Dying With Dignity NSW
PO Box 25, Broadway NSW 2007
Phone (02) 9212 4782
Fax (02) 9211 1498
www.dwdnsw.org.au
WHO WE ARE

Dying with Dignity NSW (DWDnsw) is an active law reform organisation pursuing a change in the law that will enhance self-determination and dignity at the end of life. Our aim is legislation that entitles a mentally competent adult experiencing unrelievable suffering from a terminal or incurable illness to receive medical assistance to end their life peacefully, if that is what he or she wants. As well as our role in advocacy and lobbying to bring about a change in the law, we promote the use of Advance Care Directives to assist with patient control at the end of life (EOL) and we provide our members with information about changes in the legal climate for EOL, both in Australia and overseas. We are a not-for-profit organisation limited by guarantee and we rely on membership, donations and bequests in order to continue our work.

DWDnsw supports the initiation of the Victorian Parliament’s Inquiry into End of Life Choices and welcomes the fact that it will foster a much-needed and informed debate about EOL decision-making in Australia, a process which will benefit both Victoria and the other states and territories. The question of end of life choices, including the possibility of a request for physician-assisted dying (PAD), is a very emotional issue about which there is much fear-mongering and misinformation. We urge the Legal and Social Issues Committee to conduct a rigorous and open-minded examination of the evidence from jurisdictions in which regimes of physician-assisted dying exist to determine whether in fact there is any evidence of abuse. DWDnsw believes that research conducted by both the regulating bodies and independent academic researchers indicates that, with appropriate safeguards and monitoring, such regimes operate safely.
WHY A BILL TO ALLOW PHYSICIAN-ASSISTED DYING (PAD) IS NEEDED

Patients’ Rights and Autonomy

DWDnsw believes that just as patients currently have control over the kind and extent of medical treatment they receive, they should also have control over the time and circumstances of their dying as long as appropriate safeguards are in place. This has been expressed as follows: “a competent terminally ill patient seeking a quick painless death does not represent any harm to others in society and in the absence of such a threat the state does not have the right to subjugate the individual’s autonomy”. (1)

Compassion

In a situation where a person is undergoing unbearable pain and suffering, either physical or mental, and where there are no reasonable measures which might relieve that suffering, it is a compassionate society which provides a safe environment in which such a person can ask for assistance to die. An appropriate legal framework would also provide protection for doctors who wish to compassionately assist a patient, in line with their duty of care, but who at present are not protected if they do so.

Loss of dignity and loss of quality of life

As demonstrated by the experience in Oregon (see separate document attached), where assisted dying is legal, the most important reason given by patients for requesting assisted dying is the loss of dignity and diminution in quality of life suffered by patients in the last stages of a terminal illness or degenerative disease (2). Often in such circumstances all normal autonomous action (for example, communication, control over movement, control over urination and defecation, ability to clean and dress oneself) is impossible and all quality of life is lost, that is, all the activities that used to give purpose and meaning to the person are no longer available.
**Existing End of Life (EOL) management**

A number of EOL practices are currently standard, including opioid use, withholding or withdrawing of treatment (such as CPR, antibiotics and artificial ventilation), withdrawal of artificial nutrition and hydration (ANH) and terminal sedation. In these cases patients die over a relatively longer period, often of starvation and thirst, and often in a coma. We argue that such treatments are not dignified or effective in that they extend life but not in a way that is profitable to the patient. We argue that in appropriate circumstances, and when requested by the patient, that assisted dying should be another option in the suite of EOL practices and be a natural part of good patient care, and within the offerings of normal palliative care.

An additional point here is that at the moment, in the absence of a clear framework for EOL decision-making, there are some legal grey areas even in the existing range of options available and having a clear assisted dying regime would also provide a safer framework in which to offer treatments such as withdrawal of ANH and terminal sedation.

**Euthanasia and Assisted Dying now occurring “under the table”**

There is considerable evidence from both Australia and overseas to show that there is a “euthanasia underground” (3). This evidence is summarised in the *Australia 21 Report*, as follows:

“A study by Kuhse et. al. concluded that in 1995-6, 1.8% of all deaths in Australia occurred due to VE and 0.1% were due to physician assisted suicide (PAS). ...[T]hese statistics are broadly comparable with the position in permissive jurisdictions. ... A qualitative study by Magnusson documented sustained unlawful conduct relating to voluntary euthanasia (VE) and assisted suicide (AS). .... There is also a body of anecdotal evidence... In 1995 seven Melbourne doctors (one of whom was Dr. Rodney Syme) published an open letter to the Victorian premier admitting to having performed euthanasia.” (4)
In addition, the absence of a regime for assisted dying has meant that desperate individuals have been taking extreme steps to end their lives when their suffering has become intolerable. This includes suicide by various gruesome means such as hanging, poisoning, suffocation etc. Australian Bureau of Statistics figures show that “the oldest group (85 years and over) [had] the highest suicide rate (28.2 per 100,000) in 2009.” (5)

_In some cases, palliative care is insufficient_

Palliative Care Australia acknowledges that even with access to the very best palliative care services, in some cases the management of a patient’s suffering is intractable.

In a 2006 Policy Statement the Palliative Care Australia Council wrote,

> “While pain and other symptoms can be helped, complete relief of suffering is not always possible, even with optimal palliative care.”

_The Termination of Life on Request and Assisted Suicide (Review Procedures) Act in Practice_ report published by the Netherlands Ministry of Foreign Affairs in 2010 says,

> “Unfortunately, even where patients are receiving palliative care of the highest quality, they may still regard their suffering as unbearable and plead with their doctors to terminate their lives. In such cases, euthanasia could represent a dignified conclusion to good palliative care.”

Many of our members have reported their personal stories to DWDnsw. Often, these include harrowing accounts of a loved one with intolerable suffering for whom all treatment was futile. In these rare cases it is of paramount importance that Australia has in place a coherent and transparent regulatory framework that brings matters into the open and protects both medical practitioners and suffering individuals.

_Australia is far behind comparable countries in its consideration of end of life decisions._

According to White and Wilmott (Australia 21 Report) “Australian human rights jurisprudence generally is much less developed than in other similar
jurisdictions such as Canada and the United Kingdom”. Canada has a bill of rights known as the Canadian Charter of Rights and Freedoms, and in a recent landmark case (Carter versus Canada) in the Supreme Court of British Columbia, the judge ruled that the prohibitions of assisted dying in the Canadian Criminal Code violated the humans rights enshrined in the charter and were thus invalid.

The Royal Society of Canada (the umbrella body for the three Learned Academies) has recently conducted a substantial report outlining the options for law reform in Canada and has recommended that AS and VE be decriminalised (p. 96). In June 2014 Canada’s Quebec province adopted legislation allowing terminally ill patients to kill themselves with a doctor’s help, becoming the first jurisdiction in the country to effectively legalise assisted suicide.

In the UK the Director of Public Prosecutions has developed a policy for PAD outlining the circumstances under which it is not in the public interest to prosecute such cases, patient welfare and patient’s rights being the uppermost considerations. In addition in the UK there was an All Party Parliamentary Group (APPG) on Choice at the End of Life. It commissioned a Commission of experts to examine the options for law reform in the UK (the Falconer report). The Commission took voluminous evidence from experts, stakeholders and the public and the result is a highly sophisticated account of the terrain. They concluded as follows:

“The majority of the Commissioners consider that it is possible to devise a legal framework that would set out strictly defined circumstances in which terminally ill people might be assisted to die, supported by health and social care professionals, and which would employ robust upfront safeguards to prevent inappropriate requests from going ahead. The evidence we have received in the Netherlands, Belgium and Oregon suggests that such a framework could be safer than the status quo, while also providing terminally ill people with more choice and control at the end of life.” (p. 299). Subsequently the House of Lords passed an Assisted Dying Bill through to Committee stage and an amended Bill will be put to the House of Lords in September 2015.
Assisted dying and palliative care are not alternatives – they go and should go together.

Critics of VE/AS law reform often pose palliative care as if it were inevitably a better alternative and as if it is an either/or situation, that is, either VE or palliative care. But many of the best-informed advocates of end of life choice are palliative care specialists and see VE/AS as part of good palliative care and as part of the spectrum of options available.

This view is continually emphasised by the Falconer Report which saw any assisted dying regime to be part of a holistic national plan to improve health and social care services and support universal access to high quality end of life care (p. 20). They also report research by the European Commission showing that palliative care is highly developed in those countries with assisted dying regimes and indeed, the standard of palliative care in Belgium and the Netherlands has improved since their schemes were introduced.

Dr Timothy Quill, one of the world’s leading experts on palliative care and an advocate for strictly regulated assisted dying has the following to say:

“Let me begin by reinforcing that excellent palliative care should be the standard of care for all dying patients, and no patient should be medically assisted with a hastened death because she is not receiving the standard of care. Palliative care, if applied with skill and expertise, can address most, but not all, end-of-life suffering. ... But a small percentage of dying patients will still experience suffering that can become intolerable and unacceptable, and a sub-set of those will want assistance helping death come earlier rather than later”. (6)

Australians want assisted dying law reform

Opinion polls in Australia consistently show strong support for a regime of voluntary assisted dying. Polls taken by a variety of polling organisations over the last ten years have registered rates if between 70% and 85% for change. (For more information go to the DWDnsw web-site http://www.dwdnsw.org.au/index.php/article/public-opinion).
OPPOSITION TO THE IDEA OF PHYSICIAN-ASSISTED DYING (PAD)

Religious opposition
Much opposition to PAD stems from religious conviction. We respect people’s right to a conscientious objection to PAD and would not be in favour of compelling doctors with such a position to carry out PAD. We also respect the right of people with religiously based convictions against PAD to not participate in such practices themselves. However, we firmly believe that people with religious objections to PAD should not impose their convictions on those who do not share their beliefs. We note that there is nothing inherent in having religious faith that prevents a person being in favour of PAD. The organisation, Christians Supporting Choice for Voluntary Euthanasia is of the view that a Christian view of compassion would lead to the position that in some circumstances, PAD is merciful and therefore virtuous.

The “Slippery Slope”
Opponents of PAD adduce the experience of the Netherlands and Belgium to argue that once you allow PAD for terminally ill people, it is soon extended to other categories, such as people who are “tired of life”, those with debilitating but non-terminal illnesses, the mentally ill, the handicapped and children. But this is a specious argument. There is no automatic slippery slope. Any change to a regime of PAD could not be introduced at the whim of the doctors. A regime with strict safeguards, such as those that have been envisaged in Bills introduced in both the Tasmanian and NSW parliaments in recent years, would not permit any automatic extension to new categories of cases. Any changes would have to be debated in the community and introduced by legislation after rigorous examination by the relevant parliament.

Risk of abuse
Opponents of PAD often say, “I could not support a regime of PAD if there was even the slightest risk of it being abused.” This is to demand a level of risk
avoidance which we do not demand in any other area of life. Consider our attitudes to driving. We know that driving on our roads carries what might be considered quite a high risk of injury and death. We do not say “If there is even the tiniest risk of injury or death from driving, we should ban driving cars.” What we do instead is operate a system of regulation and sanction which seeks to limit the risk to an acceptable level. It would be foolish of proponents of PAD to argue that it is possible to devise a framework for the practice that would reduce the level of risk to zero. Rather, what we would do is have a set of safeguards that minimized the risk. Most regimes that have hitherto envisaged in Australia, including the Tasmanian and NSW cases mentioned before, have contained what might be consider almost overly strict requirements for a person to be able to lawfully ask for help to die. These include:

- examination by two independent medical practitioners,
- a psychiatric examination, attesting that the person has decision-making capacity
- absence of coercion,
- a requirement that all treatments, including palliation have been tried
- the prohibition of anyone who stands to gain from the death from participating at any stage of the process,
- oversight by a regulatory body,

Such a regime would have a negligible level of risk attached to it.

Other jurisdictions

As outlined above the two jurisdictions that are most often mentioned by opponents of PAD as “horror stories” are the Netherlands and Belgium. But the regimes for PAD (or voluntary euthanasia) that have been established in those two countries are very different in nature from anything ever envisaged for Australia. However, conveniently, another case, much closer to what would be envisaged in Australia, namely Oregon, is not mentioned. This is because the case of Oregon does not support any attempt at beating up fear about PAD. I attach an appendix which describes the law in Oregon and gives details of how it has operated.
CONCLUSION

DWDnsw places emphasis on the principle of autonomy when considering end of life care. It should be a matter for the patient to decide what constitutes intolerable suffering and which treatment options best suit them. As a patron of the advocacy organisation Dying In Dignity UK, Sir Patrick Stewart said,

“We have no control over how we arrive in the world. But at the end of life we should have legal control over how we leave it.”

The Netherlands Report mentioned above reads,

“Experience shows that many patients find sufficient peace of mind in the knowledge that the doctor is prepared to perform euthanasia and that they ultimately die a natural death.”

According to the Oregon Health Authority’s annual report on The Oregon Death With Dignity Act, on average one third of patients prescribed life-ending medication in accordance with the act do not take the medication and subsequently died of other causes. However, it is reported that just having the medication, which they know can be used if their situation becomes intolerable, eases the patient’s mind and gives them extra strength to carry their burden.

And as stated earlier, a competent terminally ill patient seeking a quick painless death does not represent any harm to others in society and in the absence of such a threat the state does not have the right to subjugate the individual’s autonomy.
Footnotes


5. Australian Bureau of Statistics, 4125.0 – Gender Indicators, Australia, Jan 2012

RESEARCH REPORT ON EUTHANASIA LAWS

CASE STUDY – Oregon USA

October 2012

NAME OF ACT: Oregon Death with Dignity Act (DWDA). The Act was a citizens’ initiative passed by Oregon voters twice: first, in a general election in 1994 (but delayed by injunction until 1997); second, in a general election in 1997 where 60% of voters rejected a motion to repeal the Act. The DWDA explicitly prohibits euthanasia (i.e. a physician or other person directly administers a medication to end life).

There was a federal lawsuit against Oregon’s Death with Dignity law in 2001 initiated by Bush administration appointee, pro-life Attorney-General John Ashcroft. The federal action sought to control drug availability and prosecute physicians. The lawsuit was finalised in 2006 with Oregon’s law remaining in effect.

CAME INTO EFFECT: November 1997

AMENDMENTS: In 1999, the Oregon legislature added a requirement that pharmacists must be informed of the prescribed medication’s intended use.

CENTRAL PRINCIPLES:

The Act allows terminally-ill Oregonians to end their lives through the voluntary self-administration of lethal medications, expressly prescribed by a physician for that purpose.

Action taken in accordance with the DWDA does not constitute suicide, mercy killing or homicide under the law. It will not affect insurance policies or superannuation.

Physicians, pharmacists and health care systems (e.g. Catholic hospitals) are under no obligation to participate in DWDA.

WHO CAN PARTICIPATE IN THE ACT?

To request a prescription for medication, the DWDA requires that a patient must be:

- An adult (18 years of age or older)
- A resident of Oregon
- Capable (defined as able to make and communicate health care decisions) and
- Diagnosed with a terminal illness that will lead to death within 6 months.

OTHER PROVISIONS:

Physicians must report to the Oregon Department of Human Services all prescriptions for lethal medications.

REQUESTING A PRESCRIPTION FOR LETHAL MEDICATION

To request a prescription for lethal medication from a licenced physician, the following steps must be fulfilled:

- The patient must make two oral requests to his or her physician, separated by at least 15 days (a ‘cooling off’ period)
• The patient must provide a written request to his or her physician, signed in the presence of 2 witnesses
• The prescribing physician and a consulting physician must confirm the diagnosis and prognosis
• The prescribing physician and a consulting physician must determine whether the patient is capable
• If either physician believes the patient’s judgement is impaired by a psychiatric or psychological disorder, the patient must be referred for a psychological examination
• The prescribing physician must inform the patient of feasible alternatives to DWDA, including comfort care, hospice care, and pain control
• The prescribing physician must request, but may not require, the patient to notify his or her next-of-kin of the prescription request.

A patient can rescind a request at any time and in any manner.

WHAT KIND OF LETHAL MEDICATION?

Usually an oral dose of barbiturate (Seconal or Nembutal)

The doctor does not have to be there, but has to be if the patient requests it so long as the doctor does not administer the medication.

REPORTING AND REVIEW:

Physicians must report to the Oregon Department of Human Services all prescriptions for lethal medications. Reporting is not required if patients begin the request process but never receive a prescription. Hence, unlike The Netherlands, there are no data on the number of requests.

Cases of death from palliative care where there is no intent to kill (e.g. administering increased opioid medication, palliative sedation) are not reportable under the Act.

The Act requires the Oregon Health Authority to collect and analyse data on who participates in the Act and issue an annual report. These can be found at http://public.health.oregon.gov/ProviderPartnerResources/EvaluationResearch/DeathwithDignityAct/Pages/ar-index.aspx

If the attending physician does not comply with the prescribing and reporting requirements of the Act the Oregon Health Authority will notify the Board of Medical Examiners which will determine any disciplinary action, if any.

HOW AND WHERE IS THE LETHAL DOSE ADMINISTERED?

A pharmacist fills the prescription for the lethal medication and the patient usually ingests it at home. Most (94.1%) patients died at home; and most (96.7%) were enrolled in hospice care at the time the DWDA prescription was written or at the time of death (OPHD, 2012, p.2).

HOW MANY DEATHS HAVE HAPPENED UNDER THE ACT?

Since the law was passed in 1997, a total of 596 patients have died from ingesting medications prescribed under the DWDA.

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One of the 71 DWDA patients who died during 2011 was referred for formal psychiatric or psychological evaluation (OPHD, 2012a, p.3). There are usually a few of these cases a year, though not every year, and it has been decreasing over time (OPHD, 2011a, p.2).

Prescribing physicians were present at the time of death for six patients (8.5%) during 2011 compared to 18.7% in previous years (OPHD, 2012a, p.3).

Over the period of the law being in place there have been about 20 ‘failures’, where the patient did not die for a variety of reasons (regurgitation, just woke up, developed tolerance to the medication etc). All these patients died later (weeks, months) from their underlying illness (OPHD, 2012b, p.2).

Although the rate of prescription and deaths is gradually increasing year-by-year, Death with Dignity is the choice of a small minority of Oregon residents, comprising less than 1% of all deaths each year or, in absolute numbers, less than 100 deaths a year. There is no evidence of the feared migration of terminally ill patients to Oregon to take advantage of the DWDA.

PROFILE OF PATIENTS AND REASONS FOR REQUEST

Of the 71 DWDA deaths during 2011, most (69%) were aged 65 years or older; the median age was 70 years. As in previous years, most were white (95.6%), well-educated (48.5% had at least a baccalaureate degree), and had cancer (82.4%).

Across the period of the DWDA, the three main concerns among those who have died were loss of autonomy, decreased ability to participate in enjoyable activities and loss of dignity (OPHD, 2011a, p.1). This is similar to other years. Coming in at 4th and 5th over the period 1998-2010 were ‘losing control of bodily functions’ and ‘burden on family’ (OPHD, 2012b). Interestingly, the DWDA does not stipulate the requirement for ‘unbearable suffering’ as The Netherlands law does.

Most of the people who have died under the DWDA were elderly, well-educated, white people who were cancer sufferers. They were mainly concerned about loss of autonomy and dignity, and being unable to participate in enjoyable activities due to their illness. Being a ‘burden on the family’, though also a concern, is not cited as a main reason for requesting a prescription by a majority (two thirds) of patients on average.

This profile and reasons for request have remained consistent over the period of the DWDA.

There is no evidence of a ‘slippery slope’ of DWDA leading to non-voluntary deaths among vulnerable groups: the poor, the disadvantaged, the disabled, the mentally ill etc.¹

¹ This represents 22.5 DWDA deaths per 10,000 total deaths or a bit less than 1% of all deaths. This is slightly higher than the The Netherlands’ physician-assisted suicide rate of around 0.2%, but note that voluntary euthanasia is available in the Netherlands, and that is the more popular choice. In other words, the higher rate of self-administered suicide in Oregon is likely to be in lieu of the non-availability of euthanasia. But still, it is a very low figure.
HAVE ANY PHYSICIANS BEEN PROSECUTED FOR NON-COMPLIANCE WITH THE DWDA?

No, but there have been reported incidents of non-compliance in previous annual reports (ranging from 1 to 10, in some but not all years). In 2011 no referrals were made to the Oregon Medical Board for failure to comply with DWDA requirements (OPHD, 2012a, p.3). There have been a total of 22 referrals since 1998 (OPHD, 2011a, p.2)

PHYSICIAN-ASSISTED SUICIDE AND OTHER END OF LIFE CARE

The Oregon figures also show how many of those who died from assisted suicide were enrolled in Hospice care. I don’t know what enrolled in hospice care means and what services are provided. Is this palliative care perhaps? But in any event, about 97% of those who died in 2011 were enrolled, and over the period 1998-2010, an average of 90% of those who died were enrolled (OPHD, 2011a, p.1; 2012b, p.1).

| Physician-assisted suicide is not practiced apart from or as an alternative to end-of-life care such as hospice (palliative?) care. In fact, enrolment in hospice care has grown. This is similar to the Netherlands. |

REFERENCES


Oregon Public Health Division (OPHD) (2012b). Table 1. Characteristics and end-of-life-care of 596 DWDA patients ......................... Accessed 25/9/12