Assisted Suicide and Euthanasia: A Guide to the Evidence

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This evidence guide has been written to inform the debate about whether to legalize physician assisted suicide or euthanasia in the United Kingdom. Most of the sources cited here are also relevant to the debates on assisted suicide or euthanasia in other countries.

You can skim to get a sense of the different issues at stake and where to find further information, especially the most reliable information that is freely available online. This guide aims to be useful for students, scholars and research assistants to government officials or parliamentarians. More than this, it is offered to anyone who is concerned about these issues and wishes to assess the evidence.

Along with references for the source-data and official reports on assisted suicide and euthanasia in various countries, the guide identifies some useful articles that have been published in Peer Review Journals (PRJ). Publishing in a PRJ is of course no guarantee of the truth of an article's conclusions, for especially in law, ethics and public policy, academics frequently argue for opposite conclusions. However, being published in a PRJ is a sign that other academics have considered the argument to be well structured and the sources of evidence to be clearly identified. This provides a good starting point for debate. Unfortunately, most PRJ material is not free to the general reader, but is available only through universities or by subscription. Nevertheless, some PRJ articles are free online and sometimes there are freely available discussions based on the article. At a minimum the abstract of the article will generally be available free online. In this bibliography, all PRJ articles will be identified with a red asterisk.* Where the full text of a PRJ is freely available this will be indicated by *[full text available].

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1. Parliamentary reports

Since 1990 within the United Kingdom there have been three parliamentary reports on assisted euthanasia or suicide, each of which has been critical of such proposals. The most recent, and the most relevant to the Bills before the House of Lords and the House of Commons, is the 2015 Report of the Health and Sport Committee of the Scottish Parliament.

<u>House of Lords Select Committee on Medical Ethics (HL Paper 21-I of 1993-4)</u> There is no copy of the report available online, but a summary was provided by Lord Walton of Detchant (its chair) in a statement to the House of Lords recorded in Hansard.

House of Lords Assisted Dying for the Terminally III Committee 5 April 2005 (Mackay Committee) On this committee's findings see also I Finlay, VJ Wheatley, and C Izdebski. 'The House of Lords Select Committee on the Assisted Dying for the Terminally III Bill: implications for specialist palliative care.' *Palliative medicine* 19.6 (2005): 444-453.*

Scottish Parliament Health and Sport Committee 6th Report, 2015 (Session 4): Stage 1 Report on Assisted Suicide (Scotland) Bill. This Committee was 'not persuaded by the argument that the lack of certainty in the existing law on assisted suicide makes it desirable to legislate to permit assisted suicide... there are ways of responding to suffering (such as increased focus on palliative care and on supporting those with disabilities), which do not raise the kind of concerns about crossing a legal and ethical "Rubicon" that are raised by assisted suicide.' [292, 294]

Current challenges in the culture of healthcare in the UK

If legalized, assisted suicide or euthanasia would be implemented in the context of the NHS. In this regard it is important to be realistic about the current state of healthcare in the UK and failures that can occur and that have occurred, for example, in Mid Staffordshire and in the implementation of the Liverpool Care Pathway for the Dying Patient. These problems were not confined to one Trust or one Pathway but reflect cultural challenges within the NHS. How might assisted suicide or euthanasia be implemented in an environment of targets and 'tick-boxes' that sometimes operate to the detriment of patient care?

Mid Staffordshire NHS Foundation Trust Public Inquiry (Francis Report)

Independent Review of the Liverpool Care Pathway: More Care, Less Pathway (Neuberger Report)

2. Official statistics from jurisdictions with assisted suicide or euthanasia

Statistics for rates and characteristics of death by assisted suicide or euthanasia are available for six jurisdictions: the Netherlands, Belgium, Luxembourg, Switzerland, and in the states of Oregon and Washington in the USA. Assisted suicide is legal in Vermont or Montana, but there are no official reports on the pratice. Such statistics are only as reliable as the questions asked and the means of data collection and in all cases rely on self-reporting. In Flanders (Belgium) it has been shown that official figures underestimate rates by approximately 50% (see below). Official reports tend to gloss the figures and readers should beware of 'spin.' Nevertheless, with these caveats, official figures remain an important source of evidence for the impact of legalizing assisted suicide or euthanasia.

In the **Netherlands** euthanasia was effectively decriminalised by a court decision in 1984. This was the basis of a legal statute in 2001 legalizing euthanasia and physician assisted suicide. Since 2002 the Netherlands has produced an annual report on the cases notified to the five regional euthanasia committees. <u>These are available</u> (in English).

In **Belgium** euthanasia was legalized in 2002 and reports have been produced every two years. <u>These are available (in French) here.</u>

In **Luxembourg** euthanasia was legalized in 2009 and reports are produced every two years. Luxembourg has a small population (less than 1% of the UK population) and thus the number of cases is small. Nevertheless, over 6 years it is possible to see some patterns (a general increase in cases, an increase in non-cancer cases, more cases of women than men). See the report here (in French).

In **Switzerland** since 1942 inciting or assisting suicide has been illegal when it is for selfish motives (such as financial gain). Since 1982 this law has provided legal space for the organisation EXIT to promote assisted suicide for those 'with unbearable symptoms or with unacceptable disabilities.' However, to date, the government has only produced one official report on this activity (in 2012)

Oregon legalized physician assisted suicide in 1997 and produces annual reports. Helpfully <u>the latest report</u> includes data from previous years. Note that the figure for the number of deaths in the most recent year covered by the report will generally be inaccurate as deaths are recorded against the year of the lethal prescription. For example, if a lethal prescription given in 2012 were used in 2013 the death would be recorded as due to assisted suicide in the 2012 figures.

Washington legalized physician assisted suicide in 2009 following the Oregon model (Washington borders Oregon and to a great extent shares a common culture and history). Washington also produces <u>annual reports</u>.

There are **common patterns** which emerge in each of these jurisdictions: in every jurisdiction numbers have increased over time and continue to do so; there has also been a shift from permitting assisted suicide for cancer victims to include other diseases. In Europe this includes non-terminal conditions such as neuro-psychiatric conditions and multiple co-morbidities (for example, those associated with old age). Supposed safeguards such as psychiatric referral have also declined in frequency (see below for further details). Essentially, the practice has become more widespread and more routine.

3. Public opinion on euthanasia and assisted suicide

Within the political debate on assisted suicide and euthanasia, both sides, but especially advocates of a change in the law, frequently appeal to surveys of public opinion. In polls, there is a consistent majority of public opinion that expresses support for legalising assisted suicide or euthanasia.

In the UK polls typically show around 80% support for legalizing 'assisted dying', see for example

<u>Ipsos-Mori Poll for The Economist</u>

Populus Poll for Dignity in Dying

It should be noted that while the proposed law has the effect of amending the Suicide Act 1961 (as amended by the Coroners and Justice Act 2009) so that it is no longer an offence to 'encourage or assist' suicide, neither of the polls cited above use the words 'assisted suicide.' When the words 'assisted suicide' are used the majority in favour reduces, in some polls by up to 20%. See for example a Gallop poll conducted in the USA in 2013.

When participants are exposed to counter arguments to legalisation, support wavers, in one poll from 73% to 43%.

<u>Care Not Killing "'Assisted dying' and public opinion"</u> <u>Comres Care Assisted Suicide Poll</u>

Very similar results were shown in a poll in Scotland.

Scholarly comparisons of measures of support for assisted suicide or euthanasia have also shown that support is highly variable depending on the words used. Two examples are:

L Parkinson et al. 'Cancer patients' attitudes towards euthanasia and physician-assisted suicide: The influence of guestion wording and patients' own definitions on responses.' *Journal of Bioethical Inquiry*, 2005, 2(2), 82-89.*[full text available]

N Aghababaei, H Farahani, and J Hatami. 'Euthanasia attitude: A comparison of two scales.' *Journal of Medical Ethics and History of Medicine* 4 (2011).*[full text available]

Another reason to be cautious of such polling (and opinion polls more generally) is that they do not necessarily reflect how people actually vote when given the opportunity. Most ballot initiatives in the USA on this issue have in fact failed, despite opinion polls seeming to show strong support. Those which have passed (Oregon and Washington) only secured modest majorities (51% and 58%).

The Mackay committee produced a very useful critical review on the state of evidence at that time (2005) in relation to public opinion on assisted suicide and euthanasia (<u>Chapter 6</u> and <u>Appendix 7</u>)

'The key conclusion of this report is that, although some idea of the basic attitude of the general public is available through research sources, this does not amount to an authentic picture of public opinion which is in any way comprehensive. Deliberative research techniques, unused so far for this subject, which can produce an account of informed public opinion, are recommended if a proper understanding of public opinion is to be achieved.'

(Appendix 7, para 17)

In 2015, it remains the case that 'Research sponsors frequently appear to have been more concerned to achieve statistics for media consumption than to work towards achieving a comprehensive understanding of public and health sector attitudes' (Appendix 7, para 2).

The flaws in most yes/no polls are methodological and are not corrected merely by conducting more polls of a similar kind. Qualitative research is needed to uncover the complexities of the issue and/or the complexities of people's attitudes to the issue. For example, a study in the *Journal of Medical Ethics* showed that, if people were given a range of choices (and not just one) then more individuals were in favour of legal sanctions against euthanasia than were in support of it.

J Hagelin, T Nilstun, J Hau, H-E Carlsson 'Surveys on attitudes towards legalisation of euthanasia: importance of guestion phrasing' J Med Ethics 2004;30:521-523.*[full text available]

This complexity is also shown in qualitative research with nurses and with dying cancer patients. See here:

M Berghs, B Dierckx de Casterlé, C Gastmans 'The complexity of nurses' attitudes toward euthanasia: a review of the literature' J Med Ethics 2005;31:441-446.*[full text available]

A Jaklin, I Eliott, N Olver 'Dying cancer patients talk about euthanasia' *Social Science & Medicine* 67 (2008) 647–656.*[full text available]

It is worth highlighting the following conclusion from the latter study: 'Survey studies showing majority support for euthanasia have typically required individuals to make judgements about hypothetical and abstracted scenarios. Under such conditions, individuals are likely to draw upon the readily available and socially approved discourses of autonomy and compassion, and voice approval. To conclude that this legitimises euthanasia as social policy is to deny the import of other factors that feature when individuals have opportunity to do more than endorse or reject euthanasia.'

These complexities are by no means peculiar to the issues of assisted suicide and euthanasia, they apply more generally to use of public opinion in ethical debates around public policy. For such reasons government engagement with the public typically employs mixed methods: public events, open online consultations, stakeholder events, and representative opinion polls. The UK government's Code of Practice on Consultation makes it clear that consideration of public opinion should give particular weight to the views of 'any groups or sectors... that may be disproportionately affected by the proposals' (3.4). [In the case of assisted suicide and euthanasia this would be people who are dying, those who are living with disabilities, their carers, and healthcare professionals, especially doctors who care for the dying.] Consultations should not just ask for conclusions but 'the evidence given by consultees to back up their arguments. Analysing consultation responses is primarily a qualitative rather than a quantitative exercise' (6.1).

These principles of good practice should apply also when judging the competing claims to how 'the public' thinks of assisted suicide and euthanasia.

4. Medical opinion on euthanasia and assisted suicide

Whereas simple yes /no public opinion polls typically find a significant majority in favour of legalizing assisted suicide or euthanasia, opinion among the medical profession is generally opposed.

Thus, while the editors of the *British Medical Journal* have expressed support for assisted suicide legalisation, two <u>online surveys of *BMJ* readers</u> found significant majorities opposed: (against 'the law on assisted dying' being changed in 2011, by 69% to 31%, and against doctors' organisations being 'neutral on assisted dying' in 2012, by 83% to 17%).

This is a similar result to <u>a poll of readers of the New England Journal of Medicine</u> in 2013 which found that 65% of the readers internationally and 67% of US readers voted against permitting physician-assisted suicide.

Consultation exercises among the members of professional bodies show a similar pattern. In <u>a consultation of its</u> <u>members in 2014</u> the Royal College of General Practitioners found that 77% of members who submitted response forms wished the College to maintain its opposition to a change in the law, 18% wished to see the College move to a position of neutrality, and only 5% supported the College taking a position in favour of a change in the law.

This UK exercise is mirrored by a similar consultation by Canadian doctors in 2014.

<u>Surveys of members of the Association of Palliative Medicine</u> show large majorities against a change in the law (up to 82%) with 72% expressing a concern that such legislation would have an adverse or very adverse effect on the delivery of palliative care and care in hospices.

<u>A survey of members of the Royal College of Physicians</u> showed a clear majority opposed to assisted suicide (with 57.5% opposed and only 21.4% prepared to participate in such a practice).

This view is also reflected in <u>the official policy of the British Medical Association</u>, based on voting by representatives at annual general meetings.

A position paper for the American College of Physicians–American Society of Internal Medicine, Ethics and Human Rights Committee also provided arguments against legalisation of physician assisted suicide.

L Snyder, DP Sulmasy. 'Physician-assisted suicide.' Ann Inter Med. 135.3 (2001): 209-216.*

Research published in peer review journals finds a similar pattern with most doctors in the United Kingdom opposed to physician assisted suicide and opposition is strongest among doctors in palliative care.

<u>C Seale, 'Legalisation of euthanasia or physician-assisted suicide: survey of doctors' attitudes.' *Palliative Medicine*23.3 (2009): 205-212.*</u>

R McCormack, M Clifford, and M Conroy. 'Attitudes of UK doctors towards euthanasia and physician-assisted suicide: a systematic literature review.' Palliative medicine 26.1 (2012): 23-33.*

W Lee, et al. 'Survey of doctors' opinions of the legalisation of physician assisted suicide.' *BMC medical ethics* 10.1 (2009): 2.*[full text available]

5. Causes of concern from the experience in Oregon

The most important evidence for practice in Oregon is provided by annual reports on the Death with Dignity Act. This section also highlights some aspects that been raised in relation to Oregon practice but are not based on the reports. See also research on the impact of assisted suicide on suicide prevention (section 10, below).

According to the official Oregon report, the most frequent end of life concern cited by people requesting assisted suicide is not pain but 'loss of autonomy' (91.5%), followed by decreased ability 'to engage in activities making life enjoyable' (88.7%), 'loss of dignity' (79.3%), 'losing control of bodily functions' (50.1%) and 'burden on family, friends/caregivers' (40%), and only then 'inadequate pain control or concern about it' (24.7%), (in each case citing accumulated data for 1998-2013). Evidently, most of these concerns relate to disability and increased dependence. The concern about feeling one is a 'burden' on others is significant, much more so than fear of pain (which, also, should not be conflated with actual pain).

From the same report it is clear that in only 15.7% of cases was the prescribing physician present at the time of death (only 13.9% in 2014), that only 5.5% were referred for psychiatric evaluation (only 2.9% in 2014), and that in 38.3% of cases the person was dependent on Medicare/Medicaid insurance or other governmental insurance (up to 60.2% in 2014).

According to <u>Oregon's Prioritized List of Health Services 2015</u> cancer treatment is limited according to relative life expectancy, for example, 'treatment with intent to prolong survival is not a covered service for patients who have progressive metastatic cancer...'(Guidance Note 12). In contrast 'It is the intent of the Commission that services under ORS 127.800-127.897 (Oregon Death with Dignity Act) be covered for those that wish to avail themselves to those services' (Statements of Intent Page 1).

[NB The Statements of Intent and Guidance Notes come after the 103 pages of the prioritized list] Health Evidence Review Commission, *Prioritized List of Health Services* (1 January 2015).

It should be noted that the drugs that are used for assisted suicide are also used in execution by lethal injection in the United States. This dual use is causing availability problems with supply of the drugs.

N Jaquiss 'Penalized By The Death Penalty' Willamete Week 21 May 2014

A good overview of practice in Oregon, including some case studies as well as statistical evidence, shows problems with doctor shopping, suspect coercion and lack of sufficient psychiatric evaluation. <u>H Hendin and K Foley, 'Physician-assisted suicide in Oregon: a medical perspective.' Michigan Law Review, 2008:</u>
1613-1639.*[full text available]

Kenneth Stevens has shown that from 2001 to 2007 a majority (61%, 165 out of 271) of the lethal prescriptions were written by a minority (18%, 20 out of 109) of the participating physicians. More striking still, just 3 physicians were responsible for 23% of lethal prescriptions (62 out of 271).

KR Stevens 'Concentration of Oregon's Assisted Suicide Prescriptions & Deaths from a Small Number of Prescribing Physicians' Physicians for Compassionate Care Educational Foundation 18 March 2015.

See also 'Five Oregonians to Remember' PCCEF, 27 December 2007.

¹ I am grateful to Dr Robert Twycross for bringing this online article to my attention.

6. Causes of concern from the experience in Switzerland

Assisted suicide in Switzerland is performed almost entirely through organisations such as EXIT and Dignitas. Since 1982 (when EXIT was founded) there has been only one official government report, in 2012, and this is dependent on data provided by assisted suicide organisations. Media reporting of UK citizens dying in Switzerland plays a significant role in the UK debate, but it should be noted that most of those individuals would not qualify under current proposals for 'Assisted Dying', as they were not expected to die within six months. If the law changed in the UK either people would continue to go to Switzerland (which would have fewer restrictions) or the option of assisted suicide in Switzerland would place pressure on the UK to extend its practice to those who are not terminally ill. Research on the experience of assisted suicide in Switzerland is not reassuring.

A systematic study of 43 consecutive cases of assisted suicide in Switzerland from 1992 to 1997 found that in 10 cases (23%), the time between first contact with EXIT and the completed assisted suicide was less than a week and in 4 cases (9%) it was less than a day. In 6 cases (14%) the person had previously been treated in a psychiatric institution. In 11 cases (26%) there was no serious medical condition recorded on file, and in 5 cases (12%) the stated reason for seeking assisted suicide was bereavement. The authors of the study conclude that in the 1990s assisted suicide was 'performed by lay-people who act without outside control and violate their own rules.' A Frei et al. 'Assisted suicide as conducted by a "Right-to-Die"-society in Switzerland: a descriptive analysis of 43 consecutive cases.' Swiss Medical Weekly 131.25-26 (2001): 375-380.* [full text available]

A later study found that between the 1990s and 2001-2004 the rate of assisted suicide for non-fatal diseases increased from 22% to 34% and concluded that 'weariness of life rather than a fatal or hopeless medical condition may be a more common reason for older members of Exit Deutsche Schweiz to commit suicide'.

S Fischer, C. A. Huber, L Imhof, R.M. Imhof, M Furter, S. J. Ziegler, & G Bosshard, (2008). 'Suicide assisted by two Swiss right-to-die organisations'. *Journal of medical ethics*, 34(11), 810-814.*[full text available]

A study in 2014 found that assisted suicide in Switzerland was associated with living alone and divorce and was significantly more frequent among women. In 16% of deaths by assisted suicide no medical condition was listed. N Steck, C Junker, M Maessen, T Reisch, M Zwahlen, & M Egger (2014). 'Suicide assisted by right-to-die associations: a population based cohort study'. *International journal of epidemiology*, 43(2), 614-622.*[full text available]

Research on trends from 1991 to 2008 showed 'a tripling of assisted suicide rates in older women, and the doubling of rates in older men.'

N <u>Steck, M Zwahlen, & M Egger. 'Time-trends in assisted and unassisted suicides completed with different methods: Swiss National Cohort.' Swiss Med Wkly 145 (2015): w14153.*[full text available]</u>

The most recent figures by EXIT shows 583 deaths by assisted suicides in 2014, up 124 (27%) from 2013

Research showed that requests for assisted suicide were not based on symptom burden but on fear of loss of control. Moreover, those seeking assisted suicide had misconceptions about palliative care.

C Gamondi, M Pott, and S Payne. 'Families' experiences with patients who died after assisted suicide: a retrospective interview study in southern Switzerland.' Annals of oncology 24.6 (2013): 1639-1644.*[full text available]

Until 2006 assisted suicide had not occurred in Switzerland in a hospital setting. The difficulties of introducing it into hospital and the concerns of the palliative care team are set out below.

J Pereira et al. 'The response of a Swiss university hospital's palliative care consult team to assisted suicide within the institution.' Palliative medicine 22.5 (2008): 659-667.*[full text available]

There is also research from Switzerland on the negative impact on family members of witnessing assisted suicide. B Wagner, J Müller, and A. Maercker. 'Death by request in Switzerland: Posttraumatic stress disorder and complicated grief after witnessing assisted suicide.' European Psychiatry 27.7 (2012): 542-546.*[full text available]

Assisted suicide in Switzerland is most well known in the UK because of people travelling from the UK to die by assisted suicide. A detailed study of 'suicide tourism' shows numbers are increasing, the proportion of cancer is decreasing and the proportion of mental illness and multiple co-morbidities is increasing. Among reasons for assisted suicide the largest single cause, with 223 cases, was cancer, but 37 cited Parkinson's disease, 37 gave arthritis as a reason, 14 cases were for mental illness, and 40 gave as a reason impairment of eyesight and/or hearing.

S <u>Gauthier</u>, J <u>Mausbach</u>, T <u>Reisch</u>, & <u>C Bartsch</u> (2014). 'Suicide tourism: a pilot study on the Swiss phenomenon'. <u>Journal of medical ethics</u>, medethics-2014.*[full text available]

7. Causes of concern from the experience in the Netherlands

In addition to annual reports, based on notified cases of euthanasia there have been a series of studies of end of life practices at 5 year intervals since 1990. These were nationwide studies of a stratified sample from the national death registry. Questionnaires were sent to physicians attending these deaths and were returned anonymously. The first is commonly termed the Remmelink Report and subsequent reports followed the same pattern. Both the annual reports and the five yearly studies show incremental increases in deaths by euthanasia over time. Deaths by assisted suicide are less frequent, in part because they are associated with complications.

The first two reports showed evidence of a number of deaths without explicit patient request (in other words non-voluntary euthanasia). The rates were 0.8% and 0.7% being equivalent to 1,000 and 900 deaths in per year. The reaction of supporters was generally to dismiss the significance of these figures, rather than to see them as a possible cause for concern.

P J Van der Maas et al. 'Euthanasia, physician-assisted suicide, and other medical practices involving the end of life in the Netherlands, 1990–1995.' New England Journal of Medicine 335.22 (1996): 1699-1705.*[full text available]

J Keown, 'Euthanasia in the Netherlands: Sliding down the Slippery Slope', 9 Notre Dame J.L. Ethics & Pub. Pol'y 407 (1995).*[full text available]

J M van Delden, L Pijnenborg, and P J van der Maas. 'Reports from the netherlands. Dances with data.' *Bioethics* 7, no. 4 (1993): 323-329.*

R Cohen-Almagor 'Non-voluntary and involuntary euthanasia in The Netherlands: Dutch perspectives.' *Issues in Law and Medicine* 18.3 (2003).*

For such reasons the law and practice of euthanasia and assisted suicide in the Netherlands has been criticized twice by the United Nations Human Rights Committee.

<u>UN Human Rights Committee (HRC), UN Human Rights Committee: Concluding Observations: Netherlands, 27 August 2001, CCPR/CO/72/NET</u>

<u>UN Human Rights Committee (HRC), Concluding observations of the Human Rights Committee: Netherlands, 25 August 2009, CCPR/C/NLD/CO/4</u>

Results from the most recent 5 yearly study (published in 2012 and relating to 2010) show that deaths classified as 'ending life without explicit patient request' have declined. However, overall numbers of deaths by euthanasia have risen by more than 60% in five years. This is not due to an increase in reporting (which has declined slightly from the 2005 rate of 80%). but is due to increased numbers of requests and increased percentage of requests accepted. Another matter of concern is the steep rise in cases of continuous deep sedation (in 2010 12.3% of deaths), which may account for the rise in deaths by 'intensified alleviation of symptoms' (from 18.8% of deaths in 1990 to 36.4% of deaths in 2010). The presence of so many deaths with, or by, continuous deep sedation confounds the data as it may be used as equivalent to (voluntary) euthanasia or to life ending without request. B D Onwuteaka-Philipsen, A Brinkman-Stoppelenburg, C Penning, G J de Jong-Krul, J J van Delden, & A van der Heide (2012). 'Trends in end-of-life practices before and after the enactment of the euthanasia law in the Netherlands from 1990 to 2010: a repeated cross-sectional survey'. The Lancet, 380(9845), 908-915.*[full text available]

The latest annual report (for 2013) shows that the rate of increase in euthanasia numbers has not slowed, but instead has accelerated. There were 4,829 deaths by euthanasia or assisted suicide notified in 2013, up 15% from the previous year. As well as the increase in overall numbers there has been a disproportionate increase in euthanasia for non-terminal diseases, thus in comparison with 2012, euthanasia for multiple geriatric syndromes increased 46% (to 251 cases), euthanasia for dementia increased 130% (to 97 cases), and euthanasia for mental disorders increased 200% (to 42 cases).

This increase in euthanasia or assisted suicide for non-terminal conditions reflects opinion among professionals, with a significant number (between 24% and 39%) in favour of euthanasia or assisted suicide for individuals who experience mental suffering due to loss of control, chronic depression or early dementia. A third of doctors and 58% of nurses were in favour of euthanasia in the case of severe dementia, given the presence of an advance directive.

PSC Kouwenhoven, et al. 'Opinions of health care professionals and the public after eight years of euthanasia legislation in the Netherlands: A mixed methods approach.' Palliative medicine 27.3 (2013): 273-280.*

Other research shows a wide variation among general practitioners, consultants and members of the euthanasia committees in their judgement of whether the patient's suffering is sufficient for euthanasia.

J A C Rietjens, et al. 'Judgement of suffering in the case of a euthanasia request in The Netherlands.' Journal of Medical Ethics 35.8 (2009): 502-507.*

While euthanasia is defined as ending life on request, the Netherlands has extended life ending without request to newborn infants with disabilities. A description of the protocol (known as the Groningen protocol) is given by two authors who helped develop this practice.

A A E Verhagen, and P J J Sauer 'End-of-life decisions in newborns: an approach from the Netherlands.' *Pediatrics* 116.3 (2005): 736-739. *

Lastly, while euthanasia and assisted suicide are requested to secure an easeful death, complications are well documented, especially in assisted suicide. A study in 2000 found that 'complications [such as spasm, gasping for breath, cyanosis, nausea or vomiting] occurred in 7% of cases of assisted suicide, and problems with completion [a longer-than-expected time to death, failure to induce coma, or re-awakening of the patient] occurred in 16%' because of which 'physicians who intend to provide assistance with suicide sometimes end up administering a lethal medication themselves.' This is not only a problem of the past; in the 2013 report there were 4,501 cases of euthanasia, 286 cases of assisted suicide and 42 cases involving a combination of the two (i.e. cases which began as assisted suicide, but had to be completed by euthanasia).

J H Groenewoud, A van der Heide, B D Onwuteaka-Philipsen, D L Willems, P J van der Maas, & G van der Wal (2000). 'Clinical problems with the performance of euthanasia and physician-assisted suicide in the Netherlands'. New England Journal of Medicine, 342(8), 551-556.*[full text available]

8. Causes of concern from the experience in Belgium

Though Belgium legalised euthanasia in 2002, eighteen years after the Netherlands (in 1984), it has now overtaken the Netherlands in numbers of deaths. There were 1,803 reported cases in 2013 (more than double the 822 reported cases in 2009). According to research conducted by Chambaere (see below) these official figures underreport euthanasia by around 50%. What is more worrying is that research indicates that more than 1,000 patients a year (1.7% of all deaths) have their lives ended deliberately without having requested it. This figure has not declined with time.

The Belgium law came to prominence recently with the decision in February 2014 to extend euthanasia to children. This has caused concern among clinicians and bioethicists in other countries.

A M Siegel, D A Sisti and A L Caplan 'Pediatric euthanasia in Belgium: disturbing developments.' JAMA 311.

A M Siegel, D A Sisti and A L Caplan 'Pediatric euthanasia in Belgium: disturbing developments.' *JAMA* 311.19 (2014): 1963-1964.*

B S Carter, 'Why Palliative Care for Children is Preferable to Euthanasia.' *American Journal of Hospice and Palliative Medicine* (2014): 1049909114542648.*[full text available]

For background to the original 2002 law and its initial implementation see:

R Cohen-Almagor, 'Euthanasia policy and practice in Belgium: critical observations and suggestions for improvement.' Issues L. & Med. 24 (2008): 187.*[full text available]

See also a report analysing ten years of euthanasia practice in Belgium.

<u>E de Diesbach, M de Loze, C Brochier and E Montero Euthanasia in Belgium: 10 years on European Institute of Bioethics (April 2012)</u>

Research shows that the cases that are not reported are also less likely to involve a written request, less likely to involve specialist palliative care, and more likely to be performed by a nurse.

T Smets, et al. 'Reporting of euthanasia in medical practice in Flanders Belgium: cross sectional analysis of reported and unreported cases.' *British Medical Journal* 341 (2010): 5174.*[full text available]

Research on nurses in Belgium in 2007 showed that cases of life-ending without request were almost as common as cases of euthanasia, and that in 12% of euthanasia cases and 45% of life-ending without request it was a nurse who administered the lethal dose, actions which went 'beyond the legal margins of their profession.'

E Inghelbrecht, et al. 'The role of nurses in physician-assisted deaths in Belgium.' *Canadian Medical Association Journal* (2010): 905-910.*[full text available]

On the ongoing issue of high levels of intentional life-ending without consent in Belgium see:

R Cohen-Almagor 'First do no harm: intentionally shortening lives of patients without their explicit request in Belgium.' *Journal of Medical Ethics* (2015): medethics-2014.*[full text available]

Research has also shown that, in Belgium, continuous deep sedation is used with the intention or co-intention to shorten life in 17% of cases, but that it is rarely instituted at the request of the patient (only in 12.7% of cases). <u>E E Papavasiliou, et al. 'Physician-reported practices on continuous deep sedation until death: A descriptive and comparative study.' Palliative medicine (2014): 0269216314530768.*</u>

The most recent research (published in 2015) shows that while rates of euthanasia increase there has been no improvement in reporting and no reduction in cases of life-ending without request.

<u>K Chambaere et al. 'Recent Trends in Euthanasia and Other End-of-Life Practices in Belgium.' New England Journal of Medicine 372.12 (2015): 1179-1181</u>.*[full text available]

In the face of evidence of widespread ending of life without request some researchers have sought to excuse these actions because a third of such patients had, 'at some point' in the past, either explicitly or 'implicitly' expressed a wish that their lives be ended. However, the very attempt to downplay concerns about deaths deliberately brought about without an explicit request itself illustrates the degree to which non-voluntary euthanasia in Belgium is tolerated and is not regarded as shocking or as a practice in urgent need of correction. K Chambaere, J L Bernheim, J Downar, & L Deliens (2014). 'Characteristics of Belgian "life-ending acts without explicit patient request": a large-scale death certificate survey revisited.' *Canadian Medical Association Open Access Journal*, 2(4), E262-E267.*[full text available]

On the distinction between expressing a wish to die, a wish to hasten death, and a request, see: <u>C Monforte-Royo, C Villavicencio-Chávez, J Tomás-Sábado, & A Balaguer (2011). The wish to hasten death: a review of clinical studies. Psycho-Oncology, 20(8), 795-804.*[full text available]</u>

<u>Data from the annual reports</u> shows that an increasing percentage of those dying by euthanasia do not have cancer, but have neuro-psychiatric disorders or the comorbidities of old age. These cases increased from a combined 41 deaths in 2010 (4.3% of euthanasia that year) to 176 deaths in 2013 (9.7% of euthanasia).

Stories of individual cases are no substitute for quantitative research, but they help show the possible human meaning behind these statistics. Some illustrative examples are given below.

'Marc and Eddy Verbessem, Deaf Belgian Twins, Euthanized' The World' Post 15 January 2013.

B. Waterfield, 'Belgian killed by euthanasia after a botched sex change operation' Telegraph 01 Oct 2013

R Aviv 'The Death Treatment: When should people with a non-terminal illness be helped to die?' New Yorker 22 June 2015

E O'Gara 'Physically healthy 24-year-old granted right to die in Belgium' Newsweek 29 June 2015

9. Disability and the impact of assisted suicide and euthanasia

Groups representing people with disabilities have been at the forefront of opposition to the legalization of assisted suicide and euthanasia. Arguments from this perspective, especially in popular publications and comment pieces, have been criticised as reflecting and/or feeding on fears without showing that these fears are reasonable. However there is also more critical reflection from this perspective. This includes discussion of empirical evidence that is relevant to assessing these concerns of disabled people.

Some opinion polls among people disabled people find considerable support for legalizing 'assisted dying'.

These results are similar to opinion polls in the general population and should be treated with the same caution. It is also important also to take into account <u>polls that identify concerns among disabled people that legal changes</u> could put pressure on disabled people to end their lives prematurely.

An interesting exchange on this issue by two people with disabilities was conducted by Carol Gill and Andrew Batavia. Batavia argues that empirical data is irrelevant to the issue, which, in his view, is about values, and centrally the value of autonomy. He is in favour of legalizing assisted suicide.

A J Batavia, 'The relevance of data on physicians and disability on the right to assisted suicide: Can empirical studies resolve the issue?' Psychology, Public Policy, and Law 6.2 (2000):546-58.*

In response Gill presents data, which is relevant to the perception of disability and its role (implicitly or explicitly) in decisions to grant requests for assistance in suicide. For example, she cites research that shows that among 153 emergency care providers, only 18% of physicians, nurses, and technicians imagined they would be glad to be alive with a severe spinal cord injury. In contrast, 92% of a group of 128 persons with high-level spinal cord injuries said they were glad to be alive.

C J Gill, 'Health professionals, disability, and assisted suicide: An examination of relevant empirical evidence and reply to Batavia (2000).' Psychology, Public Policy, and Law 6.2 (2000): 526-45.*

Unfortunately, neither of these papers is freely available online. However, another very interesting paper by Gill provides a good sense of what a critical and empirically informed disability perspective looks like. More generally, the *Disability and Health Journal* (in which this paper appears) is a useful source for articles on disability and assisted suicide.

C J Gill, 'No, we don't think our doctors are out to get us: Responding to the straw man distortions of disability rights arguments against assisted suicide'. *Disability and Health Journal* 3.1 (2010): 31-38.*[full text available]

Probably the most influential article arguing that the evidence shows no negative impact of assisted suicide or euthanasia on vulnerable groups (including people with disabilities) is by Margaret Battin.

M P Battin, A Van der Heide, L Ganzini, G Van der Wal, and B D Onwuteaka-Philipsen, 'Legal physician-assisted dying in Oregon and the Netherlands: evidence concerning the impact on patients in "vulnerable" groups'. *Journal of medical ethics*, 2007, 33 (10): 591-597.*[full text available]

The methodology and conclusions of this paper have been criticised by Ilora Finlay and Robert George.

<u>I Finlay, and R George, '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(3): 171-174.*[full text available]</u>

A detailed discussion of Battin's evidence and counter-evidence from other expert witnesses is found in the <u>Irish</u> <u>Divisional Court case Fleming v Ireland [2013] IEHC 2 (especially para 67).</u>

'[T]he the expert evidence offered by Dr. O'Brien and Professor George to the effect that relaxing the ban on assisted suicide would bring about a paradigm shift with unforeseeable (and perhaps uncontrollable) changes in attitude and behaviour to assisted suicide struck the Court as compelling and deeply worrying... The Court finds the evidence of these witnesses, whether taken together or separately, more convincing than that tendered by Professor Battin, not least because of the somewhat limited nature of the studies and categories of person studied by Professor Battin...'

Battin's argument is also criticised by José Pereira on the basis that "safeguards" are largely illusory.

J Pereira, 'Legalizing euthanasia or assisted suicide: the illusion of safeguards and controls.' Current Oncology 18.2

(2011): e38.*[full text available]

Similarly, a detailed discussion of the evidence from Oregon from a disability perspective concludes that 'Battin et al.'s interpretation that people with physical disabilities or chronic illnesses are not at increased risk for DWD does not seem to be supportable given available data.'

<u>C E Drum, G White, G Taitano and W Horner-Johnson, 'The Oregon Death with Dignity Act: results of a literature review and naturalistic inquiry'. Disability and health journal, 2010, 3(1): 3-15.*[full text available]</u>

If disability includes mental illness then there is clearly a group of patients who are prima facie endangered by assisted suicide. In Oregon there has been a decline in the "safeguard" of referral for psychiatric evaluation whereas in Belgium and Switzerland mental illness can itself be a basis for euthanasia or assisted suicide. A study published in the BMJ shows how far the euthanizing of psychiatric patients has progressed in Belgium: Of 100 patients who requested euthanasia for psychiatric reasons, 73 'were medically unfit for work (they were either receiving disability living allowances or had taken early retirement),' i.e. most were categorised as having a disability. Of the 100, 38 were referred for further psychiatric evaluation, after which 17 were approved for euthanasia and 10 died by euthanasia during the study period. Of the 62 people not referred, 31 were approved for euthanasia and 25 died by euthanasia during the study period. These patients suffered from a variety of conditions including mood disorders (58 including 10 who were bipolar), borderline personality disorder (27), schizophrenia and other psychotic disorders (14), post-traumatic stress disorder (13), eating disorders (10), autism spectrum disorder (7), attention deficit hyperactivity (1) as well as other diagnoses, often combining diagnoses (e.g. a mood disorder and personality disorder). During the period of the study six participants died by (non-assisted) suicide, one from anorexia nervosa and one from palliative sedation. None was terminally ill. L Thienpont, M Verhofstadt, T Van Loon, et al. 'Euthanasia requests, procedures and outcomes for 100 Belgian patients suffering from psychiatric disorders: a retrospective, descriptive study'. BMJ Open 2015;5: <u>e007454</u>. doi:10.1136/bmjopen-2014-007454*[full text available]

10. Suicide prevention and the impact of assisted suicide

Sometimes advocates of assisted suicide are happy to use this terminology, as for example in the 'Assisted Suicide (Scotland) Bill', recently rejected by the Scottish Parliament. Other proponents avoid this language and prefer 'dying/death with dignity' or 'assisted dying/death'. However evidence indicates no sharp distinction between assisted suicide and non-assisted suicide. Evidence also suggests legalizing assisted suicide 'normalizes' suicide and is associated with increases in suicide.

It is argued that 'assisted death' of a kind legalised in Oregon, is not assisted *suicide* because (1) with 'assisted death' the person is terminally ill and (2) (non-assisted) suicide is typically the result of depression. However, according to one UK study, 'at least 10 percent of [non-assisted] suicides nationally involve[ed] some form of serious physical illness (either chronic or terminal).'

L Bazalgette, W Bradley, J Ousbey. The Truth about Suicide. (London: Demos 2011)

<u>Similarly in Switzerland</u> 'In 53% of [non-assisted] suicide cases, the cause of death certificate contains no indication of concomitant diseases. In 56% of cases where the death certificate does contain an indication the reported disease is depression. In the remaining 44% of cases, a physical illness is indicated. The <u>range of physical illnesses reported with suicide is similar to that reported with assisted suicide</u>.' (emphasis added)

Similarly a report on suicide in Oregon found that 25% of men and 26% of women who died by suicide had had physical health problems, and in the over-65 cohort, 66% of men and 56% of women had physical health problems, including conditions such as cancer, heart disease, and chronic pain.

X Shen, L Millet. *Suicide in Oregon: Trends and Risk Factors. 2012 Report*. Oregon Health Authority, Portland, Oregon.

The vulnerability of older people, those living alone and those with physical illness was highlighted in a report by the New York Task Force in 1994. The Task Force also found that depression was prevalent in this population, but largely undiagnosed and untreated (see especially chapter 2 of the report).

New York State Task Force on Life and the Law, When Death is Sought: Assisted Suicide and Euthanasia in the Medical Context (1994).

Similarly, in a study of 178 Compassion & Choices clients, of those who, in the study period, obtained lethal medication 3 out of 18 (17%) fulfilled the criteria for depression and of those who died by assisted suicide by the end of the study 3 out of 9 (33%) met the criteria for depression.

L Ganzini, E R Goy, S K Dobscha: Prevalence of depression and anxiety in patients requesting physicians' aid in dying: cross sectional survey. *BMJ* 337:a1682, 2008*[full text available]

It has been argued that legalising assisted suicide could, paradoxically, delay or inhibit suicide. This has been argued by Lord Falconer and others, but <u>a particularly clear statement is provided by EXIT</u>.

However, in Oregon between 1999 (two years after PAS was introduced) and 2010 the suicide rate among those aged 35-64 increased by almost 50% (compared to 28% nationally).

See also the report on high rates of suicide in Portland Oregon.

This increase is without counting assisted suicides, which rose in Oregon by 44% in 2013 alone.

According to the Swiss government report, 'since 2003 the number of suicides has been more or less stable, whereas the number of assisted suicide cases continues to rise.'

Suicide Contagion

A Swiss study indicates evidence for suicide contagion following media reports of assisted suicide. <u>A Frei, T Schenker, A Finzen, V Dittmann, K Kraeuchi, U Hoffmann-Richter. The Werther effect and assisted suicide. Suicide Life Threat Behav.</u> 2003 Summer;33(2):192-200.*

Research on the impact of reporting assisted suicide in Oregon has also suggested such an effect. P Stark 'Assisted suicide and contagion' MCCL White Paper May 2015

This evidence coheres with what is known about suicide, that it increases if the means are more widely available and if it is normalized, see for example <u>Euregenas (European Regions Enforcing Actions Against Suicide)</u> Suicide Prevention Toolkit for Media Professionals

See also <u>World Health Organization</u>, 2008. <u>Preventing Suicide: A resource for media professionals</u>. Geneva: Department of Mental Health and Substance Use, WHO.

Research also shows that positive 'suicide role models' reinforce high rates of suicide in a population <u>S Stack</u>, A J Kposowa. The association of suicide rates with individual-level suicide attitudes: a cross-national <u>analysis</u>. Soc Sci Q 2008; 89 (1, Mar): 39-59.*[full text available]

11. Gender and the impact of assisted suicide and euthanasia

Proponents of a change in the law frequently invoke choice (for example the US organisation 'Compassion & Choices' or the Scottish organisation 'My Life, My Death, My Choice'). This language is very similar to 'pro-choice' language in relation to abortion, and so it might seem that feminists who are in favour of increased access to legal abortion would also support legalisation of assisted suicide or euthanasia. This argument is indeed accepted by some feminists; however, it has been challenged by a number of feminists who argue that assisted suicide and euthanasia would have a disproportionately negative impact on women.

S M Wolf 'Gender, Feminism, and Death: Physician-Assisted Suicide and Euthanasia' in SM Wolf, Feminism & Bioethics: Beyond Reproduction, New York: Oxford University Press, 1996 pp. 282-317.

Wolf argues that a legal right to abortion (which she supports) does not imply a legal right to assisted suicide. S M Wolf, 'Physician-assisted suicide, abortion, and treatment refusal: Using gender to analyze the difference' in R Weir, ed. Physician-assisted suicide Indiana University Press, 1997 pp. 167-201

On this point see also:

M Spindelman, 'Are the Similarities between a Woman's Right to Choose an Abortion and the Alleged Right to Assisted Suicide Really Compelling.' U. Mich. JL Reform 29 (1995): 775.*

Whereas, in the West, the rate of suicide is much higher among men than women (roughly four times), physician assisted suicide (in Oregon and Washington) is roughly equal between men and women, and rates of assisted suicide in Switzerland reveal a higher proportion of women; this is also true of the suicides assisted by Kervorkian. S S Canetto and J D Hollenshead. 'Gender and physician-assisted suicide: An analysis of the Kevorkian cases, 1990–1997.' OMEGA-Journal of Death and Dying 40.1 (2000): 165-208.*

L M Kohm and B N Brigner. 'Women and Assisted Suicide: Exposing the Gender Vulnerability to Acquiescent Death.' Cardozo Women's LJ 4 (1997): 241.*[full text available]

See also:

<u>S S Canetto and J D Hollenshead.</u> 'Older women and mercy killing.' *OMEGA-Journal of Death and Dying* 42.1 (2001): 83-99.*

K George, 'A Woman's Choice? The Gendered Risks of Voluntary Euthanasia and Physician-Assisted Suicide.' Medical law review 15.1 (2007): 1-33.*

It has also been argued that a feminist account of relational autonomy gives more ground to be cautious about permitting assisted suicide.

A Donchin, 'Autonomy, interdependence, and assisted suicide: respecting boundaries/crossing lines.' *Bioethics* 14.3 (2000): 187-204.*[full text available]

12. Links to some campaign organisations and further resources

Whichever side of the argument you find more cogent, it is useful to look at the opposite view and the counterarguments and evidence they produce, such as it is. Campaign organisations are, by their nature, one sided, but at the very least they raise questions and identify some relevant evidence.

Organisations in favour of legalising assisted suicide or euthanasia

In 2005 the Voluntary Euthanasia Society (founded 1935) changed its name to 'Dignity in Dying.' Its immediate aim is legalising physician assisted suicide for the terminally ill not, currently, euthanasia.

http://www.dignityindying.org.uk/

Society for Old Age Rational Suicide founded by Michael Irwin in 2009 differs from Dignity in Dying and overtly campaigns for assisted suicide for people who are not dying, but are tired of living.

http://www.soars.org.uk/

The largest organisation in the USA to campaign in favour of assisted suicide is Compassion & Choices (successor to the Hemlock Society which was founded in 1980).

http://www.compassionandchoices.org/

Also founded in 1980, The World Federation of Right to Die Societies no longer counts Dignity in Dying or Compassion & Choices as 'members,' but has links to them as 'non-members.'

http://worldrtd.net/

EXIT founded in 1982 is the main organisation that arranges assisted suicide for Swiss citizens.

http://www.exit.ch/en/

Organisations opposed to legalising assisted suicide and euthanasia

Founded in 2005, Care Not Killing is a UK-based alliance of individuals, disability and human rights groups, healthcare providers, and faith-based bodies opposed to assisted suicide and euthanasia.

http://www.carenotkilling.org.uk/

The Euthanasia Prevention Coalition (EPC) has an international scope. There is also a European arm.

http://www.epcc.ca/

http://www.epce.eu/

For a disability perspective see Not Dead Yet and the rather more British (and understated) Not Dead Yet UK.

http://www.notdeadvet.org/

http://notdeadyetuk.org/

A UK initiative in response to the Rob Marris Bill (introduced July 2015) is No To Assisted Suicide.

http://notoassistedsuicide.org.uk/

For an American perspective critical of assisted suicide see the websites of *Physicians for Compassionate Care Education Foundation*, the *Patients' Rights Council* and *'Choice' is an Illusion*.

http://www.pccef.org/

http://www.patientsrightscouncil.org/site/

http://www.choiceillusion.org/

News and comment

The excellent and free bioethics news service Bioedge frequently includes stories on these issues.

http://www.bioedge.org/

Alex Schadenberg (chair of EPC) has a blog, which is also very useful for news stories.

http://alexschadenberg.blogspot.co.uk/

Living and dying well is not a campaign organisation, but presents research and analysis of evidence relevant to (and critical of) assisted suicide and euthanasia.

http://www.livinganddyingwell.org.uk/

Further academic resources

This guide is intended only as an introduction to some of the resources for assessing the evidence and arguments for and against assisted suicide and euthanasia. It is, of necessity, selective as there are many hundreds of official reports, legal cases and journal articles on these topics. Students should research independently making use of academic indices and databases such as EBSCO, Lexis Nexis, Philosophers' Index, PhilPapers and MEDLINE. You should also 'follow the footnotes' reading the sources invoked by or criticised by the article you are reading.

The search engine Pubmed gives access to the MEDLINE database, which includes very many medical journals and also journals of medical ethics, and medically related humanities and social sciences. Unlike other indices it is freely accessible and is a good place for the non-specialist to begin more serious research. http://www.ncbi.nlm.nih.gov/pubmed