Access to Palliative Care Bill

House of Lords, Third Reading
Tuesday 23 February 2016

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 170,000, which continues to grow each year.

We urge Peers to support this Bill during its Third Reading, and in particular the four provisions in the Bill outlined below.

Key points

- **Equitable access**: the BMA believes that high quality palliative care should be consistently and widely available for those who need it. We recognise, however, that such high quality care is not always available, and that some patient groups continue to have poor access to it. We strongly support the aims of the Access to Palliative Care Bill, which seeks to address this issue and provide equitable access to palliative care services.

- **Education, training and research**: we support the Bill’s aim to advance education, training and research in palliative care. All medical students, and doctors who are involved in the care of dying patients, should be trained and supported in providing that care, with specific focus on communication skills. In recognition of the significant patient benefit to which medical research can lead, specialist palliative care teams should also be supported to participate in relevant research.

- **Community setting**: we believe that 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**: we acknowledge that 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, particularly information-sharing mechanisms, can and should be made in line with the proposals contained in this Bill. It is also important that those working in the community have access to any specialist clinical and practical advice that they need at all times.

Background
The BMA believes that high quality palliative care should be consistently and widely available for those who need it. We have recently completed a research project in which we commissioned social research experts, TNS BMRB, to run a series of public dialogue events to explore the public and doctors’ experiences and perceptions of end-of-life care. The first two volumes of the final report (detailing existing evidence on end-of-life care and the findings from the events,
respectively) were published in January 2016 and provide a more comprehensive overview of many of the issues explored here. Copies can be found on the BMA’s website and in the House of Lords’ library.

The BMA’s view has been developed by doctors – who have extensive experience of supporting patients with palliative care needs – through our democratic Representative Body’s Annual Representative Meetings. It 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 of very high quality, 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”. We also acknowledge, however, 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. Similarly, the research we commissioned into end-of-life care found pockets of excellence across the country, alongside significant variations in the level of care within and between areas.

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.

In order to ensure that cases of poor palliative care do not persist, we welcome the Access to Palliative Care Bill, and fully support its aims of making provision for equitable access to high quality palliative care services, and advancing education, training and research in palliative care.

Provision 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; 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. 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. This desire to die at home was echoed by many of the participants who took part in the research we commissioned, expressing a view that home was their preferred place of death. However, very few participants voiced this preference unreservedly, noting that there could be various factors which limit this option – including the nature of the illness; the severity of symptoms; and the adequacy of support available at home.
The BMA believes that patients should have a right to choose where to receive care at the end of their lives, and where to die – but that this choice should be real and not illusory. We recognise that factors such as family support and medical condition are likely to influence whether this is possible; but 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 including specialist doctors, nurses, social workers, care workers, and others 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.

We support the provisions of this Bill which seek to address these issues, and to ensure that commissioners 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, and, indeed, it appeared in the top three concerns of those who took part in the research we commissioned. 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.

This does not just affect the person at the end of their life, but also those who support them - participants in the research commissioned as part of the BMA’s project on end-of-life care who had recent experience of bereavement reported that where there was unrelieved pain this was incredibly distressing, and often featured prominently in their memory of that relative’s death. If patients are to have a real choice about where to receive care at the end of their lives, it is crucial that systems are in place, in all areas, for those who wish to die at home to ensure that they receive high quality care through appropriate and timely availability of medication and equipment.

We support the aims of the Bill 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.

Provision 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. Many doctors who participated in the research, however, highlighted out-of-hours services as an area where provision of end-of-life care can be poor – particularly in terms of information-sharing between services and access to essential medications (similar to the issues outlined above). Other research has highlighted various organisational factors as particular barriers to the provision of good out-of-hours palliative care, including time pressures, handover issues and a lack of information from in-hours services.

Poor information sharing between in-hours and out-of-hours services can hinder the provision of high-quality care. It is crucial that – with the patient’s consent – all health professionals who have contact with the patient have all the relevant information they need (including diagnosis, prognosis, treatment plan, and the patient’s wishes). Doctors at the events we commissioned
shared many examples of good practice in place across the country, but identified out-of-hours care as a particular area where care could break down due to the lack of information in the hands of the doctor. Furthermore, many doctors working out of hours report feeling alone and being unsure of whom to call for advice, emphasising a need for systems to be in place for these doctors to access specialist clinical and practical advice, wherever and whenever that need arises.

To tackle these factors, all providers of out-of-hours services should receive training in palliative care; there should be clear information-sharing processes and protocols between services; and there should be easy access to essential medications out of hours.

Provision 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 at the beginning of their careers feeling ill-prepared to care for patients coming to the end of life. It was clear from speaking to doctors who took part in the research the BMA commissioned that not all of them felt confident in providing all aspects of end-of-life care. Significant numbers of medical students and junior doctors highlighted a lack of exposure to patients receiving end-of-life care, and often spoke of “being thrown in at the deep end” when they started working. Various other 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.

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, we support the provisions of the Bill which would place a duty on those providing training to ensure that the importance of end-of-life care issues 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. Indeed, concerns about education and training raised through the research commissioned by the BMA were not limited to doctors at the beginning of their careers. Separate studies have also 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.

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 support the Bill’s proposal to ensure that training is provided, where relevant, in post-graduate curricula and other vocational courses.

As part of this training for doctors, we also note the 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. The Ombudsman observed that healthcare professionals did not always have open and frank conversations with family members and carers, resulting in the patient’s family and carers often being 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. Anxieties around communication
were commonly raised by doctors who took part in the research that we commissioned, some of whom described conversations with patients as “difficult” or “distressing”. Open, frank and frequent communication with the patient and those important to them is critical to the provision of high quality end-of-life care. Doctors must receive the training and support to feel confident in initiating and having difficult conversations with patients and with those important to them.

Consequently, we emphasise the importance of communication skills as part of training for all doctors involved in the care of patients at the end of life.

Provision 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 support the provision in the Bill for ensuring that specialist palliative care teams have the ability to participate in relevant research.

BMA work in this area

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

We commissioned social research experts, TNS BMRB, to run a series of public dialogue events to explore the public and doctors’ experiences and perceptions of end-of-life care on our behalf. Throughout 2015, we engaged with over 500 doctors and members of the public across the UK 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 included the accessibility, availability, and quality of end-of-life care provision across the UK.

Our aim in carrying out this research was to compile a thorough and comprehensive body of qualitative evidence around end-of-life care and physician-assisted dying, which would not only inform our own discussions at the BMA, but also play a significant role in the ongoing public debate. We hope our findings will also reinforce the BMA’s voice amongst those calling for improvements in current end-of-life care provision.

The first two volumes of our final report have now been published, which draw together existing evidence on the subject, and detail the findings from the events. These are available online at www.bma.org.uk/end-of-life-care. Copies are also available in the House of Lords’ library. Volume 3, summarising the BMA’s reflections and recommendations, will be published in the spring.

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1 Details of TNS BMRB can be found at http://www.tns-bmrb.co.uk/