care services is ongoing. Each nation has published its own strategy.

‘Training is important and there are a variety of ways to access it… but it is not consistently available’

Sandra Campbell, RCN pain and palliative care forum member

England’s 2021-26 framework sets out six ambitions:

» Each person is seen as an individual
» Each person has fair access to palliative and end of life care
» To maximise comfort and the individual’s well-being
» Care is co-ordinated
» All staff are prepared to care
» Each community is prepared to help

NHS England funded the Open University to produce a ‘grab and go’ guide on how to improve palliative care. This sets out how the framework’s ambitions can be achieved and includes advice on increasing the use of advance care plans and making services seamless.

Reliance on hospices

Hospice end of life practitioner and University of Bedfordshire lecturer Chris May believes there are good intentions in plans being put in place, but it is another development – in England at least – that will have the most far-reaching impact.

After a long-running campaign by Baroness Finlay, a professor of palliative medicine, the 2022 Health and Care Act created a legal duty in relation to palliative care, making integrated care boards in England accountable for commissioning and overseeing services.

Mr May says: ‘It is the first time any part of the NHS has..."
had this responsibility. It is one of the most encouraging changes for many years. In time, that should lead to more investment and better planning.’

He says for too long end of life care has been over-reliant on hospice and charity provision. ‘They have had to resort to fundraising. It is not something you necessarily see in other areas of the NHS. You would not, for example, expect to have coffee mornings to raise money for a hip replacement. We need to re-think how we view end of life care if we are going to see real progress.’

How can I improve care?

Around 30% of hospital patients and about 80% of care home residents are in their final year of life, so nurses in NHS and social care settings may be able to influence palliative care.

Macmillan consultant nurse in palliative and end of life care Sandra Campbell, an RCN pain and palliative care forum member, says one of the biggest challenges is that not everyone takes responsibility for it. ‘More palliative and end of life care is provided by more non-specialist staff than specialist,’ she says. ‘It is only the most complex cases where specialists need to be involved, although there should be access to specialist advice for all.’

‘Key things health and care staff need to know about include assessment and care planning; managing pain, agitation, nausea and vomiting and excessive secretions; assessing physical, psychological, social and spiritual needs.

‘It is also important to recognise dying, and to understand how to assess for reversible causes of deterioration.

‘There should be more focus on moving resources from the acute sector to where people want to die. But people are not willing to let go of precious funding’

Barry Quinn, senior lecturer, school of nursing and midwifery, Queen’s University Belfast

Tips for ensuring palliative care is seamless and person-centred

Open University’s guide is mainly aimed at managers and service leads, but includes advice front-line staff can use:

» Be proactive in ensuring advance care plans are in place. This includes adapting the plans for certain groups, such as people with learning disabilities and for those whose first language is not English

» Ensure plans are shared between staff in primary and secondary care

» Support the family, friends and carers of the dying person. Show them how to become involved in the care and provide pre-bereavement and bereavement help

» Access training. National e-learning End of Life Care For All training has 120 free online modules:
tinyurl.com/nhs-end-of-life-care-for-all

Source: Open Research Online tinyurl.com/ou-palliative-care-guide

‘Training is important and there are a variety of ways to access it. But the problem is it is not consistently available.’

Advance care planning

Mr May agrees front-line staff need support. ‘Opportunities are being missed as hospital staff in particular do not always know what is available. You hear of cases where people are told they are not eligible for hospice care because that is only available for cancer patients. ‘We are still seeing half of people dying in hospital when we know that is not where they want to die. It is still only a minority of people who have advance care plans.’

He wants to see all health and care staff promoting advance care planning and initiating plans.

‘It’s not just something for the GP or district nurse to do. And you do not have to finish them. By doing more to encourage people to fill them in we would empower people and that, in turn, would help drive change.’

Nick Evans is a health journalist

Further information