Living and Dying Well

Keeping the law safe for sick and disabled people

Parliament needs evidence, not soundbites or spin

Claims that legalising 'assisted dying' would be safe do not stand up to careful analysis

By Professor Baroness Finlay of Llandaff and Lord Carlile of Berriew QC

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Both Baroness Finlay and Lord Carlile were members of the House of Lords select committee which examined Lord Joffe's Assisted Dying for the Terminally Ill Bill in 2004-05.

Living and Dying Well is a public policy research organisation established in 2010 to promote careful analysis of the issues surrounding 'assisted dying' – the current euphemism for physician-assisted suicide. Living and Dying Well takes the view, based on the evidence, that legalisation of 'assisted dying' would pose serious risks to public safety and that debate needs to focus on rigorous analysis of the evidence rather than on campaigning spin.

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Introduction

In a recent letter to Members of Parliament Dignity in Dying[1] (DiD), the campaigning group for legalisation of physician-assisted suicide, stated that "*the central question is whether we can change the law safely*"[2]. This has always been Living and Dying Well's view of the matter and we are pleased to see it is now shared by the campaigners. Sadly, the proposals for legalisation they are commending to Parliament do not live up to this prospectus, and the arguments put forward to support them do not stand up to careful scrutiny.

Living and Dying Well does not normally engage in rebuttals of what the campaigning organisations have to say. Our role is primarily one of researching, analysing and publishing the hard evidence. On this occasion, however, we believe that the information being put out by the campaigners seriously misrepresents the true picture and that an evidence-based response is necessary if Parliament is not to be misled.

The critique that follows, therefore, addresses a number inaccurate, incomplete or otherwise misleading statements made in a memorandum[3] supplied by DiD to Members of Parliament. These statements fall under three main headings – patient safety under UK law today; the safeguards recommended by DiD for any future law licensing assisted suicide; and the evidence emerging from the US State of Oregon, where these practices were legalised 14 years ago

Patient Safety in the UK

The campaigners are trying to persuade us that the law as it stands in Britain is not safe. They tell us that "*evidence demonstrates*" that around 0.5% of deaths in the UK result from either voluntary or involuntary euthanasia by doctors and that this amounts to "*approximately 2,500 deaths out of 500,000 per year*", which they describe as "*a small but significant minority*"[4].

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[1] Formerly the Voluntary Euthanasia Society

[2] Letter from DiD to Members of Parliament dated 11 July 2011

[3] 'Patient Safety and Assisted Dying', enclosed with DiD letter dated 11 July 2011

[4] 'Patient Safety and Assisted Dying', Page 1

These data come from a report by Professor Clive Seale, a medical sociologist who has researched this subject on a number of occasions. They are based on anonymous responses by doctors to various questions about deaths they have attended. Anonymity is obviously necessary in a questionnaire that asks people whether or not they have broken the criminal law, and we do not quarrel with Professor Seale's methodology. However, anonymity also makes it impossible to validate the responses – to establish, for example, whether they are based on misunderstandings of the effects of some drugs on dying patients or whether they include any deliberately mischievous responses. This is not to say the figures are necessarily inaccurate, but rather that they provide an indication rather than evidence.

It is also important to look at Professor Seale's own interpretation of the figures. In his 2009 report[5] he concludes that the incidence of illegal action of this nature by doctors in Britain is *"very low indeed"*. In an earlier report[6], comparing end-of-life decisions by doctors in Britain with those in certain other countries, he found not only that the incidence of illegal action by doctors in the UK was "*extremely low"* but also that the rate of illegal action was significantly lower here than in countries which have legalised euthanasia or assisted suicide. Giving evidence to Lord Falconer's 'commission on assisted dying', Professor Seale stated that "*it does sometimes happen in UK practice but pretty rarely"*[7] and that "*there is a kind of joint quality to decision-making in UK medical practice that is very marked compared to other countries. And with that situation decisions don't go unscrutinised"*[8]

This is not to say that the small margin of covert euthanasia indicated in Professor Seale's surveys should be regarded with any complacency. The question is: is legalisation the answer? We would normally respond to law-breaking by enforcing the laws concerned more effectively. We would only consider relaxing the law as a response if

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[5] End-of-life decisions in the UK involving medical practitioners, Palliative Medicine 2009;00:1-7

[6] National survey of end-of-life decisions made by UK medical practitioners, Palliative Medicine 2006; 20:3-10

[7] Oral Evidence, Professor Clive Seale

[8] Oral Evidence, Professor Clive Seale

there were compelling evidence that that would improve the situation. Far from such evidence existing, the reverse appears to be the case.

DiD argues that the law as it stands is deficient because "*all checks take place after a person has died*" and that "*there are no upfront safeguards*"[9]. The use of the word 'checks' is revealing. When a case of assisted suicide is suspected, there is not a 'check' but a police investigation. While such investigations are not infallible, they are more than just a check-list: they involve careful searching out and analysis of the facts rather than the series of subjective assessments and statements of intent that make up DiD's 'upfront safeguards'. The two processes are not comparable.

It is also necessary to bear in mind the deterrent effect of the present law and of the penalties it holds in reserve, which cause anyone minded to assist another person's suicide to think very carefully indeed about his or her motivation before embarking on such action. As a result the incidence of assisted suicide under the existing law is very low and the cases that come before the prosecuting authorities are generally of a nature that does not call for prosecution. Licensing assisted suicide in advance of the act would change this dynamic completely.

Safeguards

The safeguards that the campaigners say they believe to be "*the minimum that an assisted dying law should provide*"[10] are, with one minor exception, identical to those proposed by Lord Joffe in 2005 and rejected by Parliament in 2006. They take no account, moreover, of a series of recommendations made in 2005 by a UK parliamentary select committee, following an exhaustive inquiry into 'assisted dying', designed to strengthen safeguards in any future 'assisted dying' bill. For example, the campaigners' six-months-to-live timeframe for assisted suicide remains unchanged despite powerful evidence provided to the select committee by medical experts that prognosis of

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[9] 'Patient Safety and Assisted Dying', Page 1

[10] 'Patient Safety and Assisted Dying', Page 2

terminal illness at such a range is fraught with error and despite a recommendation by the committee that "*if a future bill should include terminal illness as a qualifying condition, this should be defined in such a way as to reflect the realities of clinical practice as regards accurate prognosis*"[11].

The expert evidence received by the select committee pointed to a timeframe for reliable prognosis of a few weeks at most, whereas a six-months criterion was described by one medical expert as "*pretty desperately hopeless as an accurate factor*"[12]. Yet the six-months timeframe remains unchanged, and attempts are now being made to justify it by reference to rules governing the payment of Disability Living Allowance (DLA). Under DLA rules a patient is able to by-pass the full assessment process if a doctor confirms that he or she is terminally ill and has a prognosis of six months or less. This comparison, however, fails to recognise the difference between giving a prognosis to enable financial benefits to be claimed and doing so as a basis for assisting the patient's suicide. The two situations are entirely different in terms of their gravity.

Prognosis of terminal illness is just one of a number of areas in which clear recommendations for improving safeguards have been on the table for years but have been ignored by the campaigners. This apparently wilful blindness appears to stem from a determination to replicate Oregon's assisted suicide law with a similar one in the UK. We turn now, therefore, to DiD's eulogy of the situation in Oregon.

Oregon

DiD writes that research has shown that vulnerable groups are not being put at risk by Oregon's assisted suicide law. We are not told, however, that the research in question has been criticised for its flawed methodology. To take just one example, the research to which DiD refers[13] concludes that there is "*no evidence of heightened risk*"

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[11] House of Lords Report 86-I (Session 2004-05), Paragraph 269

[12] House of Lords Report 86-I (Session 2004-05), Paragraph 118

[13] Legal physician-assisted dying in Oregon and The Netherlands: evidence concerning the impact on patients in 'vulnerable' groups, Journal of Medical Ethics 2007; 33; 591-597

from Oregon's law to the elderly. However, the researchers' definition of elderly (persons aged 85 or over) and of the control group used (persons aged between 18 and 64) reveals a serious methodological flaw. What they did was to compare the proportion of deaths from assisted suicide among the one group with the same proportion among the other. Unsurprisingly, they found a relatively low death rate from assisted suicide among the 85s-and-over, where the background death rate from natural causes is high, and a relatively high rate among those aged 18-64, where the natural death rate is low. Even more remarkable, the researchers took no account whatever of people aged between 65 and 84, which is the group that most people would define as 'elderly' and which, as official Oregon State Government figures show, accounts for some two thirds of all deaths from legalised assisted suicide. This and other weaknesses in the research cited by DiD were exposed in a critique[14] published in 2011 in the Journal of Medical Ethics.

DiD writes that "*palliative care is delivered in Oregon to a very high standard"* and that "*92.6% of patients who had an assisted death were enrolled in hospice care at the time of death*". The reality is rather different from what these words might suggest. Standards of palliative care have improved across the world since the mid-1990s, simply as a result of advances in the science and the dissemination of knowledge. Oregon, moreover, started from a low baseline. When the select committee visited Oregon in 2004, it was told by a researcher there that the enactment of the State's assisted suicide law was "*a vote of no confidence about some aspects of end of life care"*[15]*.*

The high proportion of terminally-ill patients enrolled in hospice programmes (not the same thing as being treated in a hospice) stems from a requirement that was explained to the select committee by the Director of the Oregon State Nursing Board: "*If the patient is declared to be a hospice patient, they then enter the benefit package that is part of Medicare"*[16]*.* Given that enrolment in a hospice programme in

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[14] Legal physician-assisted suicide in Oregon and The Netherlands: evidence concerning the impact on patients in vulnerable groups – another perspective on Oregon's data, Journal of Medical Ethics 2011; 37; 171-174

[15] House of Lords Report 86-II (Session 2004-05), Page 281

[16] House of Lords Report 86-II (Session 2004-05), Page 356

Oregon requires a patient to have a prognosis of six months or less, it is hardly surprising to find that most of those who resorted to legalised assisted suicide were enrolled in hospice programmes. Moreover, entering a hospice in Oregon requires the patient to waive the right to any curative treatments. As the select committee was told, "*it pretty much is a one-way ticket opting out into hospice. The hospice teams are paid governmentally for treatments that are comfort-only. You would not come back to hospital for a CT scan because it would not be paid for*"[17].

In Britain, unlike in Oregon and the few other jurisdictions that have gone down the 'assisted dying' road, palliative medicine has been a recognised clinical specialty for nearly 25 years, enabling specialist hospital and hospice teams to be built up and to advance the frontiers of the science. In 2010 a report by The Economist placed Britain first among 40 nations, including the United States, for quality of end-of-life care. Hospice care is free of charge here and covers active treatment as well as comfort care. The terms 'palliative care' and 'hospice care' do not have the same meanings in Oregon as they do in Britain.

We are told that "*assisted dying figures have not risen above 0.2% of all deaths on Oregon since legalisation*"[18]. What we are not told is that the number of deaths from physician-assisted suicide in 2010 was four times the number in 1998, the first year of the Oregon law's operation. If the latest death rate from assisted suicide in Oregon were to be replicated in the much larger population of Britain, we would be looking at between 1,000 and 1,200[19] deaths a year here from this source.

Nor are we told that there are no arrangements under Oregon's law to ensure that, once lethal drugs have been supplied to a qualifying patient to take away, their end-use conforms to the law's requirements – namely, that they should be ingested knowingly and willingly by someone of sound mind. No witnessing of these deaths is required and

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[17] House of Lords Report 86-II (Session 2004-05), Page 270

[18] 'Patient Safety and Assisted Dying', Page 3

[19] The precise figure depending on which constituent parts of the UK are included

many of the recipients do not ingest the drugs for weeks, months or (in some cases) even years. There is no way of knowing whether, when they do so, they are being coerced or otherwise pressured, whether they have lost mental capacity or whether others, with or without malicious intent, are providing assistance which is outside the terms of the law. Nor are there any arrangements prescribed for safe custody of these lethal drugs by their recipients. DiD's statement that "*the patient controls their own death*"[20] does not even recognise this serious weakness. It is pure wishful thinking.

Conclusions

What is needed if sound decisions are to be taken by Parliament as regards the legalisation of 'assisted dying' is robust evidence and careful analysis. What we are seeing in such documents as DiD's 'Patient Safety and Assisted Dying' is a mixture of soundbites and selective quotations. The document is an attempt to make bricks without straw – to construct a case for changing the law out of very little supporting evidence. Such an approach is not unusual where there is a political agenda, in which the collection and analysis of hard evidence can all too easily take a back seat to campaigning spin. But it does need to be recognised for what it is.

We are glad to see that DiD accepts that public safety rather than personal choice lies at the heart of the 'assisted dying' debate, and we note they are "*considering*" some adjustments to the safeguards they have hitherto proposed. That is to be welcomed. What we do not understand is why there is such apparent reluctance to do what we recommended in an earlier paper[21] - namely, to undertake a fundamental reappraisal of the concept of safeguarding. There are serious issues surrounding (for example) prognosis, informed consent, self-administration and the involvement of doctors, in which the evidence points to a clear need for structural changes but which are not being addressed. It is here rather than in glib presentation of half-truths that attention needs to be focused.

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[20] 'Patient Safety and Assisted Dying', Page 2

[21] "A Question of Public Safety" (available on www.livinganddyingwell.org.uk)