



living and dying well

Clear thinking on the end-of-life debate

TRUE COST? or TRUE FACTS?

An evidence-based analysis of suggestions that
assistance with suicide should be legalised in Britain



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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EXECUTIVE SUMMARY

Dignity in Dying (DiD) - known before 2005 as the Voluntary Euthanasia Society - has published a document entitled 'The True Cost' and sub-headed 'How the UK outsources death to Dignitas'. It consists largely of quotations from nineteen interviews with people who had contacted DiD. It also features the results of DiD-sponsored opinion polling.

The document's main theme is that some seriously ill people travel to Switzerland seeking assistance with suicide and that, as this can involve stress and unhappiness, the law in Britain should be changed to license such assistance here. In reality, the incidence of such deaths in Switzerland is very small - 47 out of 597,211 UK deaths in 2016. By contrast, an assisted suicide law, based on actual death rates under Oregon's law, would have resulted in just under 2,000 assisted suicides.

The document alleges that doctors shut down discussions with patients who raise the subject of assisted suicide for fear of legal consequences. In fact, doctors have clear guidance from the General Medical Council on handling such conversations sympathetically and with understanding.

It claims that the USA, Canada, Australia and several European countries "*have grasped the nettle of assisted dying*". In the USA only six out of 50 States, in Australia only one out of six States and only three out of 28 EU Members have enacted such laws. 'Assisted dying' proposals have been rejected in many jurisdictions.

The authors of the document claim to see no difference between a doctor withdrawing life-sustaining treatment at a patient's request, which is lawful, and a doctor supplying lethal drugs for suicide. The distinction is a real one and it is clear to doctors, as to most people.

The document claims that in the absence of an assisted suicide law terminally ill people are taking matters into their own hands and committing suicide. The evidence provided for this claim is thin, but in any case it begs the question: is legalising assistance with suicide rather than giving better support to terminally ill people the right response?

The end-of-life debate is a complex one calling for careful and rigorous analysis of robust evidence. The DiD document does not meet this requirement.

INTRODUCTION

In November 2017 the campaigning group Dignity in Dying (DiD)¹ published a document entitled 'The True Cost', which claimed that the UK "*outsources death to Dignitas*" (a Switzerland-based provider of legal assistance with suicide). It suggested that British law should be changed to license doctors to assist the suicides of patients here. The document was based on nineteen interviews with people who had contacted DiD in connection with journeys or possible journeys to the Dignitas assisted suicide facility in Switzerland. It also included results of opinion polling which DiD itself had sponsored.

In the paragraphs which follow we draw attention to some of the errors and misconceptions in the document. As what is being proposed is a major change in the law, we begin with an explanation of what the existing law says, why it says it and how it is applied.

THE LAW

The law in England and Wales² is clear: it is a criminal offence to encourage or assist another person's suicide. The law accords with public perceptions of suicide - that, while people who attempt to take their own lives should be treated with understanding and compassion, suicide is not something to be encouraged or assisted. This is the principle that underlies 'suicide watches' for individuals thought to be at risk of self-harm and the suicide prevention strategies that successive governments have introduced - with some success.

However, the law recognises that there could be exceptional situations where acts of assistance with suicide may not need to be prosecuted. It therefore provides³ that no prosecution may be undertaken without the consent of the Director of Public Prosecutions (DPP). Such prosecutorial discretion is a common feature of the criminal law. An act may be illegal but the circumstances in which it was performed may be such that prosecution is not an appropriate response. In 2010 the then DPP published guidance⁴ setting out the process by which prosecuting decisions are reached in cases of encouraging or assisting suicide and listing some of the mitigating or aggravating factors taken into account in reaching such decisions.

The incidence of cases of assisting suicide is very small: around 20 cases a year throughout

1 Known until 2005 as the Voluntary Euthanasia Society.

2 Suicide Act 1961. The Act does not apply to Scotland but in Scottish law assistance with suicide could incur a charge of culpable homicide.

3 Suicide Act 1961. Section 2(4).

4 Policy for Prosecutors in Respect of Cases of Encouraging or Assisting Suicides, Crown Prosecution Service, February 2010.

England and Wales cross the desk of the DPP. Prosecutions are rare: there has been one in the last ten years. This is not because, as some suggest, the authorities are unwilling to prosecute. It is because the existing law, with its prohibition of assisted suicide and the significant penalties it holds in reserve, makes anyone minded to engage in such acts think very carefully before doing so. Consequently, the incidence of the offence is small and the few cases that do occur are generally ones where there has been serious soul-searching, genuinely compassionate motivation and much reluctance.

What campaigners for 'assisted dying' want is that this system of prohibition combined with prosecutorial discretion be replaced with a regime in which assistance with suicide is licensed in advance for certain groups of people. Parliament has repeatedly rejected such proposals, most recently in September 2015 by a very large majority⁵.

MISCONCEPTIONS

The DiD document contains a number of misconceptions and misleading statements. Here we highlight some of them.

International Comparisons

In his Foreword to the document Kit Malthouse MP confidently tells his readers that the USA, Canada, Australia and several European countries have "*grasped the nettle of assisted dying*". This statement is seriously adrift from the facts. In the USA only six out of 50 States have legalised 'assisted dying'. Only three out of 28 EU Member States have enacted such laws. Only one of Australia's six states (Victoria) has passed such legislation: two others (South Australia and New South Wales) have recently rejected it. The reality is that only a small minority of jurisdictions around the world have seen fit to go down the 'assisted dying' road. Many have rejected such calls.

It is interesting that the document should describe the legislation in Canada and in The Netherlands, Belgium and Luxembourg as 'assisted dying'. DiD has been emphatic hitherto that the 'assisted dying' for which it is campaigning is limited to physician-assisted suicide (PAS), - ie the supply by a doctor of lethal drugs to a patient for self-administration. But the legislation in Canada and the three continental European jurisdictions provides for physician-administered euthanasia (PAE), whereby a doctor injects lethal drugs directly into a patient. Where PAE has been legalised, it has resulted in high death rates. In The Netherlands, for example, 1 in 25 of all deaths in 2016 was the result of PAS or PAE (largely the latter). Those laws are also showing themselves vulnerable to increasingly elastic interpretation. If these practices are considered to fall

⁵ House of Commons Hansard, 11 September 2015, Vol.599, Cols 656-727.

within the ambit of the term 'assisted dying', it is fair to ask: has the campaigning agenda here in Britain been widened?

Suicides

The document attempts to argue that the cases of assisted suicide seen by the DPP do not tell the whole story. It states that *"terminally ill people are taking measures into their own hands by attempting to end their lives in unenviable circumstances"*. This statement is based on a handful of responses from Directors of Public Health in England to a Freedom of Information Request by DiD in 2014. Only 6 out of 139 authorities approached identified terminal illness in their data on suicides. Extrapolating from this small sample DiD has calculated that approximately 7 per cent of suicides in England involved a terminal illness, amounting to about 300 deaths annually.

The document acknowledges that the circumstances of such suicides are unknown. It is impossible, therefore, to know whether any of those who ended their lives would have met the other criteria for legalised assisted suicide which DiD believes should be part of an 'assisted dying' law - for example, whether they had mental capacity or were under pressure of any kind. In any case, what is at issue here is not suicide but assistance with suicide. There is no evidence to suggest that DiD's notional 300 suicides of terminally ill people involved encouragement or assistance.

People commit suicide for many reasons and it is certainly possible that a diagnosis of terminal illness could be a factor in some attempts. There is research⁶ indicating that the incidence of suicide attempts is higher in the period immediately following diagnosis but declines thereafter. There is also research⁷ indicating that legalisation of assisted suicide does not reduce overall suicide rates. Whatever the position, it surely points to a need for terminally ill people to receive better support - medical, psychological and social - rather than that they should be given help to take their own lives. However well-intentioned 'assisted dying' legislation may be, in effect it divides society into people whose suicides we should try to prevent and others (the seriously ill) whose suicides we should see it as appropriate to facilitate.

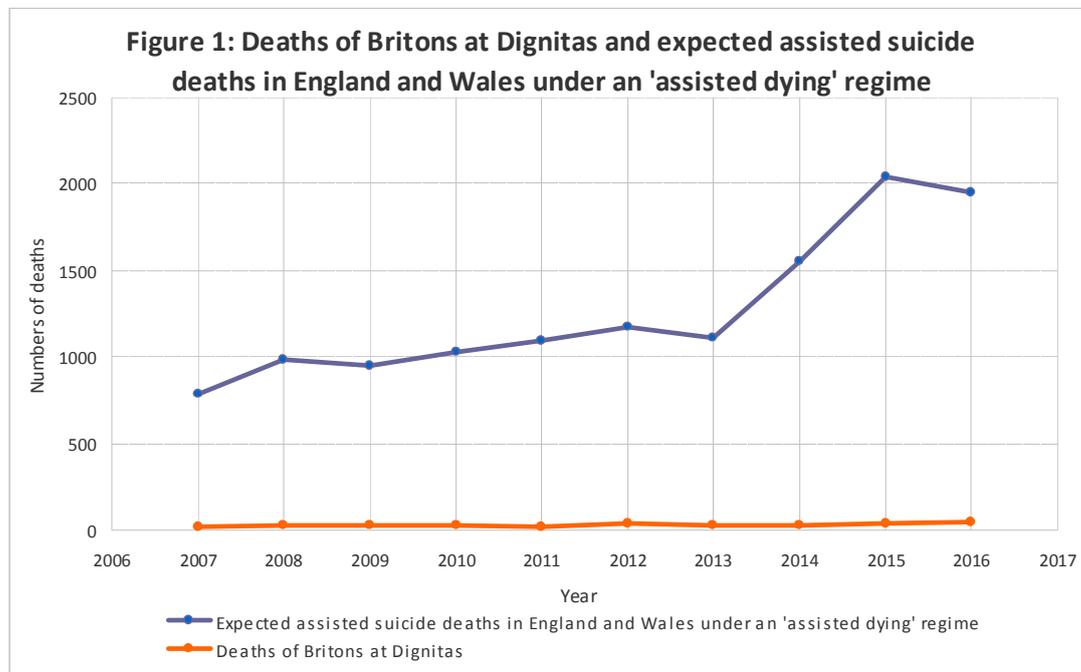
Numbers

DiD's document includes a graph showing the numbers of British people who have ended their lives in recent years at the Dignitas assisted suicide facility in Switzerland.

6 Bolton JM, Walld R, Chateau D, Finlayson G, Sareen J 'Risk of suicide and suicide attempts associated with physical disorders: a population-based, balancing score-matched analysis', *Psychological Medicine* (2015) 45, 495-504

7 Jones, DA and Paton, D, 'How does legalization of physician-assisted suicide affect rates of suicide?' *Southern Medical Journal*, Volume 108, Number 10, October 2015

Figure 1 below shows the same data alongside the numbers of people in England and Wales who would have taken their own lives in each of the last ten years if Oregon’s assisted suicide law had been in operation here. It takes officially-published annual death rates from legalised assisted suicide in Oregon and applies these to the numbers of deaths in England and Wales in each year.



Oregon’s assisted suicide law is the model for ‘assisted dying’ campaigners here in Britain. Figure 1 shows what lies behind the door of legalisation. In England and Wales we would have been looking, not at 47 assisted suicides of Britons in 2016, but at just under 2,000. The DiD document tells readers that in 2016, on average, one person went to Dignitas for assisted suicide every eight days. Based on Oregon’s experience, with an assisted suicide law there would be, on average, between five and six such deaths in England and Wales every day. Deaths of Britons at Dignitas represented 0.008 per cent of total UK deaths in 2016. To say this is not to make light of these deaths. Every death, from whatever cause and in whatever manner, is a matter for sober reflection and respect. But it is important to see the picture in its proper perspective. It is misleading to claim that *“many people seek to arrange an assisted death in Switzerland, with organisations such as Dignitas”*.

There is a reason why legalisation of assisted suicide leads to increases in the numbers of such deaths. Laws are more than just regulatory instruments: they send social messages. An assisted suicide law sends the message, however unintended, that if we are seriously ill taking our own lives is a course of action that it is appropriate to consider. It is a delusion to suppose that changing the law to license an act reproduces the status quo in legal form: in reality it changes the dynamic.

Withdrawing Treatment

A patient has a right to refuse life-sustaining treatment and, unless a doctor has reason to believe that the request stems from a misunderstanding or is not being freely made, he or she must comply. Where treatment is withdrawn, a doctor has a duty of care to ensure that the dying process is without distress. DiD's document suggests that there is no difference between such a situation and a request from a patient for assisted suicide. It quotes from an account of a patient with motor neurone disease who asked for ventilation to be withdrawn. It acknowledges that the withdrawal of ventilation *"was effective, controlled and facilitated the death she wanted"* and it argues that this is comparable to assisted suicide.

In reality, the two situations are completely different. Neither in law nor in medical ethics does a request to withdraw life-sustaining treatment constitute suicide. A patient who makes such a request is, literally, exercising a right to die - accepting death rather than seeking death. A doctor who complies with a request to withdraw treatment may know that this is likely to lead to the patient's death, but he or she is not acting with that intent. By contrast, a request for assistance with suicide is just that: it is a request to a doctor to take action with the specific intent of ending a patient's life. Intent is a crucial element of medical ethics. DiD may perhaps see *"blurred lines between seeking an assisted death and refusing treatment"*, but the distinction is clear to those who have to administer the law or to practice medicine. It is also, we would suggest, comprehensible to most reasonable people.

Discussions with Doctors

The document states that *"without a clear and transparent law on assisted dying, doctors and other healthcare professionals often feel unable to have open and honest end-of-life conversations with dying people"* and that this is *"a major barrier to the delivery of the Government's commitments to improving end-of life care"*. There seems to be some confusion in the document between end-of-life and ending-life discussions. The same confusion is apparent in its reference to the 2015 Review of Choice in End of Life Care and the importance this placed on open and informed dialogue between dying people and their care teams. The review was concerned with end-of-life care, not with assisting suicide.

The document quotes statements from some of its interviewees to the effect that doctors whom they approached in connection with a wish for assistance with suicide were unwilling to engage in such discussions. Assisting suicide is unlawful and doctors, like the rest of us, are required to obey the law. This does not mean they should turn

their backs on patients who raise the subject. The General Medical Council (GMC)⁸ has provided guidance to doctors on how they should respond to patients who raise the issue of assistance with suicide. The DiD document refers briefly to the GMC's guidance but claims that it *"is not providing doctors with enough clarity to be able to respond effectively to requests for assistance in obtaining an assisted death overseas"*. It is instructive, therefore, to see what the guidance has to say on this issue.

The GMC makes clear that doctors must *"listen to patients and respect their views about their health"* and *"create opportunities for patients to raise concerns and fears about the progression of their disease and about their death and to express their wishes"*. Where a patient raises the subject of assisted suicide or seeks information that might assist them to end their lives, doctors should *"be prepared to listen and to discuss the reasons for the patient's request"* and should *"limit any advice or information about suicide to an explanation that it is a criminal offence to encourage or assist a person to commit or attempt suicide"*.

Throughout such discussions, the GMC guidance says, doctors should:

"be respectful and compassionate and continue to provide appropriate care for the patient;

"explore the patient's understanding of their current condition and care plan;

"assess whether the patient has any unmet palliative care needs, including pain and symptom management, psychological, social or spiritual support".

The DiD document talks of a *"lack of clarity in the current law for healthcare professionals"*. Yet it is difficult to see how the legal position could be clearer.

It is impossible to know how much weight to place on the anecdotal statements recorded in the DiD document without knowing the details of the cases or what requests were made and in what circumstances. If some doctors handle such discussions insensitively, that is a matter for regret. Doctors, like the rest of us, differ in their inter-personal skills. Given that the majority of doctors have serious reservations about legalising assistance with suicide, it is hardly surprising if some of them treat such discussions with caution.

It is not, in fact, uncommon for seriously ill patients to raise fears about dying with their doctors and even to talk of 'ending it all' and, very occasionally, to ask for assistance to do so. How a doctor responds to such a conversation is very important. A good

8 'When a patient seeks advice or information about assistance to die'. GMC 31 January 2013

doctor will do as the GMC guidance requires. However, it is important to remember that seriously ill patients often look to their doctors for guidance and reassurance as well as for treatment. A doctor who agrees to engage with assistance with suicide risks sending the message, however unintended, that in the patient's situation death is a best-interests course of action.

Opinion Polling

The document quotes the results of opinion polling which DiD itself commissioned. The reader is not told what information was given to respondents, how the questions were sequenced or in what terms they were phrased and what other (unreported) responses were given. Yet such information is essential to a proper understanding of the results of opinion polling. The sequencing and phraseology of opinion polling questions can affect the views that respondents offer.

The question of whether assisted suicide should be legalised is a complex one. It transcends many fields including medicine, the law, mental health, ethics, society, disability and the experience of similar laws in jurisdictions overseas. Most of us lead busy lives and, whether we care to admit it or not, our knowledge of complex issues outside our immediate experience is to a large extent influenced by what we have read in newspapers and heard or seen on radio and television. Media presentation of the 'assisted dying' debate tends to focus on exceptional events (for example, a death at Dignitas) and to ignore normality, such as the hundreds of thousands of people who die naturally and peacefully every year in the UK. What happens to most of us for most of the time just isn't news.

It is hardly surprising, therefore, that opinion polling produces the results that it does. By contrast, when such polls are addressed to those with most first-hand experience of serious illness and dying, a very different picture emerges. For example, a 2015 poll of 1,000 GPs⁹ revealed that only 14 per cent (one in seven) of respondents would be willing to participate in any legalised assisted suicide regime. The DiD document states that "*some palliative care professionals oppose assisted dying*". This is a considerable under-statement. A recent review of its membership by the Association for Palliative Medicine, the body of doctors who specialise in care of the dying, found that 82 per cent were opposed to a change in the law and that 96 per cent would be unwilling to participate in 'assisted dying' if it were to be legalised.

Opinion polling supported going to war in 1914 and appeasement in the 1930s. Today it can be found supporting other controversial issues, such as bringing back capital

9 Medeconnect, May 2015.

punishment. To say this is not to dismiss opinion polling but to caution against accepting at face value simple Yes-or-No answers to complex questions, especially when the polls have been commissioned by groups with a vested interest in the outcome.

End of Life Care

The document acknowledges that care at the end of life has been judged to be of higher quality in Britain than in other nations. This is hardly surprising. The UK was the founder of the modern hospice movement and palliative care has been a recognised clinical specialism here for the last 30 years, longer than in any other country. In addition to community-based end-of-life care provided by GPs and District Nurses, specialist palliative care to address more challenging conditions is available in hospices and in specialist palliative medicine departments of major hospitals. In those jurisdictions where 'assisted dying' in one form or another has been legalised palliative care is in a less advanced state.

The document also acknowledges that *"the majority of people who die in the UK will not suffer pain at the end of their lives"*. However, it quotes the ONS's National Bereavement Survey that, according to bereaved relatives, 1.4 per cent of hospice patients did not receive effective pain relief and that 12 per cent received only partial pain relief. Palliative care is not a panacea: no branch of medicine is that. However, it is indisputable that painful deaths today are much rarer than was the case a decade or so ago. Modern analgesia is a sophisticated science and in the right hands it can bring substantial relief to the pain of dying.

The document quotes from accounts of interviewees of three distressing deaths of loved ones. It is impossible to comment meaningfully on these stories. Serious medical audit requires full possession of the facts and careful analysis of treatments given. This information is not available from the document. What can be said, based on specialist examination of the information provided, is that what is described in the document raises a number of questions and is not what would normally be expected in such cases. Without knowing all the facts, it is not possible to say how these situations might have been ameliorated or averted.

The accounts of suffering, as presented in the DiD document, are distressing. However, there is a need for caution against drawing the unwarranted conclusion that these are normal and everyday deaths. As DiD itself concedes, pain is well-controlled for most dying people. The availability of specialist palliative care can vary from one area of the country to another, but this is an anomaly that can be corrected with better funding and better resource allocation within health care. It does not constitute grounds for changing the law.

In fact, in the small number of jurisdictions where assisted suicide has been legalised, inadequate pain control or fear of it comes well down the list of reasons given by those who take their own lives. The top two reasons given are (to quote from the latest official report from the US State of Oregon) *“losing autonomy”* and being *“less able to engage in activities making life enjoyable”*. These are entirely understandable feelings in people with serious illnesses, but they are a far cry from the depiction of agonising deaths which features in much of the campaigning for assisted suicide.

DISCUSSION

Mr Malthouse writes of people travelling to Switzerland to seek *“a dignified death”* and of *“the horror for those who can’t get there”*. These words say much about the campaigning for legalisation of assisted suicide. They equate a dignified death with a self-inflicted death and they promote fear among vulnerable people that without legalised assisted suicide they are at risk of a horrifying death. Mr Malthouse suggests that the cases cited in the document *“offer only a glimpse of what is a deep well of anguish”*. He declares that *“it’s impossible to know how many people in my constituency have taken their own lives at home, traumatically, without the support of their doctors”*. He tells us that *“it is certain that many more have suffered the misery of an agonising and protracted death”*. Yet he offers no evidence to support these assertions.

Similarly, we are told that existing laws *“discourage proper conversations between patients and their doctors”*. They do nothing of the sort. There is nothing to prevent doctors engaging in discussion with patients who say they want help to end their lives. The only thing they may not do is encourage or assist a patient’s suicide. Most people would agree that it is not a proper role of doctors to aid and abet the suicides of patients. Doctors do, after all, have a key role to play in suicide prevention.

The document describes three deaths of persons who did not go to Switzerland for assistance with suicide. It states that *“the suffering of the individuals in these cases could have been prevented if assisted dying were legal in the UK”*. That surely depends on whether the persons concerned would have met all the criteria for any regime of legalised assisted suicide. In any case, unless DiD has in mind an assisted suicide law with wider parameters than it has so far proposed, legalisation would not halt journeys to Switzerland. Dignitas does not, for example, require a diagnosis of terminal illness or a prognosis of six months or less as a condition for assistance with suicide. In recent years we have seen such assistance given in Switzerland to Britons who were blind or tetraplegic or worried about how a diagnosed condition would develop.

There is a tendency in the ‘assisted dying’ lobby to see assistance with suicide as just

another 'choice' at the end of life and to overlook that what some may see as a choice others can see as a burden. As a specialist in end of life care put it to the Mackay Committee in 2005, if 'assisted dying' were to be legalised, seriously ill patients *"for the rest of their lives would be faced with this enduring choice as to whether they should 'go for' assisted suicide and euthanasia on the grounds that they have become a burden to their families because they perceive that they are useless"*¹⁰. It may be that some individuals are clear that they want assistance to take their own lives and feel frustrated by the law's prohibition of such acts. However, those who care for seriously ill people day in and day out are all too aware that there are many more who are anxious about how their illness will develop, worried about the stresses it is placing on those around them and struggling, perhaps for the first time in their lives, to come to terms with their mortality. These are not the resolute people who step out of the pages of campaigning literature, but they are highly vulnerable to the subtle 'to die or not to die' messaging of an assisted suicide law.

The document asserts that *"those who claim the current law is safe have no reliable evidence on which to base their claim"*. This is a remarkable reversal of the burden of proof. Those who wish to change the law must demonstrate that it can be done safely and without putting vulnerable people at risk of harm. They have not done that. If the law were being widely disregarded or oppressively enforced, there might possibly be a case for changing it. But that is not so. As observed above, the existing law holds penalties in reserve sufficient to make anyone minded to assist a suicide think very carefully before doing so and be sure that their motives and actions will withstand scrutiny. It is hardly surprising therefore that the authors of the document say they found *"no evidence of coercion or pressure placed upon people assisted to die in Switzerland"* and that *"those accompanying them were not motivated by anything other than compassion"*. But that is no guide to the dynamics of a law licensing assisted suicide. Under such a law the only risk that a malicious or manipulative assister would have to face is the possibility that the request would be turned down.

The existing law has the discretion to show compassion where such assistance has been reluctant and has derived from genuinely altruistic motives. Breaches of the law are infrequent and prosecutions are rare. The document observes that *"the majority of interviewees were not interviewed by the police when they returned from Switzerland"*, from which it draws the conclusion that *"the law has not been implemented as intended"*. Yet it also complains that some people were interviewed and that *"this resulted in anger at the implication of being involved in a crime"*. Without knowing the circumstances of each case we are not, as an evidence-based body, able to draw conclusions as to why the police interviewed some persons and not others. But it does seem that in the eyes

10 House of Lords Report 86-II (Session 2004-05), Page 554.

of the document's authors the police are (as the saying goes) damned if they do and damned if they don't.

CONCLUSION

What DiD is suggesting is that the law should be changed to license doctors to supply lethal drugs to seriously ill people with the intention that they should use those drugs to take their own lives. Such a law would run counter to the legal prohibition of intentional killing, to the ethical principles that underpin medical practice and to suicide prevention policies. It is without doubt a serious matter.

Parliament, at both Westminster and Holyrood, has examined and debated this subject in depth on many occasions over recent years and concluded that the evidence, including the emerging experience of those jurisdictions which have gone down the 'assisted dying' road, does not justify changing the existing law. The exception to the Swiss criminal code which permits non-self-serving assistance with suicide dates back to 1942: it was not intended specifically as an avenue for assisting the suicides of seriously ill people. However, that such legal permissions exist in Switzerland is not a sufficiently valid reason to change the law here in Britain. The existing law may not suit everyone's wishes - no law does that. But it is there to protect vulnerable people from harm. The DiD document provides no credible evidence that it is in need of change.

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