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ACUTE PERSPECTIVE

David Oliver: A new legal duty to provide specialist palliative care

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In February 2022 the government accepted a Lords amendment to the Health and Social Care Bill for England (now the Health and Care Act 2022) requiring every part of England to provide specialist palliative care.[1] This was welcomed by several charities and clinical specialty membership organisations that had campaigned on the issue.[2 3]

The amendment gives statutory force to commissioning of specialist palliative care by all integrated care boards in England, effectively covering the whole population and ending the postcode lottery. Before the amendment, research carried out by King's College and supported by Marie Curie had shown that, of 23 integrated care boards with published commissioning strategies, only six had identified end-of-life and palliative care as priorities.[4]

Other services, such as maternity care and dentistry, already come with this legal requirement, yet this alone hasn't ensured consistent provision and access. The devil is in resourcing, implementation, and prioritisation.

The status quo? Although the Economist Intelligence Unit in 2015 ranked the UK the best of 80 countries for end-of-life care,[5] problems do exist. The Association for Palliative Medicine has reported great regional variation in specialist numbers.[6] Two rounds of the NHS Benchmarking Network's National Audit of Care at the End of Life up to 2019-20 have shown some excellent practice, yet with great gaps in care.[7] A National Voices survey of bereaved people showed positive overall experiences for relatives of dying patients, especially if advance care planning had taken place.[8 9] But variations were seen in quality of care, communication, and choice of location at the end of life.

The covid pandemic highlighted problems such as the relative absence of advance care planning (or even pre-emptive discussions of treatment escalation and resuscitation), access to palliative care in care homes or people's own homes, and dignity and communication among people dying in hospital.[10 11]

More than 450 000 deaths a year were recorded in England in 2014-19 and more than 500 000 during the pandemic.[12 13] How does this compare with numbers of specialist staff? The UK has about 700 specialist palliative medicine consultants—600 or so working in England, with a population of 55 million.[6 14] One consultant for 100 000 people isn't a lot. Nor is one consultant for every 1000 deaths. In addition, around 5000 specialist palliative care nurses work for both the NHS and specialist charities.

The pandemic was associated with a greater proportion of people dying in their own homes, but the general pattern in the preceding five years was around 45% of adults dying in hospital, 25% in their own homes, 20% in care homes, and 5% in specialist hospices.[15] Transforming care, support, and planning for the end of life has to cover people dying or approaching the end in all of those settings.

Advance care planning to improve the quality of death is another task and raises the question of who supports patients and families to help do it well. Palliative medicine and nursing specialists can be expert guides, teachers, leaders, and developers of best practice, but improving end-of-life care is clearly everyone's business.

The new statutory duty is only a start. We also need a commitment to increase the specialist workforce, provide more consistent public funding to services traditionally reliant on charity, and, crucially, ensure that the wider clinical workforce increases its skills and confidence in this area of practice. Specialists can lead change and inform or educate the rest of us, but they can't do it all by themselves.

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