
Access to Palliative Care and Treatment of Children Bill 2019-20

House of Lords, Second Reading
Friday 7 February 2020

About the BMA

The BMA (British Medical Association) is a professional association and trade union representing and negotiating on behalf of all doctors and medical students in the UK. It is a leading voice advocating for outstanding health care and a healthy population. It is an association providing members with excellent individual services and support throughout their lives.

Access to Palliative Care and Treatment of Children Bill 2019-20

The BMA has frequently drawn attention to the shortcomings in end-of-life care and called for increased investment and provision to ensure that high-quality general and specialist palliative care is available to all who need it.

We strongly support many of the aims of the *Access to Palliative Care Bill and Treatment of Children Bill* – those which seek to address shortcomings in, and provide equitable access to, palliative care services. We urge Peers to support the palliative care aspects of this Bill in clause 1.

We welcome clause 2's ambition to support the resolution of differences of opinion regarding the treatment of children with life-limiting illness through mediation, amongst other non-adversarial approaches. However, we are concerned about the Bill's proposal in clause 2(4) to change the way courts consider treatment decisions for children with life-limiting illnesses.

Clause 1: Palliative care and support

We welcome the Bill's focus on addressing shortcomings in end-of-life care provision by ensuring that all NHS service commissioners make arrangements for general and specialist palliative care services to be available to all those who need them.

We know from speaking to our members and to members of the public that there are examples of excellent end-of-life care being provided throughout the UK, but that there remain considerable variations between location (i.e. whether people are being cared for in hospital or in the community), geographical area, and medical condition.¹

The *Access to Palliative Care and Treatment of Children Bill 2019-20* would be a crucial step in addressing those variations and ensuring that high-quality generalist and specialist palliative care is available to all who need it.

¹ British Medical Association (2016) *End-of-life care and physician-assisted dying – Volume 3: Reflections and Recommendations*. BMA: London. 2-5.



In particular:

- **We welcome the Bill’s ambition to place hospice provision on an equitable footing with all other health care services provided in a local area.** The UK is a world leader in the hospice movement, and hospice care is frequently cited by members of the public as “the gold standard” in terms of end-of-life care.² Yet there remains a huge amount of variability in hospice provision across the country, largely as result of discrepancies in funding arrangements. We believe that the Government must consider how to make hospice provision available on an equitable basis and that this Bill creates a key opportunity to address this.
- **We are pleased to see the Bill specifically mention hospice access to pharmaceutical services.** Pain and other uncontrolled symptoms are frequently cited as the main concern about death and dying, including in our own work on this issue.^{3 4} On the whole, pain can be managed well, but there remain cases of poor symptom control. BMA research highlighted that this can be particularly acute in the community setting and in out-of-hours care.⁵ Systems must be put in place to ensure the appropriate and timely availability of medication for patients, no matter where they are being cared for.
- **We support the Bill’s provisions which would ensure clinicians providing general palliative care have access to specialist palliative care advice at all times.** A huge part of end-of-life care will be provided by GPs in the community. Many of the doctors we spoke to through research work we published in 2016 highlighted that they often felt “alone” and uncertain of who to approach for advice.⁶ It is essential that specialist palliative care advice is readily available and accessible – whether in person or via email or telephone – so that a rapid response can be provided.

BMA work on end-of-life care

Throughout 2015 and 2016, we conducted a series of public dialogue events across the UK, engaging with over 500 doctors and members of the public to explore attitudes to, and perceptions and experiences of, end-of-life care and some aspects of physician-assisted dying. This included the accessibility, availability, and quality of end-of-life care provision across the UK.

We compiled a thorough and comprehensive body of evidence around end-of-life care in the UK, and we published our final report in three volumes. Volume One is a literature review of existing evidence; Volume Two details the findings from the dialogue events; and Volume Three summarises our reflections and recommendations on the work. These reports are available online at the [BMA website](#), and copies are also available in the House of Lords’ library.

² British Medical Association (2016) *End-of-life care and physician-assisted dying – Volume 3: Reflections and Recommendations*. BMA: London. 33.

³ ComRes (2015) *National Council for Palliative Care – Public Opinion on Death and Dying – 29-30 April*. Available at: <https://www.comresglobal.com/polls/dying-matters-coalition-public-opinion-on-death-and-dying/> (Accessed 10 June 2019).

⁴ TNS BMRB/British Medical Association (2016) *End-of-life care and physician-assisted dying – Volume 2: Public dialogue research*. BMA: London. 27-29.

⁵ British Medical Association (2016) *End-of-life care and physician-assisted dying – Volume 3: Reflections and Recommendations*. BMA: London. 27-28.

⁶ British Medical Association (2016) *End-of-life care and physician-assisted dying – Volume 3: Reflections and Recommendations*. BMA: London. 8.

Clause 2: Treatment of children with a life-limiting illness

We welcome the Bill's ambition to support the resolution of differences of opinion through mediation, amongst other non-adversarial approaches. We would welcome an accompanying commitment from the Government to properly resource mediation and ensure that it is readily accessible across the NHS.

We have serious concerns, however, about the proposal under clause 2(4) to change the way courts consider cases when there are differences of opinion as to what treatment is in a child's best interests.

Clause 2 (4)

We believe the current approach is preferable and does not need changing. The current approach ensures the court's starting point and focus is on a child or young person's best interests, taking into account all relevant factors, including the views of parents. The proposal in clause 2(4) would, instead, force a court to approach these cases from the starting point of a rebuttable assumption that parents' treatment proposals are in a child's best interests.

Changing the approach in this way would limit the court's ability to focus objectively and impartially on a particular child's interests. Interests also include, for example, a child or young person's own wishes, feelings and values (where these can be ascertained), as well as those of the parents. We have concerns that the level of proof required by this Bill to 'clearly establish' that 'any medical treatment proposals put forward by any person holding parental responsibility for the child' are not actually in a child or young person's best interests would be too high.

Parents' views and wishes about the treatment of their children are extremely important and, where possible, should always be sought and discussed. Where disagreements cannot be resolved and the court is approached for a view, courts frequently support parental decisions that are within the range of what could be considered in the best interest of a child. Where disagreements reach the courts, parents need to be able to access support to ensure their views and wishes are adequately represented.

Whilst it is entirely understandable for parents to want to prolong their child's life for as long as possible, we believe the court has a responsibility to ensure that children with life-limiting illnesses are not exposed to unacceptable painful, unproven, or suboptimal treatments. We believe that there is a greater risk of children and young people being exposed to these kinds of treatments if this new approach is adopted.

We believe the courts should continue to approach these cases from the starting point of children and young people, to ensure their best interests are the court's paramount consideration.

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