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Clear thinking on the end-of-life debate

OREGON TWENTY YEARS OF PHYSICIAN-ASSISTED SUICIDE LOOKING AT THE EVIDENCE



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

A booklet circulated recently in Parliament by the campaigning group Dignity in Dying (DiD) describes Oregon's Death with Dignity Act (DWDA) after twenty years of existence. The DWDA allows doctors to supply lethal drugs to terminally ill patients who are thought to meet certain criteria. It is the model advocated by the 'assisted dying' lobby for legislation in Britain. Here we examine the booklet's claim that the DWDA is "*a safe and effective assisted dying law*".

It has recently come to light that the DWDA's definition of terminal illness can include not only illnesses where the patient is unavoidably dying but also chronic and treatable conditions - for example, insulin-dependent diabetes - which will become terminal if no treatment or medication is given to manage or retard them. Research has also revealed that some patients with undiagnosed clinical depression have used legally-supplied lethal drugs to end their lives without referral for specialist assessment.

Whether a request for lethal drugs can be judged truly voluntary depends on how well the assessing doctor knows the patient and what inquiries he or she has made. Yet many requests for lethal drugs are considered and decided on by doctors who have not met the patient before and the DWDA requires no minimum inquiries to be made by a doctor assessing a request.

There is no provision under the DWDA for independent and qualitative examination of how requests for lethal drugs are being handled by those considering them. Official reports do, however, raise some worrying concerns. They raise the question whether some doctors may not be waiting the minimum time required by the law before approving requests for assisted suicide and supplying lethal drugs. They also show that few doctors are present when lethal drugs are ingested by the recipient, which can be weeks or months after prescription. There is therefore no reliable means of ensuring that no pressures or influences have been brought to bear in the meantime.

These and other concerns make it difficult to see how the booklet can legitimately claim that Oregon's 'assisted dying' law is "*thoroughly monitored and controlled by stringent eligibility and qualification processes*" and represents "*safe and trusted medical practice*".

INTRODUCTION

The campaigning group Dignity in Dying (DiD) has published a short booklet entitled 'Assisted Dying in Oregon'. It tells the reader that "*Oregon has had a safe and effective assisted dying law for 20 years*" and that "*upfront safeguards protect the public and prevent coercion*". In this report we examine these and other claims made in the booklet and assess their reliability.

However, before doing so, a word of caution is needed. The DiD booklet seems to assume that the case for legalising what it calls 'assisted dying' has been made and accepted and that the debate is about whether Oregon's law (the model for DiD's campaigning) would fit the bill in Britain. This is a misconception.

There are two questions, not one, in the 'assisted dying' debate. The first is whether the existing law prohibiting assistance with suicide should be changed so as to license doctors to supply lethal drugs to some of their patients. Campaigners for legalisation, both in England and Wales and in Scotland, have signally failed, most recently in 2015, to persuade their legislators that that is the case. Only if that question can be answered in the affirmative is it appropriate to proceed to the second-order question of what such a law might be. The same cart-before-the-horse approach was seen in May 2018 when Guernsey's legislators were asked - and declined - to commission work to devise an 'assisted dying' law for the Bailiwick without any exploration of whether the law should be changed.

We have prepared this report in order to address various claims made in DiD's booklet about Oregon's 'assisted dying' legislation. It is important, however, that our analysis should be seen for what it is - an examination of a second-order question - and that it should not distract attention from the primary question of whether the law should be changed. This is too important a question to be placed in the too-difficult tray.

OREGON'S LAW

Oregon's 'Death with Dignity Act' (DWDA) came into force in 1997. It permits a doctor to prescribe or supply lethal drugs to a person who "*has a terminal disease, is capable, and has made the request voluntarily*"¹. These judgements must be made by the doctor who is approached and agrees to consider the request (known as the 'attending physician') and endorsed by a second doctor (known as the 'consulting physician'). A doctor may decline to consider a request, in which event the patient may look around for a willing

1 Oregon Death with Dignity Act, Oregon Revised Statutes 127.815, Section 3.01

doctor or may approach an advocacy organisation for a referral to a doctor known to be willing.

A request must take the form of two oral requests, separated by a minimum of 15 days, and a written request. Where a request is approved, the attending doctor may prescribe or supply lethal drugs. The recipient is free to take these drugs away and to use, or not to use, them as he or she decides: about 30 per cent of lethal drugs supplied are not used. Where the drugs are ingested, the act may take place weeks, months or (in some cases) a year or more after receipt.

The lethal drugs must be self-administered. There is no requirement for the prescribing doctor to be present when they are ingested. A doctor who approves a request and prescribes or supplies lethal drugs is required to report the fact to the Oregon Health Authority (OHA).

COMPLIANCE WITH THE LAW

DiD claims in its booklet that in Oregon *“assisted dying is thoroughly monitored and controlled by stringent eligibility and qualification processes, mandatory state reporting by the medical team, as well as medical board oversight and justice department investigatory power when appropriate”*. In the paragraphs which follow we examine this claim under a series of headings.

Terminal Illness

The DWDA requires, as one of the conditions for supply of lethal drugs, that an applicant has been diagnosed as terminally ill. It defines terminal illness as *“an incurable and irreversible disease that has been medically confirmed and will, within reasonable medical judgement, produce death within six months”*².

It has recently come to light that this definition of terminal illness is not as restricted as might appear at first sight. In 2017 Fabian Stahle, a Swedish researcher, contacted the OHA and asked whether, under the DWDA, the criterion of terminal illness, with a prognosis of six months or less, assumes that there will be no treatment given to manage or retard the patient’s condition. According to Mr Stahle, the OHA’s response was to confirm that that was so³. It would seem possible therefore to qualify under Oregon’s law as being terminally ill not only in a situation where a person is facing an unavoidable death within six months but also where someone has a chronic but treatable condition from which he or she will die within six months without medication or treatment. So, for

² Oregon Death with Dignity Act, Oregon Revised Statutes 127.800, Section 1.01(12)

³ <https://drive.google.com/file/d/1xOZfLFrvuQcazZfFudEncp2b18NrUo/view>

example, a person with insulin-dependent diabetes could be considered to be terminally ill and qualify under the DWDA by declining or discontinuing the medication needed to manage the condition.

This potentially-broader scope of Oregon's law is implicitly acknowledged in the DID booklet, which accepts that chronic as well as terminal illnesses may qualify under the DWDA if death is likely to result within six months *"with or without treatment"*. However, the OHA's reported admission has implications for the terminology used by campaigning groups in Britain, who have argued that the manufactured term 'assisted dying' is justifiable (in place of the legally-correct term 'assisted suicide') as it involves the supply of lethal drugs solely to people who are embarked on an irreversible trajectory to death. Yet it is clear that Oregon's law, which these groups advocate as a model for legislation here, is open also to people whose early death is not inevitable and could be prevented or postponed by medication or treatment.

There is, of course, no law against refusing treatment. But a patient's exercise of a right to die by declining further treatment does not include a right to receive lethal drugs for the purpose. It may be that this possible interpretation of 'terminal illness' was not considered or intended when the DWDA was enacted. Whether or not that is so, it is difficult to regard the law as containing *"stringent eligibility and qualification processes"*.

Capacity

Few would disagree with the principle that, whether or not 'assisted dying' should be legalised, it should certainly not be available to people who lack capacity to make the decision. The DWDA requires that an applicant for lethal drugs must be 'capable'. It defines this term as *"the ability to make and communicate health care decisions to health care providers"*⁴.

Having capacity is, however, about more than having intact mental faculties and an ability to communicate decisions. It also encompasses freedom from circumstances, such as (for example) depression, which have the potential to influence or impair judgement. The DWDA recognises this. It states that *"if in the opinion of the attending physician or the consulting physician a patient may be suffering from a psychiatric or psychological disorder or depression causing impaired judgment, either physician shall refer the patient for counseling"*⁵. Is this happening in practice?

A respected and impartial study has raised doubts on this score. It examined a group of 58 seriously-ill Oregonians who had expressed an interest in ending their lives under the

4 Oregon Death with Dignity Act, Oregon Revised Statutes, 127.800, Section 1(01)(3)

5 Oregon Death with Dignity Act, Oregon Revised Statutes, 127.825, Section 3.03

DWDA and it employed professional assessment tools to determine levels of depression or anxiety among them. By the end of the study 42 of the participants had died. 18 of them had received a prescription for lethal drugs under the DWDA. 15 of these did not meet the researchers' criteria for depression: three did. All three used the prescribed drugs to end their lives. None had been referred for specialist assessment as required by the DWDA.

The report of the study concluded that *"most patients who request aid in dying do not have a depressive disorder. However, the current practice of the Death with Dignity Act in Oregon may not adequately protect all mentally ill patients"*⁶. Writing in 2014 the study's lead author, Oregon Professor of Psychiatry Linda Ganzini, believed that *"this finding supports the need for more active and systematic screening and surveillance for depression to determine which patients should be referred for mental health evaluation"* but that *"despite this finding the proportion of Oregon and Washington PAD⁷ decedents referred for mental health evaluation has remained very low and critics have called for mandatory mental health evaluation in all cases"*⁸.

The DiD booklet's dismissive remark that *"a level of sadness is normal for dying people"* is wholly inadequate as a response. Depression, which can range from sadness through to clinical depression, has the potential to distort judgement, even in people whose mental faculties are intact. Moreover, capacity is decision-specific: the more serious the decision, the greater the level of assurance required. There can be little doubt that a decision to take one's own life lies at the top end of any spectrum of gravity. Against this background it is difficult to understand why specialist capacity assessment is not a mandatory part of the process for receiving lethal drugs in Oregon and why the authors of the booklet feel able to describe the DWDA as *"a safe and trusted medical practice"*.

Voluntary Request

The DWDA requires that a request for lethal drugs should be made voluntarily. While this is an obvious requirement, its fulfilment is not as simple as might appear at first sight. The ability of a doctor to detect whether a request for lethal drugs may not be entirely voluntary but may stem from internal or external pressures or influences depends to a large extent on how well he or she knows the patient, how many discussions of the request have taken place and what, if any, independent inquiries have been conducted.

The DWDA lays down no minimum requirements in this respect. It does not require a doctor considering a request to have known a requesting patient for any minimum

6 Prevalence of depression and anxiety in patients requesting physicians' aid in dying: cross section survey, Linda Ganzini, Elizabeth R Goy Steven K Dobscha, BMJ 2008;337:a1682

7 PAD = Physician Aid in Dying

8 Legalised physician-assisted death in Oregon, Ganzini Linda, QUT Law Review, Volume 16 Issue 1, pp76-83

length of time and it leaves the level of scrutiny to be applied to a request for lethal drugs to the assessing doctor's discretion. In the words of the OHA report on Calendar Year 2017, *"it is up to the attending and consulting physicians to determine whether these requirements have been met"*⁹

A doctor who has prescribed lethal drugs is required to report the fact to the OHA and to answer a number of questions by ticking a series of boxes. The doctor is required to confirm, among other things, that the recipient of the drugs was judged to be terminally ill with a prognosis of six months or less and that he or she had capacity and was acting voluntarily. Individual doctors may perhaps discuss requests in depth with those who make them and conduct searching inquiries to try and discover whether there are any internal or external pressures behind the request. But there is no requirement on them to deal with a request in that way.

Recipients of lethal drugs in Oregon sometimes store those drugs for weeks or months before ingesting them. It is fair to argue, as supporters of 'assisted dying' often do, that this could be seen by recipients as an insurance policy of sorts - a comforting feeling that there is a way out if a terminal illness should become too much to bear. However, it also raises the question: what assurance is there that pressures have not been brought to bear to ingest the lethal drugs since they were prescribed and that the decision to ingest them is wholly voluntary? The DWDA does not require the prescribing doctor to be present when the lethal drugs are swallowed - only 1 in 6 was present in 2017 - and there is no requirement to confirm that the patient is not being pressured in any way or that he or she retains decision-making capacity. However vulnerable terminally ill people in Oregon may be before seeking lethal drugs, some may become more vulnerable once they have received them.

A fundamental issue here is that the DWDA makes no provision for independent and qualitative post-event scrutiny of how requests for lethal drugs are being handled. As noted above, doctors who prescribe such drugs have to report the fact and to answer a series of questions. But the tick-box approach that is involved is a far cry from the sort of post-event scrutiny which exists in (for example) The Netherlands and which allows for each death from euthanasia or assisted suicide to be reviewed by a body constituted for the purpose and for judgements to be made of the quality of the assessment process. The rigour of the Dutch system is, it must be said, open to question, but the machinery does at least exist and is able to shed some light on how requests for hastened death are being handled by those who are making these life-or-death decisions.

9 Oregon Death with Dignity Act, 2017 Data Summary, Oregon Health Authority February 9 2018

When the Mackay Committee visited Oregon in 2004 as part of its inquiry into the late Lord Joffe's Assisted Dying for the Terminally Ill Bill, it was told by the Oregon Department of Human Services (which was then exercising the role now performed by the OHA) that *"we are not a regulatory body"* and that its role, if there were apparent discrepancies in reports from doctors, was to notify the Oregon Medical Board (the equivalent of the UK's General Medical Council)¹⁰. The Oregon Medical Board, when questioned about this by the committee, stated that it did not *"go out specifically to monitor any particular issue with physicians. We react only to complaints received"* and that *"there may be instances where there are problems, but if they are not brought to our attention there is no way for us to investigate them. In any area of medical practice, we do not go out and affirmatively go looking for trouble, so to speak"*¹¹.

VULNERABILITY

The booklet states that *"research demonstrates that groups of potentially vulnerable people are not negatively impacted"* by the DWDA. The research referred to is a study¹², the results of which were published in 2007 and which concluded that it *"found no evidence to justify the grave and important concern often expressed about the potential for abuse - namely, the fear that legalised physician-assisted dying will target the vulnerable or pose the greatest risk to people in vulnerable groups"*. Closer inspection, however, raises questions about the study's methodology.

For example, it found that *"persons aged 18-64 years were over three times more likely than those over age 85 years to receive assisted dying"*. On this basis it concluded that there was *"no evidence of heightened risk"* from Oregon's law to elderly people. However, this finding took no account of people aged between 65 and 84, a group whom most people would regard as elderly. This is an inexplicable omission, as the official annual reports show that people in the 65-84 age group account for nearly two thirds of those who have ended their lives under the DWDA since 1997. If they are included, a rather different picture emerges.

Or, again, the study concluded that, as women were not more likely than men to resort to physician-assisted suicide, they too were not at heightened risk; and that, as requests for assisted suicide originated more frequently from people with health insurance or with high educational attainment, there was no heightened risk to the poor or to people of low educational status.

10 House of Lords Report 86-II (Session 2004-05), Page 257

11 House of Lords Report 86-II (Session 2004-05), Page 323

12 Legal physician-assisted dying in Oregon and the Netherlands: evidence concerning the impact on patients in 'vulnerable' groups. Battin, MP et al, Journal of Medical Ethics 2007; 33: 591-597

These conclusions may well be valid but their relevance is open to question. As was pointed out in an article¹³ reviewing the results of the research, vulnerability in end-of-life decision-making is more related to such things as temperament, communicative difficulties, personal problems, unrelieved symptoms or loss of self-worth than to traditional socio-economic factors such as gender, income or race. While these latter can be helpful points of reference in studies of such matters as education, employment or housing, their relevance is questionable in the context of 'assisted dying' and the DWDA.

The official annual reports issued by the OHA list various concerns which had been raised by people who have ended their lives under the DWDA. One of these concerns is (to use the words in the reports) 'being a burden on family, friends/caregivers'. Over the 20-year period of the DWDA's existence this concern was cited by 43.7 per cent of those who died under the DWDA as a reason for seeking a hastened death. Accordingly, the DiD booklet talks of "*fewer than half of those who make use of the law*" citing this concern.

In fact, the annual reports suggest that this factor may be rising up the scale. In 2014 the figure was 40 per cent, whereas in 2017 it was 55 per cent. The proportions can vary from year to year and the last few years may possibly represent something of a spike. But, if around half of people who end their lives with lethal drugs say that one of the reasons for doing so is a desire not to be a burden on those around them, that must surely provide uncomfortable reading for anyone concerned about the vulnerability of terminally ill people.

DOCTORS

The booklet states that "*most people [who make requests under the DWDA] are able to stay with their existing medical team or health care system when going through the process*". It is not clear what is meant by the phrase 'stay with their existing medical team'. It may be that a patient seeking lethal drugs under the DWDA may remain under the medical care of his or her regular doctor while asking a different practitioner to consider and decide on the request. What matters is that the doctor examining the request and making the decision to supply lethal drugs should have had first-hand knowledge of the patient over a period of time and be familiar with his or her thinking and concerns.

The OHA reports do not suggest that this is happening. In 2017, for example, there were significantly more prescriptions for lethal drugs written than there were doctors

13 Legal physician-assisted suicide in Oregon and The Netherlands: evidence concerning the impact on patients in vulnerable groups - another perspective on Oregon's data, Finlay, I and George, R, *Journal of Medical Ethics* 2011; 37:171-174

writing them. On average, according to the OHA's 2017 report, every doctor who wrote a prescription for lethal drugs did so at least twice, and one doctor wrote no fewer than 29 prescriptions for lethal drugs. The report also records that the median length of the doctor-patient relationship of those who died in 2017 by ingesting prescribed lethal drugs was just ten weeks within a range of one week to 41 years. Just how many consultations were at the lower and upper ends of this spectrum is not disclosed, but it is clear that some of these doctor-patient relationships were very short.

Lord Falconer's self-styled 'commission on assisted dying' drew attention to this problem in its 2012 report, which quoted the advocacy organisation Compassion of Choices of Oregon that *"we are the ones that make sure that a prescribing doctor can be found and a consulting doctor, and if a psychiatrist is needed then we know from experience people who have filled those roles"*¹⁴. The DiD booklet disparages the term 'doctor shopping' but it is an indisputable fact that people seeking lethal drugs under the DWDA often have to shop around to find a willing doctor.

In 2014 Ganzini reported that after 17 years of the DWDA only one in three doctors in Oregon was willing¹⁵. With only one in seven British GPs¹⁶ and less than five per cent of doctors who specialise in end-of-life care¹⁷ saying they would be willing to participate in legalised 'assisted dying', we could expect a similar situation here in Britain if ever the law were to be changed to license such practices.

EXTENSION OF THE LAW

The booklet states that attempts to widen the scope of the DWDA have been *"steadfastly opposed by supporters of the assisted dying law"*. It does not disclose the reason for this opposition. The reference quoted in the booklet reveals that supporters of the DWDA have opposed extension of the law because they are concerned that it *"would send the wrong message to lawmakers considering similar laws in other states"*¹⁸.

Though the DWDA has not been formally extended to date, the pressures are continuing and it would be naive to suppose that they will cease. In March 2017 Oregon State Legislature Bill SB893 proposed that, if a person had received a prescription for lethal drugs under the DWDA but had subsequently lost capacity, it should be open to another (designated) person to collect and administer those drugs. To the best of our knowledge this proposal remains before the Legislature.

14 Report of the Commission on Assisted Dying, Demos, Page 151

15 Palliative Care and Ethics, Ed Quill TE and Miller FG, OUP 2014, Page 270

16 Medeconnect survey of 1,000 UK GPs, May 2015

17 Survey of membership by the Association for Palliative Medicine 2014

18 Oregon Live, 3 March 2015, http://www.oregonlive.com/mapes/index.ssf/2015/03/bill_to_expand_oregons_death_w.html

PALLIATIVE CARE

The booklet states that over 90 per cent of those who take their own their lives under the DWDA are “enrolled in hospice care”. It is important to understand what this phrase means. Most hospice care in Oregon is home-based care, with patients being visited by doctors and nurses with training in palliative care. Hospice-at-home services exist in Britain, but they are a supplement to a nationwide network of in-patient and out-patient hospices and to specialist palliative medicine teams.

Oregon has only recently recognised palliative care as a specialism of medicine. The Mackay Committee was told during its visit to Oregon that enactment of the DWDA was “in some ways a vote of no confidence about some aspects of end of life care in Oregon”¹⁹. Britain is not, and never has been, in this position. Britain was the founder of the modern hospice movement. Palliative care was developed here as a recognised medical speciality thirty years ago. It is little wonder that the UK ranks first in international surveys of quality of end of life care.

CONVERSATIONS

The booklet states that “when healthcare professionals can respond openly to requests for a peaceful death, the likelihood of successfully addressing fears or reasons behind the request is much greater than when people are deterred by the law from expressing their concerns and wishes”. There is nothing in UK law preventing patients initiating or doctors responding to requests for a peaceful death. Such conversations take place commonly and openly. The only thing doctors may not do is encourage or assist patients to take their own lives, a limitation that most people would applaud. The notion that assisting the suicides of terminally ill people is needed in order to allow open conversations about the end of life is nonsense.

CONCLUSION

The booklet, understandably given its origins, sees Oregon’s experience of legalised ‘assisted dying’ through rose-tinted spectacles. However, as will be clear, there are real problems with the DWDA, not the least of them being a lack of transparency and scrutiny in the system. The OHA’s annual reports provide valuable and interesting statistical data but they tell us little of how requests for lethal drugs are being handled in practice or of what happens to those drugs once they have been supplied or of the circumstances in which they are swallowed.

19 House of Lords Report 86-II (Session 2004-05), Page 281

The annual reports do, however, raise some questions. To qualify for receipt of lethal drugs under the DWDA an applicant must make two oral requests and a written request. The two oral requests must be separated by at least 15 days. The OHA's latest report records that over the 20 years of the DWDA's existence the range of time between a first request and death was between 14 and 1,009 days. It is not clear from these data whether in some cases lethal drugs may have been supplied before the minimum waiting period has expired. The discrepancy is, admittedly, small but it needs to be seen against the background of what is a very short minimum period of personal reflection over a decision of the utmost gravity.

The DWDA allows doctors to prescribe or supply lethal drugs to patients to take home and store, often for weeks or months, and permits those drugs to be swallowed without any responsible medical oversight or any confirmation that the conditions on which they were issued continue to apply. It is difficult to see how such an arrangement can be described as *"a safe and trusted medical practice"*.

These realities, together with recent admissions (referred to above) concerning the interpretation of 'terminal illness', cast serious doubt on the claim in the booklet that *"assisted dying is thoroughly monitored and controlled by stringent eligibility and qualification processes"*.

The numbers of deaths annually under the DWDA are, as a proportion of all deaths in the State, small. But they are rising year by year - the annual number of deaths is now nine times what it was when the DWDA was introduced. The 2017 death rate is the equivalent of some 2,000 assisted suicide deaths annually in England and Wales if there were to be a similar law here.

The booklet quotes approving comments of the DWDA from persons professing a religious faith. The relevance of these comments is not clear. While some may argue that their faith disposes them either to support or to oppose legalisation of 'assisted dying', this is not in essence a religious question. It is possible to construct respectable faith-based cases to support both sides of the debate. Whether doctors should be licensed by law to supply lethal drugs to some of their patients is essentially a social question. It is about whether giving rights to some to receive lethal drugs with which to take their own lives can be reconciled with giving protection to more vulnerable people.

It is also a matter of social messaging. Laws are more than just regulatory instruments. They send social messages. An 'assisted dying' law sends the message, however unintended, that if we are terminally ill taking our own lives is an appropriate course of action. These are questions for everyone, with or without a religious faith, to consider.

True dignity in dying (as distinct from the slogan) requires an understanding of the wider end-of-life situation. This includes such issues as how we care for an ageing society where patterns of declining health can be more complex than was once the case; whether dying has become too medicalised and unfamiliar - and perhaps on that account more feared; how the pressures on terminally ill people can be alleviated, especially when local health services may be over-stretched and family support less readily available; and how we can give people nearing the end of their lives the dignity, kindness, comfort and care they deserve. These are serious and complex issues calling for careful and sensitive thought rather than the quick-fix of licensing doctors to supply terminally ill people with lethal drugs with which to take their own lives.

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