PATIENT SAFETY AND ASSISTED DYING: PROVIDING CHOICE AND PROTECTION.

Dignity in Dying campaigns for a law which would allow terminally ill, mentally competent adults the choice of an assisted death, subject to strict legal safeguards. Upfront safeguards would provide better protection to patients than current law and practice.

This briefing sets out the evidence for our position, and draws on experience and evidence from Oregon in the USA. Oregon's law has allowed terminally ill, mentally competent adults only the choice of an assisted death since 1997.

THE CURRENT SITUATION IN THE UK.

Current law and practice in the UK expose individuals and society to considerable risks.

- Evidence demonstrates patients' lives are being ended in the UK, illegally and without safeguards. 0.21% of deaths attended by a medical practitioner in the UK were as a result of voluntary euthanasia (i.e. the doctors directly and deliberately ending the patient's life, at their request) and 0.30% of deaths attended by a medical practitioner were as a result of life being ended without an explicit request from the patient (non-voluntary euthanasia).[1] These proportions translate to approximately 2,500 deaths out of 500,000 per year – a small, but significant, minority.

- Approximately 160 British citizens have been helped to end their lives in Switzerland and a further 800 are members of Dignitas[2 3], which has **much less stringent safeguards** than the law we propose.

- Other British patients who are too ill to travel, or who cannot afford to go to Switzerland, attempt suicide alone, or ask a loved one to help them die.[4] These practices take place in secret, **without safeguards**.

- The Director of Public Prosecutions' (DPP's) prosecuting policy on assisted suicide has given citizens greater clarity on how prosecutorial discretion is exercised,[5] and effectively decriminalises amateur assistance to die. However, all checks take place after a person has died, when it is too late to prevent potential abuse – there are **no upfront safeguards.**

Society must consider which best protects vulnerable people: retrospective checks such as those offered by the DPP's prosecuting policy, which take place after a person has died; or assisted dying legislation which ensures cases are considered when someone asks for help to die, when they are still alive, and when their diagnosis, prognosis and mental capacity can be checked, and possible alternatives explored.

ASSISTED DYING SAFEGUARDS.

The safeguards outlined below are the minimum that an assisted dying law should provide. These would offer protection to all individuals requesting assistance, not just potentially vulnerable adults.

- The individual must be a **terminally ill adult** who is a resident of the UK. People with a chronic illness or disability (unless they were also terminally ill) would not be eligible. There are several definitions of terminal illness currently used in the health service and by Government which could be incorporated into the legislation.[6]

- The patient must have **mental capacity** to make the decision, and be referred to a psychiatrist for assessment if there is any doubt about this.

- The process must be entirely **voluntary and initiated by the patient** – a doctor could not suggest assisted dying.

- **Two doctors,** a consultant doctor and an independent doctor, must agree that the **patient meets the eligibility criteria** set down in the legislation (terminally ill, mentally competent, making a voluntary request and so on).

- The doctors must inform the patient that they **can revoke their request** at any time.

- There must be discussions to explore **why** the patient wants an assisted death, and what pain and symptom relief is available, as well as **other palliative and supportive options**. All patients who request an assisted death must have been offered palliative care.

- A **'cooling off' period** between the request for assistance being formally accepted (i.e. after all the safeguards have been met) and receiving the life-ending prescription (e.g. 14 days) to ensure that patient has further time to consider their actions.

- The patient must **self-administer** the life-ending medication, ensuring that they make the decision and are in control of the final act. The doctor does not end the patient's life directly; rather the patient controls their own death.

- Data would be recorded to ensure the process was effectively **monitored** and reported.

EVIDENCE FROM OREGON.

Research evidence from Oregon demonstrates that the safeguards in place work well. The Oregon Hospice Association initially opposed assisted dying, but after eight years of the law it found *'There is no evidence that assisted dying has undermined Oregon's end-of-life care or harmed the interests of vulnerable people'*.[7]

In fact, Oregon's experience demonstrates that fears of a 'slippery slope' following legislation to allow terminally ill, mentally competent adults assistance to die are not founded.

- **Eligibility has not been extended:** Eligibility for assistance to die has not widened beyond 'terminal illness', nor has there been any pressure for such a change. Of the 525 people who have died using the legislation since 1997, 424 had cancer, 42 had MND, 20 had chronic lower respiratory disease and 39 had other illnesses.[8]

- **Potentially vulnerable groups are not being disproportionately assisted to die:** Research examining 10 potentially vulnerable groups including disabled people, adults aged 85 and above, the poor, and those suffering from psychiatric illness, found no evidence of heightened risk.[9] The researchers state: *'Where assisted dying is already legal, there is no current evidence for the claim that [assisted dying] will have disproportionate impact on patients in vulnerable groups.'*

- **Research is being used to improve processes:** A level of 'appropriate sadness' or depression is considered normal in terminally ill patients,[10] and the existence of depression does not mean a person lacks mental capacity. One study found that 1 in 4 patients who requested assisted dying and

1 in 6 who died had symptoms of depression.[11] However, the researchers acknowledged that some of the indicators used to measure depression may have in fact been measuring the side effects of terminal illness (e.g. loss of appetite). This has lead to increased academic and clinical discussion/work on identifying potential depression in terminally ill patients.

- **People choose assisted death for 'person centred' reasons, not due to external forces:** *Loss of autonomy, being less able to engage in enjoyable activities and loss of dignity* are the main reasons behind patients' choosing an assisted death, whilst *inadequate pain control* and *burden* are less frequently cited as reasons.[12] Research has found that where burden is mentioned, this tends to be strongly related to patients' concerns about personal autonomy, rather than being reflective of patients' communication with their families.[13]

- **People choosing assisted dying do not do so due to a lack of other options:** Palliative care in Oregon is delivered to a very high standard. Both palliative and supportive options are explored and utilised. In 2010, 92.6% of patients who had an assisted death were enrolled in hospice care at ti me of death.[14]

- **Numbers remain low:** Assisted dying figures have not risen above 0.2% of all deaths in Oregon since legalisation.[15]

- **Many more people benefit from having the choice:** Approximately 40% of patients who are given the life-ending prescription do not use it, but request it as 'emotional insurance' – so they know it is there if their suffering becomes too much. [16]

CONCLUSION.

People are being helped to die in the UK, illegally and without safeguards. An assisted dying law would provide far greater protection to people than the current law, by ensuring that checks take place before a person dies.

Dignity in Dying believes the UK should introduce a similar law to the Oregon Death with Dignity Act (1997), which, since it came into force, has demonstrated that safeguarded assisted dying can work safely and well. However, we need to ensure such a law is appropriate for the UK, and to build and improve on the Oregon model, for example, we are considering building in a compulsory evaluation with a specialist consultant psychiatrist as part of future legislation.

Evidence demonstrates that legislation on assisted dying would give dying people the choice to control the manner and timing of their death, should their suffering become unbearable. It would also make the UK a safer place for vulnerable people.

A change in the law is essential if people are to have both choice and protection.

ABOUT DIGNITY IN DYING.

Dignity in Dying campaigns for your rights at the end of life.

We are a national campaign and membership organisation. With 25,000 supporters we work to alleviate suffering at the end of life by campaigning for greater choice, control and access to services.

We want everyone to have what they consider to be a good death, including the option of an assisted death for dying adults who are mentally competent.

We believe that everyone has the right to a dignified death.

This means:

Choice over where we die, who is present and our treatment options.

Access to expert information on our options, good quality end-of-life care and support for loved ones and carers.

Control over how we die, our treatment and pain relief, and planning our own death.

We are funded entirely by our supporters and are independent of any political, religious or other organisation.

For more information contact a member of our policy team at:

Dignity in Dying
181 Oxford Street, London W1D 2JT

T 020 7479 7730
F 020 7287 1760
E info@dignityindying.org.uk
www.dignityindying.org.uk

Follow us on:
www.facebook/dignityindying
@dignityindying

ENDNOTES.

1 Seale C (2009) End-of-life decisions in the UK involving medical practitioners *Palliative Medicine* 23: 198-204

2 Daily Mail (2011) Britons die at Dignitas suicide clinic in record numbers, 17 April 2011

3 Guardian (2009) 800 Britons on waiting list for Swiss suicide clinic, 31 May 2009

4 For example, Telegraph (2010) Wife of cricket star Chris Broad took her own life amid motor neurone disease battle, 15 September 2010

5 Crown Prosecution Service (2010) Policy for Prosecutors in Respect of Cases of Encouraging or Assisting Suicide

6 For example, in order to receive Disability Living Allowance under the special rules for terminally ill people, a patient's doctor confirms that they have a progressive disease and are not expected to live for more than six months, www.direct.gov.uk.

7 Jackson, A, Oregon Hospice Association, (2006) The Reality of Assisted Dying in Oregon, All Party Parliamentary Group on Compassion in Dying, House of Lords, 19th April 2006

8 Oregon Department of Human Services (1998-2010) Summary of Oregon's Death with Dignity Act

9 Battin MP, van der Heide A, Ganzini L et al (2007) Legal physician-assisted dying in Oregon and the Netherlands: evidence concerning the impact on patients in 'vulnerable' groups *Journal of Medical Ethics* 33: 591-97

10 Ganzini L, Dobscha S (2003) If it isn't depression... *Journal of Palliative Medicine* 6(6): 927-931

11 Ganzini L, Goy E, Dobscha S (2008) Prevalence of depression and anxiety in patients requesting physicians' aid in dying: cross sectional survey *British Medical Journal* 2008:337;a1682 doi:10.1136/bmj a16782

12 Oregon Department of Human Services (1998-2010) Summary of Oregon's Death with Dignity Act

13 Ganzini, L et al (2002) 'Experiences of Oregon nurses and social workers with hospice patients who requested assistance with suicide', *New England Journal of Medicine* 2002(b); 347: 582-88

14 Oregon Department of Human Services (2011) Summary of Oregon's Death with Dignity Act Annual Report 2010

15 Oregon Department of Human Services (1998-2010) Summary of Oregon's Death with Dignity Act

16 Ganzini L, Beer Tm Brouns M et al (2006) Interest in physician assisted suicide among Oregon cancer patients *Journal of Clinical Ethics* 17: 27-38

CAMPAIGNING FOR YOUR RIGHTS AT THE END OF LIFE

Dignity in dying