# Parliamentary brief bma.org.uk



## **Assisted Dying**

## Terminally III Adults (End of Life) Bill Second Reading 29<sup>th</sup> November 2024

#### **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.

### **BMA** position on assisted dying

Policy position: The BMA represents doctors and medical students from across the UK who hold a wide range of views on physician-assisted dying. In September 2021, the BMA's annual policy-making conference (the Annual Representative Meeting (ARM)) voted to adopt a neutral position on whether the law should be changed to permit physician-assisted dying; this means that the BMA neither supports nor opposes a change in the law.

Most recently, the BMA's Medical Ethics Committee has undertaken a significant piece of work to determine how we can best protect and represent our members in response to legislative proposals to permit assisted dying. Within the context of our neutral position on whether the law should change, we have identified those issues that would significantly impact on doctors, if the law were to change, and considered what position the BMA should take on them. The views arising from this work have been approved by the four BMA Councils across the UK and are highlighted in this briefing.

Member survey: In October 2020, the BMA published the results of an all-member survey on physician-assisted dying. This piece of member research is one of the largest surveys of medical professional opinion on physician-assisted dying ever conducted. It provided invaluable insights into our wider membership's views on the matter, including our members' personal views about the law's position on assisted dying. It was one of a number of factors that informed the policy-making vote at our 2021 ARM and our Medical Ethics Committee's work on this topic.

## **BMA's neutral stance**

In September 2021, the BMA's Representative Body voted to change the BMA's policy on assisted dying. As such, the BMA is neutral on whether the law on assisted dying should change (including assisted dying with involvement from doctors). This means that we will neither support nor oppose attempts to change the law on assisted dying in the UK.

<sup>&</sup>lt;sup>1</sup> The survey was conducted on our behalf by Kantar, an independent research organisation. The results of our survey can be viewed here: <a href="www.bma.org.uk/advice-and-support/ethics/end-of-life/physician-assisted-dying/physician-assisted-dying-survey">www.bma.org.uk/advice-and-support/ethics/end-of-life/physician-assisted-dying/physician-assisted-dying-survey</a>



We will, however, represent our members' interests and concerns when considering mechanisms and provisions in legislative proposals that would have a significant impact on doctors, if the law were changed. This would include considerations such as doctors being able to choose whether or not to participate, the need for a robust legal and regulatory framework, formal oversight, collection of data, and clear guidance and emotional support for health professionals. These themes are explored in more detail in the following section.

## BMA's recent work - views to inform legislative proposals

The BMA's Medical Ethics Committee has <u>undertaken a significant piece of work</u> to determine how we can best protect and represent our members in response to legislative proposals to permit assisted dying. We have identified those issues that would significantly impact doctors if the law were to change, and considered what position the BMA should take on them.

In reaching a position on these issues, the BMA has sought to consider and balance four sets of interests:

- BMA members who would be willing to provide assisted dying if it were legalised;
- BMA members who, for whatever reasons, would not be willing to participate in assisted dying;
- patients who may wish to access a lawful assisted dying service; and
- patients who may feel anxious about the provision of such a service.

The views arising from this work have been approved by the four BMA Councils across the UK. They are listed here, with further detail on each point provided below.

If assisted dying were to be legalised in any part of the United Kingdom or the Crown Dependencies (Jersey, Guernsey and Isle of Man), the BMA would want to see legislation that gives doctors genuine choice about whether, and if so to what extent, they are willing to participate. In particular, the BMA would want to see:

#### 1. General approach

- an 'opt-in' model for doctors to provide assisted dying
- a right to refuse to carry out activities directly related to assisted dying, for any reason

## 2. Protection from discrimination and abuse

- statutory protection from discrimination
- provision for safe access zones

#### 3. Delivering an assisted dying service

- assisted dying arranged, but not necessarily delivered, as a separate service (e.g. through a network of doctors who are trained to provide the service)
- no duty to raise the issue of assisted dying with patients
- an official body to provide information for patients
- adequate funding and equitable access

#### 4. Oversight and regulation

- open and transparent regulation
- the collection and publication of data
- a review of all assisted deaths.



#### 1. General approach

## An 'opt-in' model for doctors to provide assisted dying

The BMA believes that any legislation to permit physician-assisted dying should be based on an 'opt-in' model, so that only those doctors who positively choose to participate are able to do so. Doctors who opt in to provide the service should also be able to choose which parts of the service they are willing to provide (e.g. assessing eligibility and/or prescribing for eligible patients).

The Bill: an opt-in model is not explicit in the Terminally III Adults (End of Life) Bill. However, only those doctors who meet the required training, qualifications, and experience would be able to participate<sup>2</sup>, and no doctor would be under any duty to participate<sup>3</sup>. Therefore, it is our understanding that it would only be those doctors who actively choose to do the training who would, in effect, be opting in to provide the service. If the Bill progresses, we would want it to be made explicit on the face of the Bill that this is an opt-in arrangement for doctors.

More specifically, we would also want its references to 'training' (which are to be specified in Regulations) to be more clearly defined in the Bill – our understanding is that this 'training' would be specialised training to provide assisted dying. If the Bill progresses, the specialised nature of the training should be referenced.

## A right to refuse to carry out activities directly related to assisted dying for any reason

Any legislation on assisted dying should not include a standard conscientious objection clause, as found in legislation on abortion and assisted reproduction. We are aware from our survey that some doctors do not oppose the legalisation of assisted dying but would not want to participate themselves – these doctors would not be covered by a conscientious objection clause. The BMA, therefore, believes that, if assisted dying were legalised, doctors should be able to refuse to carry out any activities that are directly related to assisted dying (such as assessing capacity, or determining life-expectancy specifically to assess eligibility for assisted dying) for any reason. As such, there should be a general right to refuse, which does not need to be based on matters of conscience.

The Bill: a right to refuse to carry out activities directly related to assisted dying, for any reason, appears to be covered in the Bill – no doctor is under any obligation to provide or assist an assisted death<sup>4</sup>; and no doctor would be under any duty to raise the subject of assisted death<sup>5</sup>.

There is, however, an inconsistency with the Bill's provision<sup>6</sup> that a doctor, who is unwilling or unable to conduct the preliminary discussion, must refer the patient to another doctor who would be willing to do so.

It is our view that the requirement on doctors should be to ensure that patients can access this information and discussion elsewhere, which could be, but does not need to be, another doctor. Therefore, if the Bill progresses, this provision should be revised to refer instead to the doctor's duty to direct patients to where they can obtain objective and accurate information, and have a preliminary discussion, about assisted dying. Later in the briefing, we suggest that this should be an official body set up to provide individual information and advice to patients, to which patients could be referred or directed to, or could self-refer.

<sup>&</sup>lt;sup>2</sup> See Clauses 5(3), 8(6), 19(2)(b)

<sup>&</sup>lt;sup>3</sup> See Clause 23(1)

<sup>&</sup>lt;sup>4</sup> See Clause 23 (1)

<sup>&</sup>lt;sup>5</sup> See Clause 9(1)

<sup>&</sup>lt;sup>6</sup> See Clause 4(5)



#### 2. Measures to protect doctors from discrimination and abuse

Through the work we have undertaken with our members, it is clear that some doctors are concerned about how their decision to participate, or not to participate, if physician-assisted dying were legalised, might impact on them both personally and professionally. For that reason, the BMA would want to see:

#### Statutory protection from discrimination

Specific provisions in the legislation making it unlawful to discriminate against, or cause detriment to, any doctor on the basis of their decision to either participate, or not participate, in assisted dying.

The Bill: there is a specific provision<sup>7</sup> stating that an employer must not subject an employee to detriment for deciding to, or not to, participate in assisted dying.

#### **Provision for safe access zones**

Provision for safe access zones that could be invoked, should the need arise, to protect staff and patients from harassment and/or abuse.

This is missing from the Bill. If the Bill progresses, we would like consideration to be given to adding a provision for safe access zones (to be invoked should the need arise).

## 3. Delivering an assisted dying service

The way in which any future assisted dying service would be delivered in practice would have a very significant impact on doctors. For that reason, if the law were to change, the BMA would want to see:

#### Assisted dying as a separate service

The BMA does not believe that assisted dying should be part of the standard role of doctors or integrated into existing care pathways – it is not something that a doctor can just add to their usual role. It is likely that most doctors would rarely receive such requests, making it difficult for them to build up the knowledge, experience, and confidence to provide the service to a high standard, which is what all patients would deserve.

Whilst it is not for the BMA to determine exactly how any assisted dying service should be delivered, our overarching view is that it should be provided as a separate service — using a network of specially trained doctors who have chosen to participate. It could be a professional network of doctors from across the country who come together to receive specialised training, guidance, and both practical and emotional support. Then they would provide the service within their own locality — for example, in the patient's usual hospital, or their home<sup>8</sup>. Or it could be a combination of some specialist centres and an outreach facility.

Doctors who wanted to assist their own patients, could do so provided they had received, or were willing to receive, the necessary training — but this would be arranged, and potentially managed, through the separate service. <sup>9</sup> The model proposed in Jersey, whereby the <u>Jersey Assisted Dying Service</u> would 'coordinate and deploy the professionals' who would provide the service, provides an example of how this could work.

<sup>&</sup>lt;sup>7</sup> See Clause 23(2)

<sup>&</sup>lt;sup>8</sup> A separate service does not necessarily mean separate from the NHS

<sup>&</sup>lt;sup>9</sup> The service would accept referrals from doctors and/or self-referrals



Having a network of doctors who have chosen to have the training in assisted dying, and coordinating the service through that network, would help to ensure consistent and high-quality care and facilitate oversight, research, and audit. It would also make it much easier for patients to find a doctor who would be willing to assist them, rather than risk patients having to approach multiple doctors before finding one who is willing, and has the training required, to help.

The Bill: there is nothing in the Bill itself about how an assisted dying service might be delivered, although the possibility of a separate service is mentioned in the explanatory notes.

#### There should be no duty to raise the issue of assisted dying with patients

The BMA would want to see specific provision in any legislation to make clear that there is no duty on doctors to raise assisted dying with patients, if it were legalised. This is necessary to avoid any suggestion that doctors have a legal duty to raise it. Doctors should be trusted to use their professional judgement to decide when and if a discussion about assisted dying would be appropriate, taking their cue from the patient as they do on all other issues.

The Bill: states that a doctor is not under a duty to raise assisted dying but not prohibited from doing so i.e. they can use their professional judgement.<sup>10</sup>

#### An official body to provide information for patients

We would support the establishment of an official body (with legal accountability) to provide factual information to patients about the range of options available to them, so that they can make informed decisions. As mentioned previously, this would ensure that doctors who did not wish, or did not feel confident, to provide information to patients about assisted dying had somewhere they could direct patients to, in the knowledge that they would receive accurate and objective information. It would also ensure that patients who may meet the eligibility criteria would be able to access the information they need without the requirement to go through their doctor and would have support to navigate the process.

The Bill: states that the relevant CMO must provide guidance and advice on the legislation, including for patients<sup>11</sup>. Whilst the Bill recognises the need for accurate, impartial information and advice for patients, it does not give any indication of how this might be delivered. The BMA believes that generic published information would not be sufficient – there would need to be an official service available to provide patients with individual advice, guidance, and support. Patients should be able to access this service directly or via a health professional.

## Adequate funding and equitable access

If Parliament decided to change the law on assisted dying, the Government would need to ensure that additional funds are made available so that the service is properly resourced, and that funding and workforce are not diverted from other, already overstretched, healthcare services. They would also need to ensure that, if assisted dying were legalised, it is available to all those who meet the eligibility criteria on an equitable basis.

The Bill: provision for funding is referenced in the explanatory notes – in terms of the scope of the Secretary of State's powers 'to ensure assistance is available' – but there is no mention of funding on the face of the Bill.

#### 4. Establishing proper oversight and regulation

<sup>&</sup>lt;sup>10</sup> See Clause 4(1) and (2)

<sup>&</sup>lt;sup>11</sup> See Clause 31

<sup>&</sup>lt;sup>12</sup> See explanatory notes on Clause 32



If the law changed to permit assisted dying, it would be essential that it was properly regulated with systems in place to ensure appropriate standard-setting, quality assurance, and to maintain confidence in the service. For that reason, the BMA would want to see:

## Open and transparent regulation

The BMA does not have a view on what form it should take but, if the law changed, we would strongly support the establishment of an independent and transparent system of oversight, monitoring, and regulation.

#### The collection and publication of data

To ensure openness and transparency, there should be a requirement for data about all assisted deaths to be collected centrally, and for aggregated data to be published on a regular basis.

The Bill: states that the Secretary of State may, by Regulations, specify the information that registered medical practitioners must provide to the relevant CMO about the 'notifiable events' listed in the Bill.<sup>13</sup> It also gives the relevant CMO responsibility for monitoring, and reporting on, the operation of the Act.<sup>14</sup>

Data collection and publication is essential for transparency and developing trust in the system. This should not be optional; the Bill should require (rather than permit) the Secretary of State to make these Regulations.

#### A detailed review of all assisted deaths

The BMA would support the introduction of a system for routinely reviewing all assisted deaths to ensure that the correct process was followed and to identify learning points to improve the management of cases. Review committees are common in countries that have legalised assisted dying.

Reviewing the details of individual deaths – including identifying the time from taking the drugs and death, and any complications or unforeseen circumstances that arose and how they were managed – can lead to improvements in how cases are managed from a medical perspective, and help to identify learning points for those delivering the service. It would also enable checks to be made in all cases to ensure that the proper process had been followed, and any necessary action taken if it has not been.

The Bill: whilst there is provision in the Bill for data collection and publication<sup>15</sup>, and for information to be recorded on the patient's medical record, there is no routine review of all assisted deaths by a specialist review committee, as happens in many other countries. If the Bill progresses, the BMA would want to see a process for the routine review of all assisted deaths added.

### Wider BMA work

Beyond the BMA's agreed policy, as outlined above, we have also conducted two pieces of work in recent years that were aimed at exploring our members' views on some aspects of physician-assisted dying:

- 1. our <u>all-member survey</u> (2020); and
- 2. our <u>ELCPAD</u> (end-of-life care and physician-assisted dying) dialogue events with doctors and members of the public (2015).

<sup>&</sup>lt;sup>13</sup> See Clause 33

<sup>&</sup>lt;sup>14</sup> See Clause 34

<sup>&</sup>lt;sup>15</sup> See Clause 33



For more information about the findings from our 2020 all-member survey, our 2015 ELCPAD project, or the BMA's position of neutrality on physician-assisted dying, please visit our website: <a href="www.bma.org.uk/PAD">www.bma.org.uk/PAD</a>

This web hub also contains a range of publicly accessible briefing materials we have developed for our members, including:

- Information about the law in the UK and how it was developed
- An overview of the law in jurisdictions internationally where physician-assisted dying is permitted
- An overview of recent surveys of medical and public opinion on physician-assisted dying
- BMA engagement and impact on legislative proposals across the UK and Crown Dependencies