

## **DYING WITH DIGNITY: Euthanasia and Assisted Dying-Update**

It wasn't so long ago that the average life expectancy was well under 60 years and death was generally relatively quick and at home.

With the advent of antibiotics and other sophisticated medication and surgery, people now live well into their 80's and 90's. However, the process of dying has become increasingly protracted and complicated, as people are more likely to die from chronic and degenerative diseases that cause a gradual decline in health over long periods of time.

In Australia, a patient has no legal right to insist on medical intervention that would end his or her life. Indeed, in most countries, euthanasia and any form of assistance given to hasten the death of a person, even at their request, is illegal.<sup>1</sup>

But what are the options for a patient afflicted with an incurable terminal illness and suffering unbearable physical pain and/or mental anguish?

### **Patients Refuse Treatment**

Patients can refuse all treatment, including food and water. However, this may result in a painful death, at least psychologically and the time of death can vary from a few days to weeks.

### **Withdrawing and withholding medical treatment**

In Australia, when patients do not have the capacity to make decisions about their ongoing medical treatment, the decision to withhold or withdraw life sustaining treatments can be very difficult, particularly where there are disputes between family and medical practitioners or concerns about the lawfulness of a proposed course of action. Occasionally the decision must be resolved by a Court or Tribunal. Courts have generally authorized cessation of treatment where it has been found to be futile and confers no further benefit on the patient. However, the courts have had to grapple with such questions as what is in the best interests of the patient; what pain and indignity is being inflicted upon the patient; and what is excessively burdensome treatment.

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<sup>1</sup> After all this is also consistent with the classical form the Hippocratic Oath, which in part stated: *Nor shall any man's entreaty prevail upon me to administer poison to anyone, neither will I counsel any man to do so...*

These cases raise difficult issues for all parties concerned - the voice of the patient can no longer be heard.<sup>2</sup>

### Continuous palliative sedation

It is also lawful for doctors to provide adequate pain relief, even if this has the unintended consequence of ending a patient's life.<sup>3</sup>

Terminal sedation involves a continuing and increasing infusion of morphine and other opiates and sedatives to relieve pain until the patient is rendered unconscious. During this time the patient is not given any food or fluids, leading to dehydration, respiratory and/or organ failure. It is then difficult to determine whether death results from the disease or the palliative care.

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<sup>2</sup> *Application of Justice Health; Re a Patient* (2011) 80 NSWLR 354; [2011] NSWSC 432: The New South Wales Supreme Court declared that life-sustaining treatment for a prisoner with end-stage lung cancer, who lacked capacity and was expected to live for only a matter of days or weeks, was futile and need not be given; *Slaveski v Austin Health* [2010] VSC 493: The Victorian Supreme Court held that continuing artificial ventilation for a 71-year-old man in a coma from a catastrophic stroke was burdensome and not in the man's best interests. The medical team did not need to provide treatment despite family requests; *Australian Capital Territory v JT* (2009) 4 ACTLR 68; [2009] ACTSC 105: The ACT Supreme Court held that artificial nutrition and hydration was not futile for a 69-year-old man with a psychiatric illness manifesting in religious obsessions which led to extreme fasting. The court declined to make the declaration sought by the government that it would be lawful to stop this treatment; *Melo v Superintendent of Royal Darwin Hospital* (2007) 21 NTLR 197; [2007] NTSC 71: The Northern Territory Supreme Court held that treatment for a 29-year-old man with catastrophic injuries sustained in a motor vehicle accident, including high-level fractures of the cervical spinal cord and brain damage, was futile. Despite family requests, the court did not require continued treatment; *In the Matter of Herrington; Re King* [2007] VSC 151: The Victorian Supreme Court declined to order that active treatment (including the administration of fluids) be continued for a woman with hypoxic brain damage who had been in a vegetative state for 6 months. It held that the medical team should progress with palliative care despite family request for more active treatment; *Queensland v Astill* (unreported, Supreme Court of Queensland, Muir J, 18 January 2006): The Queensland Supreme Court ordered blood transfusions be given to a woman injured in a motor vehicle accident despite her possessing a "no blood" card. This card did not comply with formalities of Queensland legislation and so did not operate. Treatment was ordered to promote the patient's welfare; *Messiha v South East Health* [2004] NSWSC 1061: The NSW Supreme Court held that active treatment for a 75-year-old man, who suffered severe brain damage after he collapsed at home and his brain was deprived of oxygen for 25 minutes, was futile, burdensome and intrusive and should not be continued. The court did not accept the family's view that treatment was in the patient's best interests; *Northridge v Central Sydney Area Health Service* (2000) 50 NSWLR 549; [2000] NSWSC 1241: The NSW Supreme Court reinstated active treatment for a man with brain damage following a drug overdose. The court held that the diagnosis that he was in a "chronic vegetative state" and the decision to withdraw treatment were premature, contrary to the hospital's own guidance, and not in the patient's best interests. in 2005 France, introduced the Leonetti law under which, the law allows doctors to decide to 'limit any treatment that is not useful, is disproportionate or has no other object than to artificially prolong life' and to use pain killing drugs that might 'as a side effect, shorten life.' 'Euthanasia and assisted suicide laws around the world.' by Sabine Cessou, Kim Willsher, Lauren Gambino, Philip Oltermann and Leo Cendrowicz – *Guardian*, 18 July 2014.

<sup>3</sup> The Australian Medical Association's Code of Ethics states that doctors should provide treatment for pain and suffering 'even when such therapy may shorten a patient's life'. viewed 30 March 2016, <ama.com.au>, p. 1.4(c).

Medication given with the intention of relieving suffering, not to hasten death, although it may also have that effect, is performed routinely as part of palliative care. However, the medical profession recognizes that, even with the best palliative care, some patients continue to suffer extreme pain, shortness of breath, agitation and psychological distress, and remain conscious notwithstanding therapeutic doses of morphine and other relevant drugs. In certain conditions excessive levels of opiates can increase the patient's suffering. These patients are condemned to a horrible death.

Furthermore, there is not a clear demarcation between the level of adequate pain relief for a particular patient and that level which will accelerate death. Doctors can be faced with an impossible dilemma. Doctors should be able to provide necessary pain relief without fear of potential legal repercussions.<sup>4</sup>

There is no question that in Australia, as confirmed by many surveys of doctors, and anecdotally in many jurisdictions, doctors assist patients to die. However, unlike in jurisdictions where assisted dying is lawful, it is done without guidelines, controls or review.

There is growing recognition of a person's right to determine their own destiny and whether they choose to live under any circumstances, in particular, under unbearable suffering from a terminal, incurable and untreatable condition. This year there have been two significant developments:

First, in February 2016 the Voluntary Euthanasia Bill 2016 was introduced into the South Australian Lower House of Parliament. Debate on the Bill was adjourned in June. I hope I can report on the outcome of this Bill in the near future.

Secondly, in June 2016, a Parliamentary Committee in Victoria Australia tabled a report in the Victoria Parliament entitled: Inquiry into End of Life Choices, which recommends legislation for an Assisted Dying Framework. The Report is extremely comprehensive and I draw upon its analysis of the law and practice in overseas jurisdictions, where some form of euthanasia and/or assisted dying is legal. The Committee concluded that the status quo is simply not acceptable.

Before dealing with the Assisted Dying Framework recommended for Victoria, it is appropriate to briefly summarize the law and practice in those

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<sup>4</sup> Inquiry into End of Life Choices, Parliament of Victoria Legal and Social Issues Committee, Final Report June 2016, [Herein referred to as 'The Victorian Report'], refer Chapters 3 &7, 7.2.1.

jurisdictions where some measure of voluntary euthanasia has been legalized. For the purpose of this address, I use the following definitions:

Euthanasia: Intentional termination of life by someone other than the person concerned at his or her request.

Assisted Dying: Intentionally helping a patient to terminate his or her life at the patient's request.

Currently, specific legislation permitting a prescribed assisted dying regime only exists in The Netherlands, Belgium, Canada, Luxembourg, Switzerland and the States of Oregon, Washington State and California in USA. By the end of 2016 over 100 million people on 3 continents will have access to assisted dying laws.<sup>5</sup>

## International Jurisdictions

### **Oregon USA<sup>6</sup> [Assisted suicide]**

#### Background

In 1997 assisted dying became legal in Oregon under the *Death with Dignity Act*. The legislation followed two referendums, the first in 1994 when the public voted in favour of the Bill by 51% to 49%;<sup>7</sup> and a further referendum in 1997 when the Bill was supported by 60% of the vote. The Medical Association took a neutral position in the public debate.

#### Eligibility and safeguards

In Oregon, only assisted suicide is legalized, not euthanasia. Doctors can prescribe lethal medication to patients who meet certain criteria. Patients who choose to take the medication must do so without assistance.

Under the Act, a person may be approved to receive medication for the purpose of ending their life if the following criteria is satisfied, namely that the person:

- Is an adult, that is at least 18 years of age;
- Is 'capable', defined as 'able to make and communicate health care decisions';

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<sup>5</sup> Better off Dead, Andrew Denton Journalist and Broadcaster, Episode 17 of 17 podcast episodes which thoroughly investigated Euthanasia laws and practice in Australia and internationally over 13 months to March 2016. <http://www.wheelercentre.com/broadcasts/podcasts/better-off-dead>.

<sup>6</sup> The Victorian Report Annex 3, 279-280.

<sup>7</sup> Legal proceedings to thwart its introduction delayed the legislation for 3 years.

- Is a resident of Oregon;
- Has been determined by the attending physician and an independent consulting physician to be suffering a terminal disease from which they will die within six months;
- Makes three separate voluntary requests; an initial verbal request, a written request, then a second verbal request. The verbal requests must be separated by a minimum of 15 days.

In assessing and granting a request to access lethal medication under the Act, two doctors must:

- confirm the diagnosis of the terminal disease;
- confirm the patient is capable of making and communicating health decisions;
- confirm the patient's request is voluntary;
- ensure that the patient is making an informed decision, and in doing so inform the patient of:
  - their medical diagnosis and prognosis;
  - the potential risks, and probable result of taking the lethal medication; and the feasible alternatives, including comfort care, hospice care, and pain control.

If either of the two doctors believes that the patient's judgement is impaired by a psychiatric or psychological disorder or depression, the patient must be referred for counselling. The patient cannot be prescribed lethal medication unless the counsellor determines the patient is not suffering from a psychiatric or psychological disorder or depression causing impaired judgment.

Only once the criteria have been met can a doctor provide a prescription for the lethal medication. No less than 15 days must elapse between the patient's initial oral request and the writing of a prescription and no less than 48 hours must elapse between the patient's written request and the writing of a prescription. Only the patient can self-administer such medication. This requirement proved to be a key element to the medical profession not opposing the legislation.

Patients who are approved in Oregon most commonly ingest a lethal medication without the presence of their doctor or other healthcare provider.

### Reporting and oversight

Doctors must document information concerning a patient's request for lethal medication in the patient's medical record. This includes information

regarding eligibility as described above, as well as all verbal and written requests for lethal medication made by the patient. Doctors are required to report all prescriptions for lethal medication to the Oregon Health Authority. The Oregon Health Authority is responsible for notifying the Board of Medical Examiners of any failures in prescribing or reporting requirements. Data on activity under the *Death with Dignity Act* is reported annually, and published on the Oregon Health Authority website. Consequently, there is a comprehensive oversight of the legislation and observance of the criteria.

### Deaths under the Oregon law

The number of prescriptions for lethal medications written each year has risen from 24 in 1998 to 218 in 2015. The corresponding number of patients who died as a result of taking the medication has risen from 16 to 132. The discrepancy in prescriptions and deaths each year is due to people not taking medication or dying of other causes. The number of deaths by legal medications represents less than ½% of all deaths in Oregon.

Similar laws have now been passed in Washington,<sup>8</sup> Vermont,<sup>9</sup> and most recently California.<sup>10</sup>

## **The Netherlands<sup>11</sup> [Voluntary Euthanasia and Assisted Suicide]**

### Background

While assisted dying was illegal under the Dutch Criminal Code, from 1973–2002, the courts recognised the defence of necessity. A doctor could invoke the defence of necessity when carrying out a patient's request to die was the only available means to end unbearable and irremediable suffering.

To clarify the scope of assisted dying, in April 2002 the Dutch Government passed the *Termination of Life on Request and Assisted Suicide (Review Procedures) Act 2002*.

Significantly, the guidelines for the euthanasia laws came from the Royal Dutch Medical Society.

Assisted dying, whether through voluntary euthanasia or assisted suicide,

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<sup>8</sup> *Washington Death and Dignity Act 2009*.

<sup>9</sup> 2010.

<sup>10</sup> 2015.

<sup>11</sup> The Victorian Report Annex 3 269-271.

remains a criminal offence in principle, however, doctors are not prosecuted if they report to a Regional Euthanasia Review Committee and meet all due care criteria.

Assisted dying is most commonly provided in a patient's own home. Doctors typically administer a barbiturate intravenously, which puts the patient to sleep. This is followed by injection of a lethal neuromuscular blocker.

### Eligibility and safeguards under the Netherlands regime

Eligibility and safeguards are based on a model requiring 'due care' on the part of the doctor assisting a patient to die. Assisted dying is legal only if the 'due care' criteria established in the Act are met. It is not a quick or easy process.

The attending doctor must:

- be satisfied that the patient has made a voluntary and well-considered request;
- be satisfied that the patient's suffering was unbearable, with no prospect of improvement;
- have informed the patient about his or her situation and his or her prospects;
- have concluded, together with the patient, that there is no reasonable alternative in light of the patient's situation;
- have consulted at least one other independent doctor who must have seen the patient and given a written opinion on the due care criteria referred to above; and
- have terminated the patient's life or provided assistance with suicide with due medical care and attention.

In addition to the 'due care' criteria described above, the framework under the Act includes the following elements:

- generally accessible by adults aged 18 and over, but children aged 16–18 can also access assisted dying with parental consultation, as can children aged 12–16 with parental consent;
- it applies not only to the terminally ill but also the chronically ill and people with mental suffering;
- there is no need for competency at the time of a patient's death — a doctor may provide assisted dying to a patient 16 years or older, where they made the request in writing prior to losing competence;
- there is no mandatory mental health assessment, but if a doctor

determines that a patient's judgment may be impaired by poor mental health, they may decide the request does not meet the 'well-considered' part of the due care criteria;

- there is no residency requirement; and
- there is no mention of a specified cooling-off period, but the doctor must be satisfied that a request is 'well-considered'.

### Life Ending Clinics

By 2012, it became evident that some General Practitioners were unwilling to deal with certain kinds of cases, primarily applications involving psychiatric illness and dementia. GP's either did not have the requisite skills or experience or were simply unwilling to help such patients. This led to the establishment of Life Ending Clinics to deal with such complex applications.

In the case of dementia, the Clinic will only deal with patients at the early stage where the patient is still capable of giving instructions and making rational decisions. A detailed application form must be completed, contact is made with the patient's treating doctors and the medical file obtained. A detailed assessment of the patient is then conducted by specialist Clinic Doctors, which may involve psychiatric assessment. Interviews may be conducted over weeks or months until there is complete satisfaction by the patient's GP, an independent psychiatrist and the End of Life Clinic team that the patient is sufficiently mentally competent to make a rational and informed request, not affected by depression or undue influence of family. Finally, an independent 'Scan Doctor' is appointed to be satisfied that the Due Care criteria has been satisfied. If the patient's application is then approved, a date will be appointed. The patient is given the choice of taking a lethal drink themselves or being given an injection by a doctor. The End of Life Team also operate mobile Clinics to respond to a patient's wish to die at home. In 2014 the End of Life Clinics dealt with 231 euthanasia cases.

Significantly, two thirds of euthanasia requests are declined and patients will be diverted to more suitable treatment programs or palliative care.

### Reporting and Oversight in The Netherlands

Where assisted dying occurs, doctors are required to report the death to the municipal pathologist, who then notifies a Regional Euthanasia Review Committee. These Committees, which consist of a medical doctor, an ethicist and a legal expert, assess whether the doctor has fulfilled the statutory Due Care criteria. If the Committee concludes that the criteria have been met, the doctor is exempt from criminal liability and no further action is taken. If the Committee finds that the doctor has not acted in accordance



with the Due Care criteria, it reports its findings to the Public Prosecution Service and the Regional Health Inspector. These two agencies then consider what action, if any, should be taken against the doctor. There have been no prosecutions.

Since introduction of the legislation in 2002, reported deaths have increased from 1182 in 2002 to 5306 in 2014 [of which 231 were handled by the End of Life Clinics], which represents 4% of all deaths annually.

### **Belgium [Voluntary Euthanasia and Assisted Suicide]**

Euthanasia was first legalized in Belgium in 2002 [*Act of Euthanasia 2002*]. The law says doctors can help patients to end their lives when they freely express a wish to die because they are suffering intractable and unbearable physical pain or mental suffering.

An application for euthanasia will only be granted if the patient is assessed to have a medically futile condition of constant and incurable physical or mental suffering that cannot be alleviated.

Where a request is made by a patient suffering a non-terminal illness, two doctors independent of each other as well as a psychiatrist, make a thorough investigation of the request and all available treatments.

Determining the parameters of unbearable mental suffering is the most difficult challenge for the medical profession, but the euthanasia cases involving mental suffering fall into an extreme category.

Patients can also receive euthanasia if they have clearly made such request before entering a coma or similar vegetative state.

Assisted suicide is not mentioned in the law, which does not specify a method of euthanasia. However, the physician has to be present at the bedside of the patient to their last breath, unlike the Oregon model where the doctor gives only the prescription of drugs.

In February 2014, Belgium made international headlines when it became the first country in the world to allow euthanasia for children of any age. There is no age limit for minors seeking a lethal injection, but they must be conscious of their decision, terminally ill, close to death and suffering beyond any medical help. They also need the assent of their parents to end their lives.<sup>12</sup>

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<sup>12</sup> Ibid.

It is noteworthy that the euthanasia laws in Belgium were prompted by the concerns of physicians working within the palliative care sector, where it was recognised that there are limits to palliative care, both in terms of adequately managing chronic and debilitating pain as well as psychological distress. Doctors working in these jurisdictions refer to the increasing futility of advanced medical treatment, which may be successful in prolonging life but at a terrible cost to the patient.

In Belgium public support for the euthanasia laws is at least 85% with only 10% opposed.

Despite having the most liberal euthanasia laws in the world, only 2% of deaths in Belgium are attributable to euthanasia, which has been a fairly steady proportion since its introduction.

In 2013, euthanasia cases accounted for over 1800 deaths; about 80 per cent were cancer patients or had neurological disorders; 97% of euthanasia patients suffered terminal or chronic diseases and 3% were psychiatric.

More than 50% of patients seeking euthanasia in Belgium are diverted to other options. This is a significant outcome and reflects the experience revealed by health professionals involved in the process that, upon making a request for euthanasia, patients will discuss their reasons for wanting to die, perhaps for the first time; the option of a quick but gentle death may avoid a patient resorting to a violent one and often avoids the choice of premature death altogether as the process of assessing an application for euthanasia creates an opportunity for health professionals and the patient to seriously explore other treatment options.

In both the Netherlands and Belgium, because of the rigorous system for reporting and review of all deaths due to euthanasia, there are comprehensive safeguards in place to ensure that the legislative criteria and duty of care are observed. Only one case has been referred for prosecution.

Significantly, organizations representing the disabled in Oregon, the Netherlands and Belgium have all reported that they do not consider that the euthanasia laws place disabled people at any greater risk or devalue their lives. Furthermore, they confirm that there is no evidence of abuse or coercion of the elderly or disabled.<sup>13</sup>

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<sup>13</sup> Andrew Denton, Australian Journalist and Broadcaster, as part of a 13 month investigation in 2014 and 2015, conducted extensive interviews with Representatives of Senior Citizens and Organizations for the Disabled in these jurisdictions.

## **Switzerland<sup>14</sup> [Assisted Suicide]**

### Background

Swiss assisted dying law primarily resides in Articles 114<sup>15</sup> and 115<sup>16</sup> of the Swiss Criminal Code. Assisted suicide, if done without selfish motives is legal, while assisting or inciting suicide with selfish motives is illegal. Euthanasia is illegal in all cases.

The practical effect is that assisted suicide is only a crime where the following elements are proven:

- a suicide was committed or attempted;
- a third party encouraged or helped in the suicide;
- the third party acted on selfish grounds; and
- the third party acted deliberately, with intent.

### Eligibility and safeguards

Unlike the other jurisdictions, Swiss law does not contain a statute with a framework of eligibility criteria and safeguards for assisted dying. As such, there are none of the usual eligibility requirements such as terminal illness or unbearable and irremediable suffering. Neither is assisted dying restricted to citizens or residents of Switzerland. Assisted dying in Switzerland need not be performed by a doctor; in fact, the vast majority of assisted deaths that take place in Switzerland are not supervised by doctors. A doctor is required, however, if a person wants to use a lethal drug which may only be accessed by prescription.

Switzerland has tolerated the creation of organizations which provide assisted dying services for a fee. Most deaths take place in a patient's home, or at one of these organizations.

The four most prominent organizations in Switzerland that assist people to end their lives are:

Dignitas

Exit — German Switzerland

Exit — French Switzerland

Exit International.

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14 The Victorian Report Annex 3, 272-273.

15 Any person who for commendable motives, and in particular out of compassion for the victim, causes the death of a person at that person's own genuine and insistent request shall be liable to a custodial sentence not exceeding three years or to a monetary penalty.

16 Any person who for selfish motives incites or assists another to commit or attempt to commit suicide shall, if that other person thereafter commits or attempts to commit suicide, be liable to a custodial sentence not exceeding five years or to a monetary penalty.

### Reporting and oversight

Right to die organisations (listed above) notify the police and coroner when they assist a person to die. The police and coroner investigate to determine if any crime has taken place, in the most part determining whether there were selfish motives, but also examining any doubts about the deceased's competence and the autonomy of their choice. If the police and coroner find no wrongdoing the death is reported as suicide.

The Victorian Parliamentary Committee noted that reform achieved through prosecutorial guidelines or a defence of 'benevolent intent' means that assisted dying remains a criminal offence. The Committee concluded that the Swiss approach does not provide the necessary explicit safeguards, accountability and transparency that the Committee thinks necessary for a robust assisted dying framework in Victoria.

### Deaths under the Swiss law

There are no official data in Switzerland on the numbers of assisted suicides that take place each year, as the rate of assisted suicide is not collected centrally. Griffiths et al<sup>17</sup> observe that there are approximately 62,000 deaths in Switzerland each year and academic studies suggest that between 0.3 per cent and 0.4 per cent of these are assisted suicides. This figure increases to 0.5 per cent of all deaths if suicide tourism is included (assisted suicides that involve non-Swiss nationals).

### **Canada<sup>18</sup> [Voluntary Euthanasia and Assisted Suicide]**

Currently, **Québec** is the only province in Canada to have introduced a scheme for assisted dying, when the *Respecting End-of-Life Care Act* came into effect on 10 December 2015.<sup>19</sup>

The Act provides for 'medical aid in dying' in the form of voluntary euthanasia and assisted suicide for patients who are:

- 18 years of age and capable of giving consent;
- at the end of life;
- suffering from a serious and incurable illness;
- in an advanced state of irreversible decline in capability; and
- experiencing constant and unbearable physical or psychological pain

<sup>17</sup> The UK Commission on Assisted Dying noted the work by John Griffiths, Heleen Weyers and Maurice Adams in their book *Euthanasia and Law in Europe*

<sup>18</sup> The Victorian Report Annex 3 273-279.

<sup>19</sup> In response to the Select Committee on Dying with Dignity's final report in March 2012.

which cannot be relieved in a manner they deem tolerable.

The Act contains the following safeguards:

- two doctors must be satisfied the request is an informed one, that it is made freely and without external pressure;
- the patient must be informed of their prognosis and other therapeutic possibilities and their consequences; and
- no specified cooling-off period, but a doctor must verify the persistence of suffering and that the wish to obtain assisted dying remains unchanged at reasonably spaced intervals.

The legislation does not specify whether depression or mental illness is a limiting factor for eligibility, however, the patient must be capable of giving consent.

The Québec legislation established a Commission on end-of-life care [The 'Commission sur les soins de fin de vie'] to oversee the application of assisted dying. A doctor who provides assisted dying must notify the Commission within 10 days. The Commission assesses whether the doctor complied with the requirements of the Act. If at least two-thirds of members of the Commission believe the Act was not complied with, the conclusions are forwarded to the institution concerned and to the Collège des Médecins du Québec.

The law was challenged in December 2015, and was temporarily suspended by Québec's Superior Court until a Federal prohibition against assisted dying was lifted. This suspension was later overturned by Québec's Court of Appeal. In addition, the Supreme Court of Canada ruled in January 2016 that Québec's assisted dying law can remain in effect until Federal legislation is enacted. Representatives from Canada's Justice Ministry noted that Québec's assisted dying legislation does not conform to the Canadian Charter due to its limitation to terminal patients. As a result of the Carter decision [referred to below], Québec's assisted dying framework will need to be extended to accommodate those who are not terminally ill.

#### Deaths under the Québec law

Official statistics on the number of assisted deaths under the Act are yet to be released.

#### **Canada generally**

Legislation to legalize assisted dying in all of Canada was introduced in the Canadian Parliament in April 2016, as required by the Supreme Court's

ruling in *Carter v Canada (Attorney General)*, BCSC 2012 ('Carter').

### Background to proposed Federal legislation

In February 2015, the Supreme Court unanimously ruled in Carter's case that the prohibition on assisted dying was unconstitutional. The ruling was suspended for 12 months to allow the Canadian Government to enact the constitutional right to assisted dying for consenting adults with intolerable physical or mental suffering.

In July 2015 the then Canadian Government established the External Panel on Options for a Legislative Response to Carter. The Panel consisted of three members with expertise in end of life care. It published its final report in December 2015.

In December 2015, the incoming Trudeau Government requested a six-month extension to introduce legislation in response to the Carter decision; and established a Special Joint Parliamentary Committee on assisted dying to address the Carter decision and to review the report of the External Panel. The Special Committee tabled its report in February 2016 and made recommendations to implement a legislative framework for assisted dying.

On 15 January 2016, the Supreme Court granted the Canadian Government a four-month extension to pass assisted dying legislation.

The Special Committee recommended eligibility for people who are:

- 18 years old and eligible for public health care, that is a Canadian citizen or permanent resident;
- suffering from a 'grievous or irremediable medical condition'; and
- enduring intolerable physical or psychological suffering that is related to the condition.

Although the Special Committee limited eligibility to those at least 18 years of age, it also recommended investigating eligibility for 'competent mature minors', subject to a study of moral, medical and legal issues.

It also recommended the following legislative safeguards and oversight mechanisms:

- two medical practitioners must confirm the patient's eligibility;
- Canadian Health Department must table an annual report on assisted dying cases; and
- mandatory review of legislation every four years by a parliamentary committee.

In its recommendations, the Special Committee did not include a mandatory cooling off period between the request for assisted dying and when it is provided to the patient. It stated that cooling off periods should be flexible, based in part on the progression of the patient's medical condition. The Special Committee also stated that individuals should not be excluded from eligibility because they have a psychiatric condition.

### Proposed Federal legislation

On 14 April 2016 the Canadian Government introduced Bill C-14: An Act to amend the Criminal Code and to make related amendments to other Acts (medical assistance in dying). The Bill aims to legalise assisted dying through amendments to the Criminal Code of Canada.

The provisions of the Bill are narrower in scope than the recommendations of the Special Committee. A person is eligible for assisted dying if they meet the following criteria:

- they are at least 18 years old and capable of making decisions about their healthcare;
- they are eligible, or would be eligible despite any waiting period, for health services funded by a government in Canada;
- they are suffering from a 'grievous and irremediable medical condition';
- the request was made voluntarily; and
- they give informed consent.

A person is considered to have a 'grievous and irremediable medical condition' if:

- they have a serious and incurable illness, disease or disability and they are in an advanced state of irreversible decline in capability;
- any of these conditions causes enduring physical or psychological suffering that is intolerable to the patient and that cannot be relieved under conditions that they consider acceptable; and
- their death is reasonably foreseeable, taking into account all of their medical circumstances, without prognosis necessarily having been made as to the specific length of time until their death.

Assisted dying may be administered by a medical practitioner or a nurse practitioner. The Bill provides the following safeguards which must be determined by the practitioner administering assisted dying:

- the patient must meet the eligibility criteria;
- the request must be signed after the patient was informed their death is reasonably foreseeable and that they may withdraw their request at any time;

- the request must be signed by two independent witnesses; and
- a second independent practitioner must confirm the patient's eligibility.

Fifteen days must elapse between the time the patient signs the request and when assisted dying is administered. When an administering practitioner prescribes a drug for assisted dying, they are required to inform the pharmacist dispensing the drug of its intended purpose. The administering practitioner must provide the patient with an opportunity to withdraw their request immediately before administering the drug.

The Bill specifies penalties for failure to comply with safeguards, forgery and destruction of documents. In addition, it creates exemptions under the Canadian Criminal Code for practitioners and pharmacists who are involved in assisted dying.

The Bill provides for the Canadian Health Minister to make regulations to establish monitoring and reporting processes for the assisted dying framework. After five years of operation, the Act is to be reviewed by a joint parliamentary committee.

The provisions of the Bill do not address mature minors, people suffering only from mental illness and advance requests. Rather, the preamble states that the Canadian Government has committed to developing non-legislative measures to deal with these issues. These issues will be referred for consideration to an expert body.

### **California USA [Assisted Suicide]**

California has a population of nearly 40 million people. In October 2015, California passed the *End of Life Option Act 2015* legalizing physician assisted dying, based upon the Oregon law, whereby a patient can obtain a prescription for lethal medication which they can administer either personally or with the assistance of a loved one.

### **Summary of Key Features of International Regimes**

Legislative support for assisted suicide is limited to a small number of jurisdictions,<sup>20</sup> while voluntary euthanasia is permitted in even fewer jurisdictions.<sup>21</sup>

Eligibility criteria varies significantly. In particular, there is no consistency as to whether the patient must:

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20 Oregon; Netherlands; Belgium; Luxembourg; Washington State; Canada; and California.

21 Netherlands; Belgium; Luxembourg; and Canada.



- be an adult;
- be competent at the time death occurs;
- have a terminal illness;
- be afflicted with pain and/or mental suffering;
- be resident in the jurisdiction; or
- personally administer the lethal medication to themselves

Furthermore, there is variation in:

- the number and nature of health professionals required to be involved;
- the manner of assessing a patient's request;
- whether and how a patient is to be professionally informed;
- whether a cooling off period applies;
- the relevance of depression and other mental health issues; and
- reporting requirements and review.

For instance, some jurisdictions, such as Oregon and other states in the United States, prescribe specific waiting or cooling-off periods between an initial request and the provision of a lethal drug. The Victorian Committee concluded that it is unreasonable to mandate an arbitrary cooling-off period that denies some people who would otherwise qualify to access this option at the end of life. This point was highlighted by doctors working in hospice care in Oregon who explained that many requests for assisted dying come from patients extremely close to death, who then die before the prescribed 15-day cooling-off period lapses.

European legislation is less specific, with wording along the lines of doctors being certain of the 'durable' nature of the request, and holding multiple interviews with the patient at reasonable intervals, having regard to the evolution of the patient's condition.

## **Australia**

It is probably not well known that in 1995, Australia's Northern Territory became the first jurisdiction in the world to pass laws allowing a doctor to end the life of a terminally ill patient at the patient's request. The Federal Parliament reversed those laws and assisted dying still remains illegal in Australia.

Extensive polling over a 5 year period to 2015 in Australia shows overwhelming public support to the following question:

“When a person has a disease which cannot be cured and is living in severe pain, do you think that doctors should be allowed by law to assist the patient to end their life, if the patient requests it?”—

Up to 76% in July 2015 – expressed approval for assisted dying, with support being consistent across all education levels.<sup>22</sup> Only 10-15% expressed opposition.

But of the nearly 30 attempts to pass a new law in the last 15 years, not one has come close to succeeding.

This situation may change as a result of the recent Victorian Parliamentary enquiry.

### **Terms of reference: Inquiry into end of life choices**

On 7 May 2015 the Legislative Council authorized a Parliamentary Committee to examine the following:

The need for laws in Victoria to allow citizens to make informed decisions regarding their own end of life choices and, in particular, the Committee should —

- (1) assess the practices currently being utilised within the medical community to assist a person to exercise their preferences for the way they want to manage their end of life, including the role of palliative care;
- (2) review the current framework of legislation, proposed legislation and other relevant reports and materials in other Australian states and territories and overseas jurisdictions; and
- (3) consider what type of legislative change may be required, including an examination of any federal laws that may impact such legislation.

**The Committee recommended that the choice to die must only be available to adults with decision-making capacity, and who are suffering from a serious, terminal condition and are nearing the end of their lives, as determined by a primary doctor and an independent secondary doctor.**

**The Committee does not support an assisted dying framework that extends beyond this. Assisted dying should provide an option that can limit suffering at the very end of life, not a way to end life for those who are otherwise not dying.**

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<sup>22</sup> Andrew Bunn of Essential Media Communications, interview with Andrew Denton 8 Nov. 2015.

**Only Victorian residents would be eligible and it would not be available to people with dementia or mental health issues.**

The evidence shows that simply knowing there is an option of assisted dying can be immensely beneficial to a person nearing the end of life, whether or not they choose to use it. In Oregon, approximately 30 per cent of people who are prescribed a lethal drug under the assisted dying framework do not take it. For some the feeling of control that such an option provides helps to ease suffering and the fear of a painful death. This was reflected in evidence the Committee heard from people who are seriously ill and want another option at the end of life.

The Committee recommended a detailed legal framework, which I will refer to shortly.

The Victorian Government now has six months to consider whether to adopt those recommendations.

The Victorian Committee recognized that under the existing legal framework, Victorians with serious and incurable conditions and irremediable suffering are exposed to the possibility of a traumatic death. Some are driven to suicide. The State Coroner provided disturbing evidence to the Committee of people, particularly frail, elderly and vulnerable Victorians, taking their lives in horrific circumstances, alone and prematurely, to avoid implicating their loved ones in their death and possible criminal prosecution.<sup>23</sup>

Whilst most pain and suffering can be alleviated through the provision of better palliative care, the Committee heard from health practitioners that not all pain can be alleviated.

Consequently, some people are dying terribly at the end of a terminal illness.

Furthermore, some Victorians have been prosecuted for assisting a loved one to die, with offences ranging from aiding and abetting suicide to attempted murder.

However, our criminal justice system is showing extraordinary leniency in dealing with them. Without exception, police, prosecutors and judges have used their discretion to ensure those prosecuted for helping loved ones to die do not face the full effects of the law: guilty pleas are accepted to lesser charges and judicial discretion is exercised in the imposition of non-custodial

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<sup>23</sup> In my home State of Victoria Australia, suicide was only decriminalized in 1967. Inciting suicide and aiding and abetting suicide remain illegal. However, there is no legal right to commit suicide and the law permits anyone to use such force as may reasonably be necessary to prevent a person from suiciding: Section 463B of the *Crimes Act 1958*.

sentences.

Whilst this may be a desirable outcome on a case-by-case basis, it threatens to bring the law into disrepute and undermine public confidence in the administration of justice.

As previously mentioned, the evidence is also that some doctors are assisting patients to die, at their request. However, this is currently happening without regulation, scrutiny or supervision and without transparency or accountability.

The Committee recognized that there are a number of Victorians who wish to have the option of choosing assisted dying and if available such option would reduce the extraordinary suffering they encounter at the end of life, and the toll this takes on loved ones.

Research into Victorian and international jurisdictions satisfied the Committee that the methods used in assisted dying are sound and help that small cohort of patients who want this option to achieve a peaceful death.

The evidence is clear from international experience, particularly in the jurisdictions of the Netherlands, Belgium and Oregon USA, that assisted dying can be provided in a way that guards against abuse and protects the vulnerable in our community in a way that unlawful and unregulated assisted dying does not. Lawful assisted dying is currently provided in robust, transparent, accountable frameworks. The reporting directly from such frameworks, and the academic literature analysing them, shows that the risks are guarded against, and that robust frameworks help to prevent abuse.

**The Committee identified four fundamental principles which should underlie an assisted dying regime:**

**First**, such regime cannot be implemented in isolation. It must be incorporated into existing end of life care processes in order to protect and support patients and ensure sound medical practice. Ensuring high standards of patient care requires that health practitioners and regulatory authorities work together in implementing an assisted dying framework;

**Secondly**, there should be no unencumbered 'right' to assisted dying. Access will be determined by the careful assessment of a robust set of criteria by those best placed to do so: the person themselves, a primary doctor, and an independent secondary doctor;

**Thirdly**, no doctor, other health practitioner or health service should be forced to participate in assisted dying; and

**Fourthly**, an assisted dying framework must incorporate the culture and values of the people it serves. While some technical aspects of international frameworks may transfer well to Victoria, some may need refinement to align with the legal and medical values and culture that are essential to Victorians.

For example, a patient in Oregon can receive a prescription for a lethal drug and choose not to see their doctor again. This is because choosing the level of interaction with a doctor reflects the value of self-determination that is fundamental in American culture. Conversely, the more involved nature of the doctor–patient relationship in the Netherlands renders it untenable that a doctor would not be present when a patient undergoes assisted dying.

It is important to note that notwithstanding submissions made by groups opposed to euthanasia and assisted dying,<sup>24</sup> the Committee found no evidence to support expressed concerns. On the contrary, doctors, medical and legal experts, palliative care specialists and disability rights groups in jurisdictions where assisted dying is legal impressed the Committee in the rigorous safeguards, monitoring procedures and high levels of compliance in their jurisdictions. The only concerns raised by members of the public, in jurisdictions such as the Netherlands and Belgium, were that people cannot access assisted dying quickly enough.

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<sup>24</sup> The Australian Christian Lobby; the Catholic Archdiocese of Melbourne; Doctors Opposed to Euthanasia; the Australian Catholic Bishops Conference; and the Australian Family Association; and oversees Dr Theo A Boer, Lindeboom Professor of Health Care Ethics, Theological University Kampen; Ms Margaret Dore, Attorney, Choice is an Illusion; Ms Carine Brochier, Project Manager, European Institute for Bioethics Brussels, Belgium Victorian Report 213.

## **Assisted Dying Framework – A Summary<sup>25</sup>**

The recent Victorian Parliamentary Report recommended the introduction of legislation to allow adults with decision making capacity, suffering from a serious and incurable condition which is causing enduring and unbearable suffering to request assisted dying. It is for the patient and not anyone else, to determine what is bearable or unbearable for them.

Where the Oregon, Québec and Canadian models include capacity and adulthood as essential criteria, the broader Netherlands and Belgium models do not.

Any assisted dying legislation should include an 18-month period between Royal Assent and operation, to allow appropriate time to prepare for implementation on a practical and clinical level.

### **1.1 Activity being regulated**

Assisted dying should in the vast majority of cases involve a doctor prescribing a lethal drug which the patient may then take without further assistance.

The singular exception is where people are physically unable to take a lethal drug themselves. In this case, a doctor should be able to assist the person to die by administering the drug.

### **1.2 Conscientious objection**

No doctor, other health practitioner or health service can be forced to participate in assisted dying.

### **1.3 Eligibility criteria and assessment**

Assisted dying is intended to provide an option that can limit suffering at the end of life, not a way to end life for those who are otherwise not dying.

A request for assisted dying must be approved by a primary doctor and an independent secondary doctor. Each doctor must be properly qualified to make a professional diagnosis and prognosis regarding the patient's specific condition. Each doctor must independently judge whether the person's request satisfies all of the criteria outlined below.

The exception to this is the suffering component. It is essential that the

<sup>25</sup> The Victorian Report, Annex 1: Assisted Dying Framework Summary.

patient must be experiencing enduring and unbearable suffering that cannot be relieved in a manner which they deem tolerable. This is fundamental to patient-centred care, and is a subjective measure judged by the patient themselves.

### The person

An adult, 18 years and over, with decision making capacity about their own medical treatment.

Patients whose decision making capacity is in question due to mental illness must be referred to a psychiatrist for assessment.

Ordinarily resident in Victoria and an Australian citizen or permanent resident.

### The condition

At the end of life (final weeks or months of life).

Suffering from a serious and incurable condition which is causing enduring and unbearable suffering that cannot be relieved in a manner the patient deems tolerable.

Suffering as a result of mental illness only, does not satisfy the eligibility criteria.

### The request

Must come from the patient themselves.

Cannot be included in an advance care directive.

Must be completely voluntary, free of coercion.

Must be properly informed.

The patient's request must be repeated three times:

- an initial verbal request
- a formal written request, which must be signed by two independent witnesses
- a final verbal request.

Must be enduring. The primary and secondary doctors must be

independently satisfied that the patient's request is enduring and that a reasonable amount of time has passed between the patient's initial request and the provision of a lethal drug. In making this judgement the primary and secondary doctors must have regard to the patient's particular condition and its likely trajectory. The primary and secondary doctors must also assess the reasonableness of the request. This is to ensure that the patient truly understands and appreciates the nature and consequences of the decision to request assisted dying, as well as the alternatives to assisted dying, and that the patient's request is not ambivalent.

Patient may withdraw their request at any time. Once withdrawn, the request becomes void, and the primary and secondary doctor must assess any subsequent request from the beginning.

### The Approval

A request for assisted dying must be approved by a primary doctor and an independent secondary doctor. Each doctor must be properly qualified to make a professional diagnosis and prognosis regarding the patient's specific condition.

Each doctor must independently judge whether the person is:

1. at the end of life;
2. suffering from a serious and incurable condition which is causing enduring and unbearable suffering that cannot be relieved in a manner the patient deems tolerable;
3. making a voluntary decision, free from coercion; and
4. making a properly informed decision.

The primary and secondary doctor must each properly inform the patient:

- of the diagnosis and prognosis of their condition, as well as the treatment options available to them, including any therapeutic options and their likely results;
- of palliative care and its likely results;
- that they are under no obligation to continue with a request for assisted dying, and may rescind their request at any time; and
- of the probable result and potential risks of taking the lethal drug.

In cases where either doctor is concerned that the patient's decision making capacity may be impaired by mental illness, they must refer the patient to a psychiatrist.

The psychiatrist should then determine whether the patient is suffering from



mental illness that makes them incapable of making informed decisions about medical treatment. It is important to note that the psychiatrist is a third doctor who is independent from the first and second doctors.

## 1.4 Implementation Taskforce

There are clinical and practical implementation issues in establishing an assisted dying framework that require further investigation. Accordingly, the Committee recommended that the Government establish an Implementation Taskforce of experts and health practitioners to investigate and advise on the best approach to these issues before the assisted dying framework commences.

## 1.5 Oversight, review and reporting

### 1.5.1 Assisted Dying Review Board

The Assisted Dying Review Board is to review each approved request for assisted dying.

Membership of the Assisted Dying Review Board:

1. a representative of End of Life Care Victoria
2. a doctor
3. a nurse
4. a legal professional
5. a community member.

The function of the Board will not be to approve or reject requests from patients to access assisted dying, which is the role of the primary doctor and independent secondary doctor in each case. Neither will the Board hear appeals from patients whose requests to access assisted dying have been rejected. The purpose of the Board is to ensure that doctors are complying with requirements of the assisted dying framework. If the Board finds a breach of the assisted dying framework, it should forward its report to the appropriate authority. Depending on the nature of the breach, this may be Victoria Police, the Coroner, or the Australian Health Practitioner Regulation Agency. Those bodies will then determine whether to investigate the case further.

The Board should report to Parliament on the operation of the assisted dying

framework, including any trends it identifies and recommendations for improvement. For the purposes of increased transparency and accountability, during the first two years of operation these reports should be every six months. Following that the Board should report annually. This is consistent with the Oregon model, which is broadly followed in Washington State, Vermont, and California, requires doctors to report all prescriptions for lethal medications to the Oregon Health Authority. The Oregon Health Authority is responsible for notifying the Board of Medical Examiners of any failures in prescribing or reporting requirements. Data is then reported publicly on an annual basis.

The Committee also considered that more detailed information is necessary to inform all end of life care, not only assisted dying.

### 1.5.2 End of Life Care Victoria

The Government should establish a new entity to champion end of life care, and provide information and guidance on end of life care to health services, practitioners and the Victorian community. End of Life Care Victoria will work closely with palliative care and other end of life care health practitioners and services to enhance and support the excellent work already being done in the Victorian health system. End of Life Care Victoria will aim to increase engagement with end of life care in the community and the health sector as a whole. This recommendation adopts aspects of the Québec model of assisted dying includes a Commission on end of life care. Among other responsibilities, the Commission:

1. evaluates the implementation of end of life care legislation;
2. refers to Government any matter relating to end of life care that requires Government attention or action;
3. reports to Government on the status of end of life care in Québec; and
4. oversees the application of specific requirements relating to assisted dying.

The framework proposed by the Victorian Committee is principally based upon the Oregon regime, but with even further controls by way of reporting, oversight and review.

The eligibility criteria are narrow, applying to persons facing imminent death.

Whilst this may cover many and perhaps most relevant cases, it is not as

extensive as the Dutch and Belgium criteria of unbearable and untreatable suffering. Without such an extension, many people will not be helped namely, those suffering debilitating paralysis, degenerative disease and extreme cases of mental suffering where unbearable and untreatable suffering can extend for many years. It also does not deal with prior wishes expressed by a patient in a form of a 'living will' or medical directive.

### **Euthanasia and Death with Dignity under Japanese Law**

I understand that in Japan there is no legislation which deals with euthanasia, although an official administrative guideline on 'death with dignity' has been made.<sup>26</sup>

In the Japanese context, cultural factors and the complex hierarchy of social relationships appears to make the prospect of laws dealing with euthanasia and assisted dying far more complex. I do not provide any analysis of the Japanese context at this stage, but merely leave you with some of the difficult issues and questions which Japanese academics have already identified.<sup>27</sup>

How does the deeply ingrained cultural tradition that a Japanese person does not exist as an individual, but as a member of the family, community, or society to be reconciled with a patient's right to self-determination?

Are the elderly in Japan more likely to entrust decisions about their healthcare to family members?

Do families of elderly patients together with healthcare professionals tend to take the initiative regarding healthcare decisions for the patient without their explicit consent?

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<sup>26</sup> 'The Ministry of Health, Labour and Welfare, The Guideline on the Decision-Making-Process of Terminal Care' May 2007.

<sup>27</sup> I refer in particular to an article published in BMC Medical Ethics online 4 Feb 2014 'Contemporary issues concerning informed consent in Japan based on a review of court decisions and characteristics of Japanese culture' by Sakiko Masaki, Hiroko Ishimoto, and Atsushi Asai. Department of Bioethics, Kumamoto University Graduate School of Life Science, Kumamoto, Japan <http://www.biomedcentral.com/1472-6939/15/8/prepub>

Do health care professionals tend to equate informed consent (of the patient) with the mere disclosure by the doctor of medical conditions and recommendation of treatment options?

The extent to which health care providers give comprehensive advice about diagnosis and treatment options appears to remain somewhat problematic. Historically in Japan, there was no requirement for physicians to disclose the true diagnosis to a person suffering from cancer; they only notified family members. This has led to a series of decisions by the Japanese High Court and Supreme Court which have confirmed the following:

1. Physicians in Japan do not have a legal duty to inform patients of a cancer diagnosis;
2. However, physicians have a legal duty to inform the family if the patient is not notified;
3. Conversely, the physician has no legal duty to tell the patient's family if the physician has already informed the patient;
4. Patients are entitled to refuse treatment based on religious faith; and
5. Physicians have a legal duty to inform a patient of as many alternatives as possible, and court decisions demanding compensation for damages based on inadequate information disclosure continue.

In the context of a decision being taken to either administer or withdraw life support or life prolonging measures, where a patient has already lost consciousness, the following questions arise:<sup>28</sup>

First, how can the patient's right to self-determination be expressed: in a 'living will' or advance medical directive or by a substitute legal guardian previously appointed in writing;

Secondly, what is the extent of the doctor's exercise of professional judgement;

Thirdly, what is the criteria for determining the 'best interests' of the patient;

Fourthly, what is the role of the family; and

Fifthly, how is the Official Guideline being interpreted and applied in practice.

Finally, on 23 July 2016 the Japan Times reported upon a documentary aired on NHK about people who kill their elderly, incapacitated relatives because they can no longer take care of them. The program suggested that

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<sup>28</sup> See generally 'Euthanasia and Death with Dignity in Japanese Law' Professor Katsunori Kai, Waseda Law School Waseda Bulletin of Comparative law Vol. 27.

the caregiving burden on families has become intolerable for many. In the past six years there have been 138 murders or attempted murders of elderly people by their relatives. Currently, more than 5.5 million seniors are being cared for by their families which represents about 70 percent of all seniors in need of care.

This situation would certainly not be unique to Japan but highlights the critical need for comprehensive aged care and palliative care facilities.

These are matters for further analysis and another paper, perhaps at our next conference ICQoL in 2017.

### **Acknowledgments**

In preparing this paper I wish to emphasize that I have not conducted any original research. The material has been derived principally from the Victorian Parliamentary Inquiry into End of Life Choices, Final Report June 2016; and a series of podcast programs conducted by Andrew Denton Journalist and broadcaster, based upon research and extensive interviews conducted within Australia and internationally over a 13 month period up to March 2016.

**Judge Pamela Jenkins**

Victoria Australia

August 2016