

Palliative Care

House of Commons, Adjournment Debate
Wednesday 4th November

About the BMA

The British Medical Association (BMA) is an apolitical professional association and independent trade union, representing doctors and medical students from all branches of medicine across the UK and supporting them to deliver the highest standards of patient care. We have a membership of over 154,000, which continues to grow each year.

Key points

- The BMA believes that high quality palliative care should be consistently and widely available for all those who need it. However, such high quality care is not always available and some patient groups continue to have poor access to it. The measures below seek to address this issue.
- **Education & training:** all medical students and doctors who are involved in the care of dying patients should be trained and supported in providing that care, with a specific focus on communication skills.
- **Research:** specialist palliative care teams should be supported to participate in relevant research, in recognition of the significant patient benefit to which medical research can lead.
- **Community setting:** patients have a right to choose where they receive care and where they wish to die, and that choice should not be restricted inappropriately or unnecessarily. Commissioners should, as far as possible, ensure that the necessary services are in place to support all patients who wish to be cared for at home – particularly with regard to accessing adequate pain relief and other symptom control.
- **Out-of-hours services:** a substantial proportion of palliative care is provided out of hours, when services are often ill-equipped to meet the needs of patients. Improvements to out-of-hours services can and should be made to deal with this challenge.
- The BMA will shortly be publishing a report on a series of deliberative events held with doctors and the public on various issues relating to end-of-life care, which will explore many of the issues outlined below in more detail.

Background

BMA policy, which is passed through our democratic Annual Representative Meetings (ARMs), calls for continuing improvements to be made in the provision of palliative care, and, specifically, that:

- high quality palliative care should be universally available to all members of our society
- better information should be made available to the public about what good palliative care can achieve
- better training in palliative medicine is needed for all doctors involved in the care of dying patients.



We recognise that palliative care is frequently done well, and note that the UK's expertise in this area is internationally recognised. A recent study ranked the UK as the best in the world for palliative care, describing the quality and availability of services - through a combination of NHS care and the established hospice movement - as "second to none".¹ However, we also acknowledge that unfortunate cases of poor end-of-life care can be found, some of which were detailed most recently in the 2015 report of the Parliamentary and Health Service Ombudsman.²

The reasons for failure in care at the end of life vary, but a lack of co-ordinated care, poor communication with patients and family members, and inadequate out-of-hours services are some common themes. These factors are in addition to discrepancies in the provision of services between local areas, which lead to a variation in the range and nature of services provided across the country. This variation is found particularly within the community setting, as outlined in the section below.³

The BMA is calling for equitable access to high quality palliative care services and an end to cases of poor palliative care. Furthermore, we would like to see the advancement of education, training and research in end-of-life care.

1. Palliative care in the community

Increasing numbers of patients express their wish to die at home – up to 82 per cent of patients, according to families who responded to the National Survey of Bereaved People (VOICES) survey in 2014;⁴ and the Department of Health's *End-of-life Care Strategy* emphasises the importance of extending generalist care, and involving specialist palliative care, in order to facilitate this.⁵ However, despite this preference, the majority of people still die in hospital, with only 21.6 per cent of deaths in England in 2010-12 taking place at home.⁶

The BMA believes that patients have a right to choose where to receive care at the end of their lives, and where to die, and that these preferences should be respected as far as possible. We recognise that factors, such as family support and medical condition, are likely to influence whether this is possible. However, for many patients their difficulties in being cared for at home may be due to a lack of appropriate services, which needs to be addressed. These problems include difficulties in accessing sufficient specialist professionals who can deliver services to meet all reasonable requirements; receiving appropriate equipment to aid medical professionals providing care in the home; and accessing essential medications at all times. *The BMA believes that commissioners should support patients who wish to be cared for in the community, as far as possible.*

Pain relief is often cited as the main concern about death and dying for many people.⁷⁸ Whilst there is widespread availability of opioid analgesics in the UK, and, on the whole, pain can be managed well, there remain cases of poor symptom control. This is particularly true for those patients being cared for at home, who may struggle to access the same standard of pain relief as those in hospital: surveys have shown that significantly more people report that pain is not relieved at all, or all of the time, at home.⁹ *We call for measures to ensure that the disparity in pain relief between the community and hospital settings should end, and for arrangements to be put in place to ensure doctors can access essential medications at all times.*

2. Out-of-hours services

A large part of supporting people to die at home involves out-of-hours services – for example, up to two-thirds of the care of cancer patients at home falls within the out-of-hours period.¹⁰ Yet,

these services available are often ill-equipped to address the needs of palliative patients, and GPs have highlighted various organisational factors as particular barriers to the provision of good out-of-hours palliative care. They range from time pressures and feeling alone or unsure of who to call for help and advice, to handover issues, such as a lack of information from in-hours services.¹¹ *To tackle these factors, all providers of out-of-hours services should receive training in palliative care; there should be formal handover processes for hand-over between daytime and out-of-hours services; and there should be easy access to essential medications out of hours.*

3. Education and training

Caring for dying patients will always be difficult for doctors, regardless of their level of experience, and the BMA is concerned that doctors are not being equipped with the right tools to provide this care. The review into the Liverpool Care Pathway, in 2013, found that medical training in palliative care was inconsistent, and often inadequate, resulting in a large number of junior doctors feeling ill-prepared to care for dying patients at the beginning of their careers.¹²

Various qualitative surveys have also highlighted the need for better education and training in palliative care. One survey, of newly qualified junior doctors in a UK deanery, found that a “lack of exposure” to the care of dying patients was common to all medical schools and to the early years of practice.¹³ *The BMA has longstanding policy that calls for training in end-of-life care strategies to be part of all medical schools’ curricula. As such, those providing training should ensure that the importance of pain control and palliative care is appropriately included in medical training to prepare junior doctors.*

We recognise that education and training do not end upon graduation from medical school, and there is evidence to suggest that even experienced clinicians struggle to address some of the palliative care needs of patients. One study indicated that many doctors might not be confident in their knowledge or expertise of palliative care, and found that 63 per cent of doctors felt they required specific training in palliative care.¹⁴ *The BMA has clear policy calling for better training in palliative medicine for all GPs and hospital doctors involved in managing dying patients. Accordingly, we call for training to be provided, where relevant, in post-graduate curricula and other vocational courses.*

As part of this training for doctors, we also note the recent concerns of the Parliamentary and Health Service Ombudsman, who found that poor communication was a key theme in the complaints received about end-of-life care.¹⁵ The Ombudsman observed that healthcare professionals did not always have open and honest conversations with family members and carers, meaning that the patient’s family and carers were often ill-equipped to deal with the severity of the situation and the choices they had to make at the end of the patient’s life. *Consequently, we emphasise the importance of communication skills as part of training for all doctors involved in the care of dying patients.*

4. Research

The BMA firmly believes that medical research can provide significant benefits for patients, and that reasonable steps should be taken to construct a mechanism for patient-based research to be carried out. *Accordingly, we believe that specialist palliative care teams should have the ability to participate in relevant research.*

Ongoing BMA work

In January 2015, the BMA launched a major new project examining end-of-life care and physician-assisted dying.

This has involved engaging with doctors and members of the public across the spectrum of medicine and society to explore concepts, perceptions, and understanding of a number of practical and ethical issues surrounding the care and options at the end of life. These include the accessibility, availability, and quality of end-of-life care provision across the UK.

In carrying out this research, we aim to compile a thorough and comprehensive body of qualitative evidence around end-of-life care and physician assisted dying, which will not only inform our own discussions at the BMA, but also play a significant role in the ongoing public debate.

The project will conclude at the end of 2015, and our final report will contain more information on many of the issues outlined above. Further information about this project and its aims can be found on the BMA website at <http://bma.org.uk/working-for-change/improving-and-protecting-health/end-of-life-care>

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¹ Economist Intelligence Unit (2015) *The 2015 Quality of Death Index: Ranking palliative care across the world. A report from the Economist Intelligence Unit commissioned by the LIEN Foundation*. Economist Intelligence Unit: London.

² Parliamentary and Health Service Ombudsman (2015) *Dying without dignity: Investigations by the Parliamentary and Health Service Ombudsman into complaints about end-of-life care*. PHSO: London.

³ Dixon J, King D, Matosevic T *et al.* (2015) *Equity in the Provision of Palliative Care in the UK: Review of Evidence*. London School of Economics/Marie Curie: London.

⁴ Office for National Statistics (2014) *National Survey of Bereaved People VOICES: 2013*. ONS: London.

⁵ Department of Health (2008) *End-of-Life Care Strategy: Promoting high quality care for all adults at the end of life*. DH: London.

⁶ Office of National Statistics (2014) *Mortality statistics: deaths registered in 2013*. ONS: London.

⁷ Sue Ryder/Demos (2013) *A time and a place: what people want at the end of life*. Sue Ryder/Demos: London.

⁸ ComRes (2015) *National Council for Palliative Care – Public Opinion on Death and Dying – 29-30 April*. Available at <http://comres.co.uk/wp-content/uploads/2015/05/National-Council-for-Palliative-Care-Publis-opinion-on-deaht-and-dying.pdf> (Accessed 6 October 2015).

⁹ Office for National Statistics (2014) *National Survey of Bereaved People VOICES: 2013*. ONS: London.

¹⁰ Taubert M, Noble SIR, Nelson A. "What challenges good palliative care provision out-of-hours? A qualitative interview study of out-of-hours general practitioners?" *BMJ Support Palliat Care* 2011; 1: 13-18.

¹¹ Magee C, Koffman J. "Supporting general practitioners to provide out-of-hours palliative care." *BMJ Support Palliat Care* 2014; 4: 107.

¹² Neuberger J (2014) *More care, less pathway: A review of the Liverpool Care Pathway*. Independent Review of the Liverpool Care Pathway: London.

¹³ Gibbins J, McCoubrie R, Forbes K. "Why are newly qualified doctors unprepared to care for patients at the end of life?" *Medical Education* 2011; 45: 389-99.

¹⁴ Ingleton C, Gardiner C, Seymour JE *et al.* "Exploring the education and training needs among the palliative care workforce." *BMJ Supportive and Palliative Care* 2013; 3: 207-12.

¹⁵ Parliamentary and Health Service Ombudsman (2015) *Dying without dignity: Investigations by the Parliamentary and Health Service Ombudsman into complaints about end-of-life care*. PHSO: London.