

THE BRITISH MEDICAL ASSOCIATION'S (BMA) RESEARCH INTO ASSISTED DYING

A joint response by:

CAMPAIGN FOR
DIGNITY
IN DYING.

HPAD
Healthcare Professionals
for Assisted Dying

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A **neutral** stance would enable the BMA to participate effectively in the debate, a debate that, critically, is of the utmost importance to **patients**.

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This year the BMA published the findings of its research into end-of-life care and assisted dying. The research included a review of existing evidence, a number of ‘dialogue events’ held across the country and ‘reflections and recommendations’ from the BMA intended to inform internal debate on these issues. This response addresses the BMA’s findings on assisted dying.

Dignity in Dying and Healthcare Professionals for Assisted Dying (HPAD) welcome the fact that the BMA has, for the first time, formally explored with groups of doctors and patients the issue of assisted dying. However, despite its efforts we believe that the BMA’s approach to this report and to the whole issue of assisted dying has been and remains incomplete and biased.

This piece of research may placate some within the BMA and beyond, who do not wish the current law to change, but are fearful of being seen to ignore the clear wishes of the public. However, it contributes little to the assisted dying debate.

It is well established that the vast majority of the public consistently support assisted dying (1) and that doctors hold a range of views on the issue (2). Whilst research on the views of the general public and of doctors is important, policy on the matter must be guided by the fundamental principle of patient choice and by evidence from relevant jurisdictions. If the BMA is serious about having an informed internal discussion then it must be more honest in its efforts to inform that discussion.

The BMA's in-principle opposition to date

The BMA acknowledges that one of its ambitions is for “the factual reality of physician-assisted dying” to be embedded in debates “so that the ‘in-principle’ debate becomes a discussion of the practical issues that need to be considered”. Unfortunately, the BMA’s “longstanding policy of opposition” to assisted dying, about which it has never surveyed its membership or the public, has severely limited its willingness to examine the evidence or ask the relevant questions.

Moreover, its active and misleading lobbying and briefing of parliamentarians - with the aim of defeating proposed assisted dying legislation as early in the parliamentary process as possible - has denied the medical profession and the public the very practical debate it claims to seek. For example, the BMA has briefed parliamentarians that it opposes assisted dying because “It would be unacceptable to put vulnerable people in a position where they felt that they had to consider precipitating the end of their lives” (3). This clearly ignores independent, robust and widely available evidence from Oregon demonstrating that potentially vulnerable groups are not adversely affected by legislation (4). It is disappointing that a professional body should choose policy-based evidence over evidence-based policy.

Exacerbating ‘misconceptions’ rather than limiting them

The BMA acknowledges in the report that “there was a lack of knowledge of certain aspects and much of the detail” on the process of assisted dying. In conducting the research the BMA looked to “limit misconceptions” for participants in the ‘dialogue events’ it commissioned. This was with the stated purpose of “inform[ing] our internal debate and discussion”.

However, the way in which the research has been conducted raises concerns about whether the BMA actually exacerbated rather than limited the misconceptions of participants. We therefore fear the BMA has not lived up to its ambitions and that the report’s conclusions will make only a minimal contribution to an informed debate and discussion.

Hypothetical laws rather than those proposed

The BMA ‘dialogue events’ focused on gathering views about hypothetical ‘assistance to die’ models. It chose to ask ‘what if’ questions, rather than seeking participants’ views specifically on the law recently debated in both the House of Lords and the House of Commons. This raises questions about the applicability of the observations that stem from the dialogue events.

Ensuring that the assisted dying model is robust and safe is a priority for **Dignity in Dying** and **HPAD** and it should be for the BMA, the public and parliamentarians. However, this requires direct engagement with evidence of how laws very similar to the law actually being proposed have worked in practice, rather than debate around hypothetical propositions and irrelevant legislation. The proposed law recently debated by both Houses of Parliament is based on assisted dying laws in Oregon, Washington and Vermont, albeit with additional safeguards including judicial oversight.

Distorted conversations about complications

In its report the BMA highlight concerns raised by participants, both doctors and patients, on medical complications of assisted dying in Oregon. We believe that a full and honest examination of medical complications in assisted deaths is important to ensure they are prevented or minimised. Disappointingly however, this is an area where instead of limiting the misconceptions of participants, the information provided by the BMA to participants may have significantly misled them.

In particular, the materials presented to participants placed disproportionate emphasis on the very small number of cases where people taking the life-ending medication experienced complications. Moreover, the information provided to participants on the length of time it took for patients to die seems intended to engender ‘shock’ amongst participants rather than clarity. In his analysis of the BMA findings, which was published by the BMJ, Dr Paul Teed highlighted some of the incomplete information provided to participants:

Participants were told that the time between ingestion and death ranges from one minute to 104 hours, which resulted in some being “shocked,” no doubt at the image of the long, protracted death they might fear; yet they were not told that the time between ingestion and unconsciousness is 1-38 minutes, which would have allayed such fears. They were told that 23 out of 530 people have experienced complications in the Oregon cases and that known complications in physician assisted dying include nausea and vomiting, seizures, and muscle spasms. They were not told that the only recorded complication from Oregon is “regurgitation” and, in fact, there are no records of anyone experiencing a seizure or muscle spasms in the 530 of 859 cases that Oregon has information on. This information is all publicly available.

Dr Paul Teed

Importantly, in wholly failing to address the laws actually proposed by parliamentarians in the UK, the BMA research failed to inform participants how some of these complications might be mitigated. For example, to specifically address the rare issue of medical complications the legislation most recently proposed in England and Wales stipulated that, unlike in Oregon, the care professional would deliver the life-ending medication in person and would then stay with the individual to ensure that the medical procedure is followed correctly.

The doctor-patient relationship: facts rather than feelings

Having ourselves conducted research on the impact on the doctor-patient relationship of assisted dying we welcome the fact that the BMA has also sought to explore this relationship. In a 2015 poll of 5,000 GB adults, 87% said that their trust in doctors to act in their best interests would not be negatively affected by a change in the law to allow assisted dying (1).

Although the BMA reported this finding in Volume 1 of its report, it is not acknowledged in their 'Reflections and Recommendations'. As this is the only piece of quantitative evidence on the impact of assisted dying on the doctor-patient relationship, the inclusion of this figure would have undoubtedly helped inform discussion and debate.

Despite being the primary focus of the research, the issue of the potential impact on the doctor-patient relationship is the area where the BMA provides the least hard evidence. Perversely, the research focused solely on what patients and doctors felt might positively or negatively affect the doctor-patient relationship rather than also exploring with participants how the relationship has been impacted positively or negatively as a result of law change elsewhere.

We recognise that the relationship between doctors and patients is complex, but exploring evidence from jurisdictions that have already introduced the kind of law proposed in this country is of critical importance. For example, since assisted dying was legalised in Oregon dying people more routinely raise end-of-life choices and care options, knowing that they can have honest discussions and plan for their future care (5).

Furthermore, Oregon is rated amongst the best states in the USA for the quality of palliative care (6). If the intention was to explore the doctor-patient relationship then this additional context and information is important.

Exploring new 'eligibility models' for assisted dying

We welcome the BMA exploring participants' views on different 'eligibility models' of assisted dying, i.e. who might be involved in assessing someone's eligibility. This is a valuable detail to explore and reveals the potential for the BMA to actively engage in the practicalities of the debate rather than rejecting outright any proposals that are made.

Were the BMA to explore 'eligibility models' further it should consider wider evidence that is available. Dignity in Dying have commissioned our own focus groups with doctors and nurses which indicated overall consensus that medical professionals should be central to the eligibility process and gave less support for medical professionals to sit entirely outside it (7). Participants of these focus groups also suggested the need for an independent person to oversee the process and that specialist expertise is available for assessing capacity and prognosis. This reflects the eligibility model proposed by and debated by Parliament most recently in September 2015.

Recommendations for an honest way forward

It was our hope that this research, commissioned by the BMA, would add significantly to the debate around assisted dying. We also hoped that it would mark a new open, transparent and honest approach by the BMA to the issue. Such an approach would see it engaging with the details of the actual laws proposed in the UK and with the full range of evidence available from relevant jurisdictions rather than hypothetical laws or evidence from non-comparable jurisdictions; bypassing this evidence has weakened the relevance of their research findings.

The BMA claims there is a lack of understanding of how a law would work and its report does little to address this. Inappropriate use of evidence and language has led to further ‘misconceptions’ about the impact of an assisted dying law – a finding, paradoxically, reported by the BMA - and has thus hindered rather than helped honest debate.

The recent adoption of assisted dying laws in jurisdictions such as California and Canada means that the question of assisted dying legislation in the UK is not going to go away.

The debate will continue and the BMA has a responsibility, to its members and to society as whole, to be part of that debate. In order to be able to contribute its undoubted expertise we urge the BMA to adopt an evidence-based policy.

The BMA needs to acknowledge the wealth of relevant information that already exists, the known wishes of patients and the diverse views of doctors. In order to be helpful to its members and their patients the BMA must move away from its longstanding in-principle opposition, which only reflects the views of a select group of the profession.

A **neutral** stance would enable effective participation in the debate, a debate that, critically, is of the utmost importance to **patients**.

1. Populus (2015), YouGov (2014)
2. Based on a number of surveys and polls, asking different questions: medeConnect (2015), medeConnect (2014), Medix (2014), Seale (2009) Legalisation of euthanasia or physician-assisted suicide: survey of doctor's attitudes Palliative Medicine 23: 205-12, Lee W, Price A, Rayner L and Hotopf M (2009) Survey of doctors' opinions of the legalisation of physician assisted suicide BMC Medical Ethics 10 (2)
3. <http://bma.org.uk/-/media/files/pdfs/working%20for%20change/policy%20and%20lobbying/pa-briefassisteddyingbill-16-01-2015.pdf>
4. Battin et al (2007) Legal physician assisted dying in Oregon and the Netherlands: evidence concerning the impact on patients in "vulnerable" groups J. Med. Ethics 2007; 33; 591-597
5. Tolle et al (2004) Characteristics and Proportion of Dying Oregonians Who Personally Consider Physician-Assisted Suicide The Journal of Clinical Ethics 15(2): 111-122
6. Morrison RS, Meier DE, Augustin R, Souvanna P (2015) America's Care of Serious Illness: A state-by-state Report Card on Access to Palliative Care in our Nation's Hospitals Joint publication by Centre to Advance Palliative Care and National Palliative Care Research Centre
7. YouGov/DiD (2016) Implementing the Assisted Dying Bill: findings from focus groups with doctors and nurses