

How should palliative care respond to increasing legislation for assisted dying?

Assisted dying is a contentious issue. Debates about it continue predominantly in the popular press, public discourse and within governments across the world. Assisted dying is the umbrella term that incorporates euthanasia and some forms of physician assisted dying. Euthanasia is where a doctor administers a lethal injection whereas in physician assisted dying the physician may be required to assess the patient as competent, terminally ill and provide a prescription for a lethal concoction that the patient self-administers. There is a changing picture in relation to legislation but broadly speaking euthanasia and physician assisted dying are legal in Belgium, the Netherlands, Luxemburg and most of Canada (except Quebec where they only legalised euthanasia). In various US states and Victoria in Australia some form of physician assisted death is legal. In Switzerland, legislation from the 1940's permits someone to assist in a death if they do not profit from it. When doctors assist, they are acting in this way almost as a civil act. Rates of euthanasia are increasing where it is legal, whereas rates of physician assisted dying tend to remain lower especially in countries where euthanasia is also legal (1,2).

Palliative care clinicians and researchers tend to react to media coverage of public stories and increasingly parliamentary debates, rather than proactively shaping the debates. Expert opinion by palliative care clinicians and researchers is proffered, however, there is greater scepticism about the opinions of 'experts' in general and the role of all experts in society is being challenged in a greater way than ever before (3).

One high profile story in Italy involves the DJ Fabiano Antoniani who was paralysed in a car crash, and was given assistance to go to Dignitas in Switzerland. This led to a parliamentary debate on whether assisted dying, including euthanasia, should be legalised in Italy. The judiciary could not decide whether the person who has assisted him should be tried, and took the decision that this needed to be decided in parliament rather than the courts. The Italian parliament has until September 2019 to decide whether to legalise euthanasia and assisted dying (4). In Italy, as in many countries, there is growing support for assisted dying legalisation that mirrors support across Europe (5). With such popular support there might be a greater likelihood that the assisted dying legislation will be passed in Italy, because the ruling party, the Five Star Movement, is seen as a populist group in support of populist causes (3). It is unclear how much this worldwide increase in legislation for assisted dying is as a response to popular views.

Growing popular support puts most palliative care organisations and practitioners at odds with this movement. In 2014 and 2019 the Royal College of Physicians (RCP) in the UK conducted a survey about whether their members thought there should be a change in the law on assisted dying but also whether the RCP should support such a stance (6). In 2019, ahead of the vote, the RCP stated that any change in stance of the RCP in relation to assisted dying would require a 60% majority. There was little change from the 2014 results in the 2019 survey with a 60% majority either way not reached, so the RCP now have a neutral stance in relation to assisted dying. When asked if individually physicians supported a change in the law, those in favour increased from 32.3% to 40.5% with a similar percentage fall in those opposed. Most of those surveyed were not from specialist palliative care, but many will be providing generalist palliative care and are often the key person to provide assistance in dying if legalised.

There are a range of opinions within palliative care related to assisted dying, which are summed up well by the paper in this edition of Palliative Medicine by Blaschke. They interviewed 16 health professionals in Australia about their views on assisted dying (7). The interviews took place during the lead up to the legislation to legalise assisted dying in Victoria. They found an uneasy relationship

between the two predominant positions of seeing life as 'inherently valuable and meaningful regardless of the amount of suffering involved' and 'the right to personal autonomy and control over how one wishes to die'. However, their interviews also showed that 'safe and compassionate care for the dying person' unified both sides of the debate. This unifying stance may be the way forward as more palliative care practitioners find themselves working in areas which permit assisted dying. A follow up study to see if views change post legalisation will be interesting once such legislation has bedded in.

Whilst most palliative care organisations worldwide support the EAPC White Paper (8) and International Association for Hospice and Palliative care (9) opposing assisted dying, the support is not unanimous (10). Countries such as Belgium, the Netherlands and Luxembourg have managed to assimilate assisted dying legalisation into their palliative care services (8). In these countries, there is full involvement of medical teams in the legal processes but this is not the case in all countries that permit assisted dying. In Switzerland, assisted dying is largely a civil rather than medical act. The Swiss Academy of Medical Sciences offers some guidance on how doctors should proceed but doctors feel they are often acting in a legal vacuum (11). Indeed Swiss palliative care doctors generally do not want to be involved in any part of the act including referring their own patients to right to die organisations. Many doctors in the Benelux countries who do assist in a death feel they are supporting the patient's right to choose. However, even if they agree with this right and do not conscientiously object, they can struggle with the actual process and decide they need to minimise the number of procedures they carry out or move to facilities where this might be less common for their own self-preservation (12).

So if you are working in an area where assisted dying is legalised or becomes legalised what would palliative care clinicians' responses be? The response of many palliative care practitioners may be to conscientiously object and opt out of any involvement. However, at what point does opting out begin? If a patient brings up the subject of assisted dying does the practitioner opt out at this point? If they do then they may fail to provide 'safe and compassionate care for the dying person' (5).

The paper by Porta-Sales (2019) in this edition raises whether we should facilitate patients to discuss whether they have considered hastening their death. When this was initiated through a semi-structured interview they found that 98% of their participants reported no distress in talking about and exploring whether they considered hastening their death (13). Allowing people the chance to have these conversations may be uncomfortable but may even prevent a hastened death in the same way talking about suicide reduces such attempts. However, they also found that for the 22% of patients who had considered hastening their deaths most had not spoken about this to anyone. Palliative care interventions aim to address psychological and spiritual care needs so surely we should be open to such conversations and indeed initiate them perhaps using the tool they suggest. If we fail to explore patients' anxieties and discuss them, we are potentially offering our patients a disservice. If we do not address these concerns then we need to explore why we do not do so? We need to consider how to maintain a patient's autonomy and this may include directing them to someone who is more comfortable to have this conversation. They suggest that conversations with palliative care doctors will instead be a protracted discussion of palliative care options, which in itself may act as a barrier to gaining an assisted death.

The debate in palliative care rarely moves much beyond whether assisted dying is right or wrong and for some reading this that may be true for you too. However, an increasing number of countries are making the decision to legalise. We need more research to inform the debate. We do not understand why rates of euthanasia increase but physician assisted deaths remain lower. We need greater clarity on what the experience is of raising the wish to hasten death with clinicians from the

patient and the family perspective. The wider impact on families and society has relatively little research. Ultimately, society will decide whom to elect and who will then decide what to legislate. Palliative care needs a voice at the table.

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