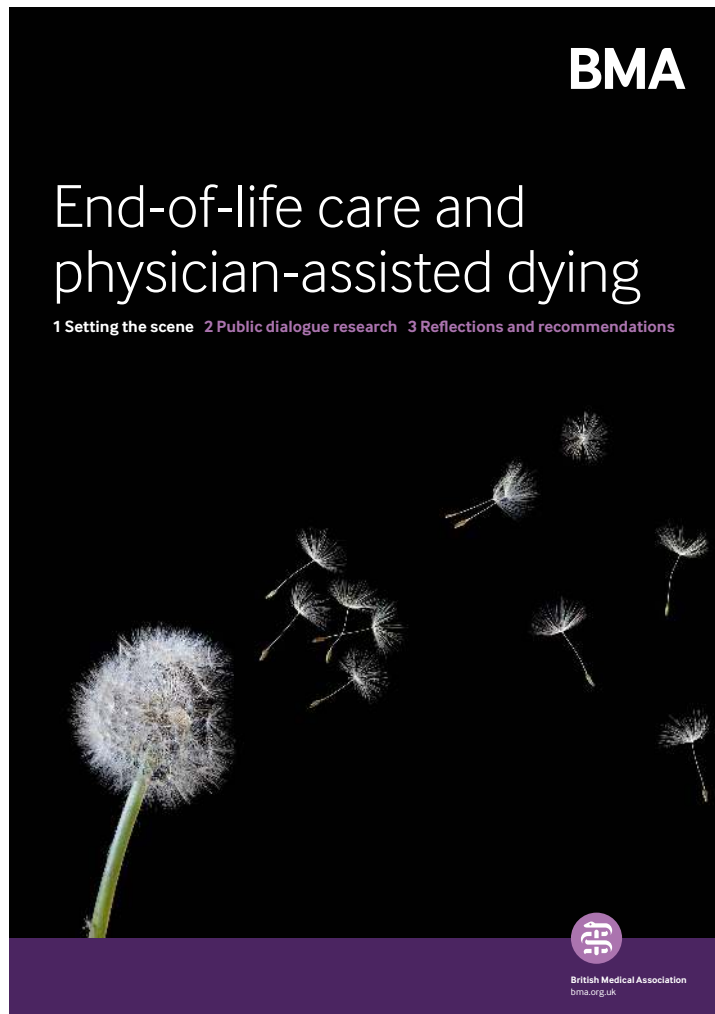


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End of Life Care and Physician-Assisted Dying

An analysis of criticisms of the project group's report



Living and Dying Well is a public policy research organisation established in 2010 to promote clear thinking on the end-of life debate and to explore the complexities surrounding 'assisted dying' and other end-of-life issues.

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INTRODUCTION

The BMA has published a report by a project group entitled “End of Life Care and Physician-Assisted Dying”. The ELCPAD Report (as we will refer to it hereafter) is divided into three sections. The first (‘Setting the Scene’) attempts to summarise evidence surrounding the two subjects of end-of-life care and physician-assisted dying. The second (‘Public Dialogue Research’) records views expressed in dialogue events around the UK involving 237 doctors and 269 members of the public. The third (‘Reflections and Recommendations’) explores a number of issues arising out of the previous two sections.

We had not intended to comment on the report. We do so now reluctantly because the campaigning group Dignity in Dying (DiD), which lobbies for a change in the law to license physician assistance with suicide, has published a negative and in our view unwarranted assessment of the report. We are therefore issuing this short paper to make clear our own view of the report and to correct various misconceptions in DiD’s assessment.

THE REPORT

There are some aspects of the report about which we ourselves have reservations. In particular, we would question whether licensing doctors to supply lethal drugs to terminally-ill people can properly be considered under the same heading as end-of-life care. While we recognise that some may see physician-assisted suicide as just another choice at the end of life, we consider there is a clear distinction between the *end-of-life* and the *ending-life* debates - a distinction which both the law and clinical ethics recognise.

On the other hand, the report contains many helpful recommendations to improve end-of-life care and to support doctors in this important part of their work and we consider that overall it provides a fair summary of the position on these two difficult subjects and makes a number of valuable observations. Certainly, it does not warrant the attack on it that DiD has launched and to which we now turn.

THE CRITICISMS

The greater part of the ELCPAD Report is concerned with examining the state of end-of-life care and making recommendations for improvement. Most, if not all,

of these - such as the need for better communication between health care staff and terminally-ill patients and their families and for better access to specialist palliative care expertise for hard-pressed doctors and nurses providing end-of-life care in community medicine - will command broad support. Yet this major and medically-important part of the report is ignored in DiD's assessment, which is concerned solely with the political issue of whether physician-assisted dying should be legalised.

PATIENT CHOICE

DiD states that BMA policy on legalisation of 'assisted dying' *"must be guided by the fundamental principle of patient choice and by evidence from relevant jurisdictions"*. There seems to be some confusion here between patient choice and patient consent. It is a fundamental principle of clinical practice that treatment must have the consent of the patient. Where possible, patients' wishes regarding treatment should also be met. That is not, however, the same thing as saying that treatment should be determined by what a patient requests. For example, doctors may refuse to supply antibiotics to patients if they consider they are unnecessary and that prescribing them would increase the risks of developing antibiotic resistance and thereby endangering the wider community. A surgeon may decline a request to perform an operation which in his or her view is unneeded or would be dangerous to the patient. Patient choice is an important aspect of clinical practice but it is not the sole consideration in determining treatment.

RELEVANT JURISDICTIONS

DiD asserts that the report has not been guided by *"evidence from relevant jurisdictions"* There is, in fact, an entire (34-page) chapter in the first volume of the ELCPAD report on 'International Evidence on Assisted Dying'. DiD's complaint seems to be that the review should have been restricted to those jurisdictions, such as Oregon, which have legislation similar to the physician-assisted suicide for which it has been lobbying in this country.

This view seeks to impose a narrow focus on the project team's work. The report states clearly at its outset that the term *'physician-assisted dying'*, which it had adopted, covered *'physician involvement in measures intentionally designed to terminate a patient's life'* and where administration of lethal drugs *'may be by the patient him or herself (physician-assisted suicide) or by the physician or another*

person (*euthanasia*)'. In other words, it covered the physician-assisted suicide seen in Oregon and the physician-administered euthanasia found in The Netherlands.

We ourselves have reservations over use of the term 'physician-assisted dying' in the report - because the acts envisaged are designed not to assist dying but to precipitate death. But, whatever view one might take on terminology, the definition adopted in the report requires a broad rather than a narrow review of the subject. The review was surely not conducted in order to validate one particular version of 'assisted dying' but rather to inform the BMA and the public of the picture as a whole.

PUBLIC DIALOGUE

The ELCPAD study included 21 public dialogue events (10 with members of the public and 11 with doctors) in ten geographic locations across the UK. Over 500 people participated in these events and the results are summarised in Part 2 of the report. The objectives, as one might expect from research conducted on behalf of the BMA, were focused on clinical-related issues, including patients' attitudes to death and dying, perceptions of end-of-life care, the potential impact of legalising 'assisted dying' on the doctor-patient relationship and the implications of such legislation for doctors.

DiD has criticised this public dialogue research because *"it chose to ask 'what if' questions rather than seeking participants' views on the law as recently debated in both the House of Lords and the House of Commons"*. Here again we see the misconception that the purpose of engaging in dialogue with doctors and the public was to seek their views on a particular set of proposals - proposals, it should be noted, which were rejected last September by Parliament - rather than to get a feel for professional and public perceptions of the dying process, of the care available to support it and of the implications of introducing legislation to hasten the deaths of seriously-ill people.

DiD states that it commissioned its own focus groups, though these had a narrower focus and fewer participants - there were two online groups containing in total 20 doctors or nurses. Participants were given material in advance, including a copy of last year's DiD-sponsored Assisted Dying Bill and a summary of data from Oregon, and they were asked to concentrate on the "mechanics" of such a law. According to DiD, *"both groups contained only participants who were moderately*

supportive, neutral or moderately opposed in principle to assisted dying". This, we are told, would ensure *"that a measured debate about the detail of what was proposed, rather than the principle of it, took place"*.

It seems a remarkable suggestion that the principles involved in 'assisted dying' should be ignored and that the debate should be restricted to the detail. There are important social, ethical and clinical questions involved here - not the least of them being whether doctors should involve themselves in deliberately bringing about the deaths of some of their patients. Such issues of principle cannot just be brushed aside.

That aside, two of the issues which were raised with DiD's focus groups deserve mention here. One is the question of who should be responsible for assessing eligibility for 'assisted dying'. DiD records the overall view of those who took part in its focus groups that *"medical professionals should be central to the eligibility process"*. In other words, if ever Parliament were to legalise 'assisted dying', it must be part of clinical practice.

The other is the suggestion that the BMA's policy of opposition to legalisation does not reflect the range of opinion of its members. This brings us to what is DiD's main theme - that the BMA should abandon its opposition to legalisation of 'assisted dying' and switch to a position of neutrality.

BMA POLICY

DiD states that *"the BMA must move away from its long-standing in-principle opposition"* to physician-assisted suicide and adopt a neutral stance in the debate. It claims that *"a neutral stance would enable effective participation in the debate"*. The implication of this claim is that the BMA cannot give serious consideration to whether the law should be changed until it has abandoned its policy in the matter.

In fact, the BMA has made a significant contribution to the debate on this issue with its year-long ELCPAD study - a study in which known protagonists on both sides of the 'assisted dying' debate participated. The report may not have produced the outcome which perhaps DiD hoped it would, but it is undeniable that the project group has examined the subject in some depth. It is not clear to us why only those who have no position in the matter of 'assisted dying' should be seen as qualified to engage with the debate. After all, DiD itself can hardly be regarded as neutral.

The argument that the BMA is incapable of addressing 'assisted dying' effectively because it has a policy in the matter simply will not fly.

DiD's reference to the BMA's "*long-standing in-principle opposition*" implies that the Association has not considered the practical issues involved in legislation. This is not so. Both the debates which have taken place at successive Annual Representative Meetings and the ELCPAD study itself have addressed issues of practicality as well as those of principle.

A common argument for neutrality that is often heard is that the question of whether the law should be changed is a matter for society as a whole, not for the medical profession. This argument might perhaps carry more weight if what was being proposed was the legalisation of assisted suicide. But it is not: what DiD is proposing is the legalisation of *physician-assisted* suicide. Indeed, it reinforces the point, stating that its own small focus groups believed that "*doctor involvement is crucial*".

Yet many, if not most, of the factors involved in such decision-making are social rather than clinical in nature. How is a doctor to know, for example, whether a request for assisted suicide stems from a settled intent rather than being a response to depression or despair? How is a doctor to know whether there are any family or other pressures at work in the background of such a request? These are crucial considerations in any decision-making process but they deal with issues which, in today's world of multi-partner practices and fewer home visits, are beyond the first-hand knowledge of many, if not most, busy doctors working in community medicine or on hospital wards. Indeed, some of the responses from DiD's own focus groups drew attention to the burden which proper consideration of requests for 'assisted dying' would place on hard-pressed doctors.

If doctors are to have these responsibilities placed on them, it is only right that they should be able to express a view in the matter. Surveys of medical opinion indicate that the majority of doctors have serious reservations over legalising 'assisted dying' and that few would be willing to participate in any such regime. Of course there are some who take a different view. In any professional body differences of opinion on individual issues are inevitable. But that is no reason why the BMA should stand back and wash its hands of an issue which goes to heart of clinical practice - whether doctors should involve themselves in deliberately bringing about the deaths of some of their patients.

DiD says that the BMA has not surveyed its membership. Perhaps it should - that is not for us to say. But, if it does so, it should be to establish what the majority of its members think, not to provide a vehicle for sectional lobbying. This means there would need to be transparent wording and a minimum threshold of participation set to prevent activists (on either side of the debate) distorting the result.

CONCLUSION

The project team has taken on a difficult task in examining the state of end-of-life care and the issues surrounding legalisation of physician-assisted dying. We have our own reservations on some aspects of the report. Overall, however, we believe the project team has produced a valuable report which deserves broad support.

We consider that the criticisms made by the lobby group DiD, in which the BMA is accused of lack of honesty, of by-passing evidence and of hindering rather than helping debate, are unwarranted. These criticisms may be motivated by the group's disappointment that the study has not produced conclusions which are conducive to its political agenda. That was not, however, why the study was commissioned and we believe the report has broadly succeeded in striking a reasonable balance between polarised views.

On the question of neutrality, the lobbyists for legalisation of 'assisted dying' cannot have it both ways. If they insist, as they do, that doctors should carry the heavy burden of responsibility for examining requests for assisted suicide, for deciding who should and should not qualify and for supplying lethal drugs, they must allow them, through their representative body, to have a voice in whether or not such acts should be legalised. It is a question of 'no decision about me without me'.

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