

Euthanasia in Western Australia 2010: Background and Analysis

In September 2010, Western Australia's Legislative Council, the Upper House of that State's Parliament, voted down a Private Member's Bill to introduce voluntary euthanasia by a margin of 24 votes to 11. This article reviews the general context and content of the Bill and the public debate on euthanasia before offering more focused analysis.

The *Voluntary Euthanasia Bill 2010* was the fourth attempt in fifteen years to introduce euthanasia in Western Australia (WA), and it is unlikely to be the last: the Bill's sponsor, Hon Robin Chapple MLC (Green), has promised to make another attempt if he is returned at the next State election. Similar bills are already proposed for South Australia, Tasmania, New South Wales and Victoria, and euthanasia is also under discussion in Australia's Federal Parliament.

In the years since Mr Chapple's first attempt to introduce voluntary euthanasia in 2002, the legal landscape of end-of-life decision-making in Western Australia has changed considerably. Prompted by controversies surrounding the cases of BWV in Victoria and Terri Schiavo in the USA, WA's *Acts Amendment (Consent to Medical Treatment) Act 2008* created two legal instruments by which a person may exercise some autonomy over the refusal of medical treatments, including life-sustaining treatments, in the event that they are rendered non-competent: binding Advance Health Directives (so-called 'living wills') and Enduring Powers of Guardianship (known elsewhere as medical power of attorney). In the view of the pro-euthanasia lobby, however, this Act does not go far enough: it only comes into effect once a patient has been rendered non-competent, and it stops short of permitting the person to request active intervention to end his or her life.

These 'limitations' were highlighted in WA in the case of Christian Rossiter, a 49-year-old former stockbroker suffering spastic quadriplegia after a series of spinal injuries. Fed by percutaneous endoscopic gastroscopy (PEG) tube, Mr Rossiter wanted his suffering to end but found himself caught between his legal right to refuse medical treatment on one hand, and his carer's legal duty to provide the necessities of life on the other. When the WA Supreme Court upheld Mr Rossiter's right to refuse even his life-sustaining PEG tube, euthanasia supporters predictably decried his inability to seek more active intervention to end his life. Despite the Chief Justice's plea, Mr Rossiter became an emblem of an energetic pro-euthanasia campaign in WA, so the fear of lingering

suffering and slow painful death continued to echo in public conversation surrounding Mr Chapple's Bill. (Mr Rossiter subsequently died quite peacefully of natural causes, having refused any treatment for a chest infection but otherwise receiving expert palliative care.)

The WA Legislation

Under the *WA Voluntary Euthanasia Bill 2010*, persons eligible to make requests for euthanasia had to be of sound mind, aged 21 years or older, a resident of WA for three years, able to communicate, and suffering a terminal illness causing considerable pain, suffering or debilitation. The request for euthanasia had to be made freely and in writing, and witnessed, but not in the presence of any near relative. A medical practitioner to whom such a request was referred, and who agreed to assess it, would have been required to provide the applicant with information concerning the illness, its potential treatments including risks and benefits, the availability of counselling and palliative care, and the methods available to carry out the request. If a second medical practitioner verified that the requirements of the Act had been met, then the applicant could make a second request for euthanasia after the lapse of fourteen days, and euthanasia could then be administered by 'a recognized drug.' If the applicant at any time gave any indication of revocation, or ceased to be competent or able to communicate, all requests for euthanasia were automatically annulled. Once death had occurred, the medical practitioner was obliged to report it to the Coroner, who was required to make a formal report to the responsible Minister and to Parliament, but was not

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otherwise required to investigate the death.¹

Although Mr Chapple's 2010 iteration was more prescriptive than the 2002 version of his Bill, important issues were still left unresolved. Among those of major concern to Parliamentarians were

- the definition of 'terminal illness', defined in the Bill as any illness which, 'in reasonable medical judgment,' will result in death within two years. Members felt this definition was too broad, and too reliant on the doctor's subjective assessment: sometimes it can be impossible for medical professionals to agree on difficult prognoses.
- lack of definition of 'pain, suffering or debilitation': given the subjective nature of 'suffering' this provision was thought too broad to be legislated effectively.
- the medical practitioner accepting a euthanasia application needed to have no particular knowledge of palliative care or pain control, or any experience in diagnosing or managing clinical depression, or indeed any specific training in managing the patient's particular illness.
- the Bill would have required a medical practitioner to make important judgments outside the normal clinical field, for example, whether the applicant was acting under duress or external pressure.
- the requirement to report incidents of euthanasia to the coroner without requiring the coroner to investigate each incident, seemed to some Parliamentarians altogether too arbitrary.

Parliamentarians who opposed the Bill offered broadly similar arguments:

- that euthanasia for pain and suffering is unnecessary given rapid advances in palliative care and pain control;
- that appropriate care decisions are best left to the clinical judgment of medical practitioners;
- that the provision of euthanasia may reduce pressure on the medical community to continue research in palliative care and pain control; and that there is no legislative measure able to limit the creep of euthanasia to other classes of non-suffering, non-dying persons.

The last of these objections was quite effective. Data from the Dutch and Belgian experiences were used freely by both sides in the public conversation, as data often are, but Holland's undeniable creep from 'voluntary euthanasia' to 'non-voluntary euthanasia' to 'involuntary euthanasia' caused great consternation among legislators.² It is clear that once euthanasia is permitted for one class of citizens, there are no logical reasons to deny it to other classes of citizens: indeed Holland is currently debating euthanasia for those who are simply 'tired of living'.³ This point was made to telling effect by prominent Perth lawyers.⁴ Parliamentarians clearly recognized the dangers inherent in attempting to circumscribe by legislation a practice which has proved

uncontrollable in other jurisdictions.

Analysis

Opposing sides in the 2010 debate were united on two issues: the need to conduct the public conversation about euthanasia in a spirit of civility and respect, with due attention to empirical data as far as possible; and the need for all West Australians to have better access to state-of-the-art palliative care. But there were considerable differences in interpretation.

In particular, data generated from the Netherlands were interpreted differently by each side. On close inspection, Dutch Government data over the years are hard to compare longitudinally because study parameters have changed with each iteration,⁵ which may go some way to explaining this paradox. From the many meta-analyses of the official data, however, it seems indisputable that legislating for euthanasia has done little to control the self-regulatory practices of Dutch physicians: there are more cases of non-voluntary euthanasia in each study,⁶ while as many as one in five cases of euthanasia is not reported at all as Dutch law demands.⁷

Both sides also supported palliative care, but understandings of palliative care differed. In general terms, the pro-euthanasia lobby portrayed palliative care primarily as pain control, which permitted it to highlight the limits of medical knowledge in this regard. Those opposing euthanasia were generally careful not to overstate the capacity of medicine to relieve pain, but more importantly presented a whole-of-life understanding of palliative care: it is about allowing the person to live as well as they can when cure is no longer possible. As Welsh palliative care specialist Ilora Finlay puts it:

Modern palliative care is about more than relieving pain and other symptomatic suffering. It seeks to unravel what is causing distress - whether physiological or existential - to empower patients to receive care how and where they wish and generally to restore quality to the last days, weeks, or months of their lives.⁸

It is tempting to interpret these differing views of palliative care as nothing more than an echo of divergent views among the medical professions, but as the WA debate progressed a more disturbing truth gradually emerged: those driving the campaign for euthanasia were far less interested in pain control and palliative care than they were in promoting personal autonomy. Baroness Finlay again:

It is ironic that almost simultaneously with improvements in care for the dying, there has been a rise in the volume and stridency of calls for the legalization of euthanasia. The explanation lies in the arguments now being put forward by pro-euthanasia campaigners. Their arguments no longer focus on relief of terminal suffering but rather on the promotion of personal choice and control. . . . In a recent pamphlet *Dignity in Dying [formerly the Voluntary Euthanasia Society]* stated that 'no amount of good palliative care can address some patients' concerns regarding their loss of autonomy,

loss of dignity and loss of control.⁹

Perhaps this explains why the pro-euthanasia case is so difficult to counter in public debate. What seems at first a conversation about medicine and necessary pain control is in fact a conversation about autonomy and personal preference - it has nothing to do with medicine or symptom relief or palliative care at all.¹⁰ But as the argument for legalizing euthanasia has shifted from physical pain and suffering at the end of life to autonomy and existential suffering in much broader terms, the 'pain-and-suffering' language used by pro-euthanasia campaigners has not changed.¹¹ This makes it easy for campaigners to whip up emotive support for legislative reform while their real goal lies elsewhere.

This hidden agenda for euthanasia law reform explains the 'bracket creep' evident in the Netherlands, where after years of legal euthanasia the public conversation is now about the rights of those who are simply 'tired of living'. So too the WA Euthanasia Society's use of Christian Rossiter only while it suited their cause. The dangerous consequences of such an impersonal and unbalanced notion of autonomy, which are explored elsewhere, cannot be overestimated.¹²

Fortunately, a majority of WA's Legislative Council saw through this ploy and defeated Mr Chapple's voluntary euthanasia Bill. Future attempts to introduce euthanasia will hang not only on who communicates best with legislators at that time, but also and ultimately on our ability to resist the 'unbalanced autonomy' argument on one hand, and our success in improving access to excellent palliative care on the other.

ENDNOTES

- ¹ For the WA *Voluntary Euthanasia Bill 2010* as well as previous WA euthanasia bills, see Parliament of Western Australia, <http://www.parliament.wa.gov.au/web/newwebparl.nsf/iframewebpages/Bills+-+All>
- ² See, for example, Cristina Odone, *Assisted Suicide: How the chattering classes have got it wrong*. (London: Centre for Policy Studies, 2010), <http://www.scribd.com/doc/39694762/Assisted-Suicide-How-the-chattering-classes-have-got-it-wrong>
- ³ For an account of the Dutch Completed Life Campaign, see Kerri Anne Brussen, "Euthanasia: A Dutch Perspective," *Chisholm Health Ethics Bulletin* 15, no. 4 (Winter 2010): 4-8 at 6-7.
- ⁴ Peter Quinlan, *Should there be a legal right to die? A discussion about the Voluntary Euthanasia Bill 2009 (WA)*, (lecture, Jewish Medico-Legal Conference, Perth WA, 30 May 2010), <http://www.nd.edu.au/downloads/news/media%20releases/PeterQuinlan.pdf>
- ⁵ Richard Fenigsen, "Dutch Euthanasia: The New Government Ordered Study," *Issues in Law and Medicine* 20, no. 1 (2004): 73-79 at 78.
- ⁶ Wendy E Hiscox, "Non-Voluntary Euthanasia in the Netherlands and Belgium," in *Incapacity and Care: Controversies in Healthcare and Research*, ed. Helen Watt (Oxford: Linacre Centre, 2009), 75-94.
- ⁷ Judith A C Rietjens et al., "Two Decades of Research on Euthanasia from the Netherlands: What have we learned and what questions remain?" *Bioethical Inquiry* 6 (2009): 271-283 at 271.
- ⁸ Ilora Finlay, "The art of medicine: Dying and choosing," *The Lancet* 373 (30 May 2009): 1840-1841 at 1841.
- ⁹ *Ibid*, 1840.
- ¹⁰ *Ibid*, 1841: "There is evidence from countries that have gone down the 'assisted dying' road that, once the campaigners achieve one goal, they simply move on to the next in an attempt to widen the goalposts further."
- ¹¹ *Ibid*, 1841: "The uncritical use of such language, however, makes it easy to stir up public sympathy for legislative change. The case for legalization has shifted to existential suffering but the language being used to justify it has not moved on."
- ¹² See Odone, also Joseph Parkinson, *Over the Edge: Individual Autonomy and Flat-Earth Ethics*, (Curtin University Annual Ethics Lecture 2009), <http://www.bioethicsperth.org.au/Upload/Curtin%20University%20Annual%20Ethics%20Lecture%2018%20November%202009.pdf>

All on-line resources accessed 5 November 2010.

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Physician Assisted Suicide in the United States of America

This paper is a brief history of suicide, euthanasia, and physician assisted suicide in the United States of America which aims to provide an understanding of the continued and persistent effort in the USA to legalise physician assisted suicide. Oregon and Washington State Dying with Dignity Laws are reviewed as examples of legalised physician assisted suicide.

Euthanasia is a compound Greek word: 'eu' which means 'good' and 'thantos' which means death. Although it is only physician-assisted suicide (PAS) that has been decriminalised in three American states, euthanasia and PAS are analogous to one another. There are at least two moral agents involved in either process. In both acts, the physician is as committed to the act of hastening death as the patient. In euthanasia, the physician injects a lethal medication into the patient. In PAS, the physician is part of the act by providing the lethal medication for the patient to inject. Therefore, without the direct involvement of the physician, there would be no medical provision for the death.¹

Ancient World and Early Christian View

The Pythagoreans of the ancient Greek world did not believe in euthanasia or suicide. This tradition was based

on religious beliefs that all life forms were related and the transmigration cycle of the soul could not be interrupted.² Hippocrates, a physician in this tradition, provided the basis of the modern-day Hippocratic Oath. Athenian law viewed suicide as a crime, refusing a customary burial to the guilty person. Plato saw natural death as the fulfilment of human life where one could come into contact with truth, but suicide as evading one's duties.³ After an unfair trial, Socrates decided in favour of willingly taking hemlock to commit suicide in face of a judicial order for his execution. This was his choice rather than escaping into exile from his cherished Athens.⁴ Aristotle, in his quest for justice stated that although suicide did not involve an injustice to a third person, it was not acceptable as the law does not permit an act which could be harmful to the state and is contrary "to right reason."⁵ Stoic philosophy, which greatly influenced the Roman Empire,

advocated living according to nature. However, this philosophy accepted suicide if living virtuously was no longer possible.⁶

The Bible does not directly condemn suicide but the act has always been a serious sin. Clement of Alexandria was the first Christian to speak out against suicide, stating human life was sacrosanct as deemed by the divine.⁷ St Augustine in the 5th century suggested suicide was a breach of the Sixth Commandment “Thou shalt not kill.” Highlighting the difference between intentional and unintentional killing, St Augustine feared a slippery slope if deliberately seeking death to avoid our earthly predicaments was acceptable. St Thomas Aquinas in the 13th century built upon St Augustine’s foundation. To Aquinas, all people know, through practical reasoning, that life is one of the basic human goods. Therefore it would be immoral to reject the basic human good of life by making a deliberate rational choice to end your life or by assisting another to do so. Common laws on suicide find their genesis in the Christian teaching on suicide and the sanctity of life which evolved from the thoughts of Augustine and Aquinas. Funerals were refused to those who committed suicide by the Council of Braga in 562. 13th Century laws stated those who killed themselves would forfeit their goods and property. However, as in Christian law, it is not a crime if a person who is suffering a mental illness, which removes their capacity to reason, takes their own life.⁸

Early American Law

Early American law on suicide followed the English law of forfeiture. They included in this an ancient pagan tradition of burying the suicide’s corpse at a crossroads. This was to keep the ghost confused by the traffic coming in all directions and thus the ghost could not escape. Later Christian influence continued the custom. However it was thought that the burial at crossroads “helped to lay the ghost by making the Sign of the Cross”.⁹ By the early 18th century Virginia and Pennsylvania no longer practised forfeiture. Massachusetts had stopped in 1672 but continued the restrictions on burials. The 19th century saw New Hampshire, Maryland, Delaware, New Jersey, North Carolina and Rhode Island no longer viewing suicide as a criminal act. Some suggested that the decriminalisation of suicide acknowledged that the states accepted an individual’s autonomy. Indeed, from this they claimed a *right* to commit the act. In reality, the decriminalisation of suicide accepted that the penalties of forfeiture enforced on the family penalised them and had no impact on the person who had committed suicide. By 1868, nine of the thirty-seven American states had made assisting suicide a crime. Euthanasia has always been treated as murder.¹⁰

In 1870, an Englishman Samuel Williams called for the use of anaesthetics and morphine to intentionally end a patient’s life. In the 1890s, the euthanasia debate moved beyond the medical profession to involve lawyers and social scientists. In New York, lawyer Albert Bach supported euthanasia, speaking at conferences to gain

support. Lawyers demanded greater patient rights and less physician authority. Physicians challenged the lawyers, concerned about the reputation of their profession.¹¹

Twentieth Century Attempts for Legalisation

Many American states allow a state law to be altered through citizen-initiated petitions. The issue can then be put to ballot as a referendum question.¹² A challenge to the law on assisted suicide in Texas occurred in 1902 in *Grace v. State*. Based on the decriminalisation of suicide, it was argued, assisting suicide should not be a criminal act.¹³ The challenge was overturned. A statute was adopted declaring the assistance of suicide to be a criminal act. In 1906, a euthanasia bill in Ohio was defeated by the Ohio legislature, 79:23.¹⁴ A right-to-die bill was unsuccessfully introduced into Florida’s legislation in 1967. In 1969 a bill in Idaho also failed. California passed a *Natural Death Act* in 1976, followed by a further ten states. This gave legal standing to living wills.¹⁵

The Hemlock Society was founded in 1980. To this society, the ingestion of hemlock by Socrates was rational suicide. For them, hemlock symbolised personal choice, which they claimed was “central to Socrates’ action.” Socrates chose death rather than being exiled, similar to a terminally ill person who may choose death when given a choice.¹⁶ In 1990 the Hemlock Society in Oregon introduced the *Death with Dignity Act* to the Oregon legislature. This Act failed to move out of committee. In 1991, a series of amendments by the Hemlock Society to a proposal known as Initiative 119 to Washington States’ 1979 living will law, would have seen euthanasia and PAS legalised. However it was defeated after receiving 46% of the vote. In 1992, Proposition 161 on the ballot in California was defeated after receiving 46% of the vote. This proposition would have also legalised both euthanasia and PAS.¹⁷ Compassion in Dying was established in Washington in 1993 and began to sponsor challenges to state laws against assisted suicide. Washington State’s anti-suicide law was overturned through a court ruling in 1994. Making this judgement, Judge Rothstein wrote, “The court does not believe that a distinction can be drawn between refusing life-sustaining medical treatment and PAS by an uncoerced, mentally competent, terminally ill adult.” The anti-suicide law was re-instated in 1995.¹⁸

To attract more support in 1994, Measure 16, a *Death with Dignity Act* in Oregon was drafted to permit only PAS by lethal drugs and not euthanasia.¹⁹ The act was approved by a vote of 51-49%. An injunction was immediately put in place so that the act could not be put into effect. In 1997 another vote in Oregon on the *Death with Dignity Act* passed the act with a 60-40% majority. It became law on 27th October 1997. A challenge by the Attorney-General to the Oregon Act occurred in 2006, however it was defeated by the US Supreme Court.²⁰ Michigan voted against PAS in 1998 by 70-30%

majority.

The Hemlock Society morphed into End-of-Life Choices in 2003. It was stated, “We also need access to the halls of government in the states and in Washington DC - access that the name Hemlock is currently denying us.”²¹ A further transformation occurred in 2005 when Compassion in Dying merged with End-of-Life Choices to form Compassion and Choices.²² Some original members of the Hemlock society formed “Final Exit.” They are the only group in America committed to helping non-terminal individuals access to life-ending intentions.²³

Between January 1994 and June 2009, 113 legislative proposals were put forward in 24 American states to legalise PAS or euthanasia.²⁴ In 2008, an Act similar to the Oregon *Dying with Dignity Act* was approved by voters in the Washington State with a 59-41% majority. The Montana Supreme Court in 2009 ruled PAS was not an illegal act within the constitution of the Montana State.²⁵

Although there were many attempts to legalise euthanasia or PAS, there were other issues and factors influencing the debate in America.

It’s Over Debbie

In 1988 the *Journal of the American Medical Association* published an anonymous report “It’s Over Debbie.” The report described an on-call gynaecological resident administering a lethal dose of morphine sulfate to a patient with ovarian cancer.²⁶ There was much outrage through the journal with more than 150 letters received. 4:1 letters were against the actions of the resident. A further 3:1 were against the journal for publishing the report. The journal advocated that the correct place for responsible debate on euthanasia was within the realm of their journal.²⁷ The authenticity of the article was questioned.²⁸ A literary analysis of the article raised some questions over the interpretation of the article.²⁹

Dr Jack Kevorkian

The euthanasia debate was further fuelled between 1990 and 1998, by Dr Jack Kevorkian, a pathologist who developed a suicide machine, and assisted in over 120 suicides. Alarming statistics emerged from the analysis of 69 of his patients. Only 25% were terminally ill. 71% were women, and divorced. Those who had never married were overrepresented in his patients. These findings highlighted the vulnerability of certain groups.³⁰ Kevorkian was considered a maverick and his methods were not endorsed by those in the right-to-die movements. He worked within his county in Michigan, with people flying in to see him one day and dead the next. All patients released the lethal medication themselves except for his last patient. *Sixty Minutes* aired his tape of him injecting this patient. This was the fifth time he had been tried and the courts succeeded this time in convicting him of murder.³¹

Quinlan, Curzan and Schiavo

There have been three prominent legal cases in the United States which have influenced the euthanasia

debate in the last thirty-five years. Karen Quinlan entered an unresponsive or so called “vegetative” state in 1975. Legal wrangles lasted for about a year, resulting in her mechanical ventilator being removed, but not her feeding tube. Karen survived for another ten years and died of pneumonia. Nancy Curzan entered an unresponsive state in 1983, with the legal arguments lasting almost three years. The physicians treating Nancy refused her parents’ request to remove the feeding tube. Nancy died in 1990 after the withdrawal of her tube. The United States Supreme Court ruled that life sustaining treatments could be removed. Based on patients having a right to refuse life-sustaining treatments, a court may rule on those unable to make a decision for themselves, such as in this case. Terri Schiavo entered an unresponsive state in 1990. Disagreements within her family over the removal of her feeding tube were battled out in the courts for seven years. On 18 March 2005, Terri’s feeding tube was discontinued and she died of dehydration on 31 March 2005.³²

Legal Challenges

Not only were there legal challenges to allow those in unresponsive states to die, there were also constitutional challenges to the state laws that forbade PAS. A patient in Washington State who requested a prescription for a lethal dose of drugs was refused and committed suicide by jumping off a bridge. The doctor involved, three other physicians and three dying patients challenged the law in Washington State. After a ruling in their favour at the state level and defeat at the Ninth Circuit Court, it was finally heard in the United States Supreme Court. In New York, a patient also requested a prescription for a lethal dose of drugs. Her physician complied and the patient committed suicide. Her doctor along with two other physicians and three dying patients challenged the New York law and received a ruling in their favour. This case was also heard in the United States Supreme Court. The Supreme Court in June 1997, ruled by a majority of 9:0, that there was no constitutional right to PAS. Therefore states could endorse a law that either permitted or did not permit PAS, but the law prohibiting PAS was not unconstitutional.³³

Oregon – 1997- Physician-Assisted Suicide

The Oregon *Dying with Dignity Act* was ratified five months after the Supreme Court passed its ruling on PAS. Oregon has been considered the experimental state demonstrating how such an act could be implemented.³⁴

The decision to participate in the Act is at the request of the patient to their physician. No data can be released to the public or the media due to the confidential nature of the law. However, the Department of Human Services collects and publishes data in an annual report. Within twelve months of publication of this report, all documentation regarding the death is destroyed.³⁵ Thus no independent evaluation of the data can occur. In the first few years the Oregon reports utilised the term “PAS.” Since October 2006 the reports refer to a “death under the Oregon Death with Dignity Act.” Since November 2006, “aid in dying” or “patient-directed

“dying” has been used by the American Public Health Association.³⁶

To participate in the act the following requirements must be met by the patient:

- Must be at least 18 years of age.
- Must be of competent mind to make an independent voluntary request.
- Must be deemed as being terminally ill and expected to die within the next six months.
- Must be a resident of Oregon, the following can be used as evidence to fulfil this condition:
 - Possession of an Oregon driver’s licence
 - Registration to vote in Oregon
 - Ownership or lease agreement for property in Oregon
 - Oregon tax return filed in the last financial year.
- Two independent written requests must be made two weeks apart, and signed by two witnesses, one who is unrelated to the patient.
- A second physician must examine the patient and agree with the patient’s physician.
- If the patient is suspected of suffering from a psychiatric illness, then the patient must be referred to a psychiatrist.
- The physician must inform the patient of all end-of-life care options.
- The request can be withdrawn at any time.

Prescriptions can be sent by mail or delivered personally by the physician to the pharmacist. Once the prescription is filled, the lethal medication can be provided to the patient, attending physician or an “expressly identified agent of the patient.”³⁷ All prescriptions must be reported to the Oregon Department of Health.³⁸ Dr Katrina Hedberg (an author of the Oregon Annual reports) stated in a testimony to the House of Lords Select Committee “The law itself only provides for writing the prescription, not what happens afterwards.”³⁹ Consequently there are no safeguards once the prescription has been written. As the physician does not have to be present at ingestion, there is no means of knowing if coercion occurred or any of the myriad of other abuses.

The well-known euthanasia law in the Netherlands has two distinct differences to the *Dying with Dignity Act* in Oregon. In the Netherlands the physician can provide either assistance with suicide or perform euthanasia where they inject the lethal dose. In Oregon the physician cannot inject the lethal dose, which is self-administered. In the Netherlands, the patient does not have to be terminally ill but experiencing “unbearable and hopeless suffering” with no prospect of improvement, while in Oregon the patient must be terminally ill, with no mention of pain or suffering. This requirement does not encourage the physician to delve into the underlying concerns of the patients’ request.⁴⁰

In 1998, 21 people died under the Oregon Act. In 2009, 59 people died under the Act, although 95 prescriptions

were written. Between 1998 and 2009, 460 people had utilised the Act to die. However, only 38 patients had been referred for a psychiatric evaluation. The main end of life concerns between 1998-2009 were loss of autonomy (90.8%), less able to engage in activities making life enjoyable (87.3%) and loss of dignity (85.2%). Surprisingly, only 22.1% were concerned about inadequate pain control.⁴¹ A patient regained consciousness 65 hours after they had taken their prescribed lethal medication. This patient died of their underlying illness 14 days later. Since the inception of the Act the time taken for the 460 people who have died varied from one minute to 104 hours.⁴²

Hendin and Foley in 2008 reported on several cases in Oregon. They raised a concern that more emphasis was placed on meeting the requirements of the law than the patients’ needs. For example, there was a concern by the medical director of Compassion in Dying that quick action was required before a patient became incompetent and would be unable to make a decision for herself. The physician who wrote the prescription is later detailed as regretting his decision: “I didn’t personally discuss the case with her regular physician and had only a very cursory contact with her second.” As the executive director of Compassion in Dying states: “If I get rebuffed by one doctor, I can go to another...”⁴³

Loss of autonomy is the most often quoted reason for desiring control over the end of one’s life. The motive behind accessing lethal medication is to end one’s life sooner rather than later. However, Lee reports on a phenomenon that is commonly observed in patients who access lethal medication. They often experience a feeling of peace and well being and an inclination to live longer, once they have acquired the lethal medication.⁴⁴ The most striking of the cases that Lee cites is a patient with ovarian cancer who obtained the medicine and is quoted as saying: “I felt I had more energy to fight the cancer and just to live in the present time. It just took a big weight off my shoulder somehow, knowing at least that that was one thing that maybe I didn’t have to worry about.” This patient ingested the medication *three years* later.⁴⁵ To access a prescription for lethal medication a patient must be assessed by two physicians who deem them to be terminally ill and death is imminent, expected within the next six months. This case clearly does not fit the legal statutory requirements of the Oregon law, and could lead us to question do others?

Two often cited cases of the ruthlessness of the Oregon Act are the cases of Barbara Wagner and Randy Stoup. In both cases the patients’ health fund sent correspondence refusing to pay for treatment that could prolong their life. In Barbara’s case the letter stated: “treatment of advanced cancer that is meant to prolong life, or change the course of this disease is not a covered benefit....would cover palliative, or comfort, care, including if she chose, doctor-assisted suicide.” Randy was denied medication for his prostrate cancer and was told suicide was a treatment option. Oregon’s health plan gives five examples of “comfort /palliative care” for terminally-ill patients. The fifth option is assisted suicide. Both patients

subsequently were able to access the treatment they desired. Randy through his government Health plan, and Barbara directly through the drug manufacturer.⁴⁶ What was unacceptable in these cases was the offering of suicide as an option for a terminally-ill person.

Washington – Yes on 1-1000 campaign

Constantly defending the Oregon Death with Dignity Law is the Death with Dignity National Centre. It is a non-profit organisation which is often at the forefront of legal battles of Dying with Dignity Laws.

The Death with Dignity 2007 Annual Report stated the following:

We have spent the last year actively researching and collecting data to determine the state which is most likely to adopt a Death with Dignity law. Through these efforts, we have identified Washington as the state most likely to move forward in offering its terminally ill citizens expanded options at the end of life. There is a strong local contingent of individuals in that state who are eager to form the basis of a statewide effort. In addition, a popular former governor of Washington, Booth Gardner, is committed to this cause. We, at the Death with Dignity National Centre, are proud to provide our political experience and expertise to these talented and committed people of Washington.⁴⁷

The 2009 Annual Report stated:

It has been a year of accomplishments for our organization and for the Death with Dignity movement as a whole. During this year, the people of Washington enacted and implemented the second Death with Dignity law in the nation, based on Oregon's landmark legislation. Similar efforts have tried and failed in various states during the last ten years, but the Washington victory was solid with 58% of voters supporting the law. Throughout the course of the campaign, we expended nearly two-thirds of our combined organizational resources on the campaign, while continuing to provide vital education tools and information to terminally ill individuals, their family members, and health care workers. This total commitment to success in Washington strained our resources and forced us to consider staff cutbacks in the year following the election. Notwithstanding the organizational costs, this commitment to success in Washington was a demonstration of our mission-driven approach to providing leadership to the movement. We expend our resources for the purpose of fulfilling our mission—to safeguard the existing Death with Dignity laws and to promote them in other states....

We look forward to 2010 with optimism, as we conduct research and organizing activities in anticipation of the next Death with Dignity campaign.⁴⁸

The *Yes on 1-1000* initiative was heavily subsidised by the Death with Dignity movement. Making history, Death with Dignity raised \$4,890,019 compared to \$805,518,

donated by 166 Catholic parishes, organisations and dioceses in 40 states for the opposition campaign. By 2 July 2008, 320,000 signatures had been collected, 100,000 more than required to take the initiative to the ballot. On 13 August 2008, the Washington *Death with Dignity Act* was confirmed to the ballot.⁴⁹ The Washington law, voted in by ballot on 4 November, 2008, was enacted on 5 March, 2009, based on the Oregon law.⁵⁰

Montana – 2009

Compassion and Choices was the driving force behind a 2009 Montana Supreme Court case to uphold a 2008 ruling on a “right-to-die” case (*Baxter v Montana*).⁵¹ The Montana Supreme Court upheld that the Montana State Constitution “guarantees the terminally ill the fundamental right to ‘die with dignity,’ a right that includes assistance from a physician who would be protected from criminal liability.”⁵² The court acknowledged a doctor who provided lethal medication could not be convicted of homicide as they could plead innocence as the act involved the consent of the patient.⁵³ This ruling supported the December 2008 District Court ruling that “state homicide laws unconstitutionally restrict terminally ill patients’ right to dignified deaths.”⁵⁴ However the Supreme Court put it to the state legislators to decide if PAS was illegal by reversing the District Court ruling that there was a constitutional right to PAS. A 5:2 vote ruled there was no Montana statute that made PAS illegal.

There are now two bills being prepared. One is to formally legalise assisted suicide, based once again on the Oregon experience. The other bill is to explicitly forbid the practise. These bills will be introduced into the new legislative session in January 2011.⁵⁵

Vermont

In November 2010 Peter Shumlin was voted as Governor of Vermont. He was quoted as saying during his campaign:

As Governor, I will strongly champion death with dignity legislation. I have been a sponsor of this legislation for multiple years and I have a track record of bringing people together to get tough things done...As Governor, I will make this a top priority and in my State of the State address will ask the legislature to take this civil rights issue up and pass it prior to adjournment in 2011.

Patient Choices at the End of Life are the group in Vermont supporting the legislation. This group has strong ties with the Death with Dignity National Centre.⁵⁶

Conclusion

Suicide and assisted suicide have been an issue in society for a very long time. For the early Church Fathers the value of human life was inexplicitly connected to the notion of life being a gift determined by God, thus a person could not end their life at their own choosing. The argument to legalise assisted suicide rode on the back of the decriminalisation of suicide, the advances in medical knowledge, and an increased appreciation of the

autonomy of individuals. In the American society, there have been groups of individuals who have been very strong supporters of PAS. They are vocal and ready to challenge and do whatever it takes to thrust their cause further and further, constantly seeking which state they can target next. Groups change names to make themselves more acceptable, change terminology to create “morally” acceptable terms. With more than 100 attempts to legalise euthanasia and or PAS in the last 15 years, these groups are not going to give up their fight easily. The lack of transparency and safe guards in the Oregon Law demonstrate the complexity if not impossibility of framing laws that adequately protect vulnerable people. The efforts of powerful lobby groups have introduced PAS into three of the fifty American states. We must resist similar developments in Australia.

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Catholic Teaching about Tube Feeding

After exploring the sources of Catholic teaching about tube feeding, this article summarises that teaching in four points. Because tube feeding usually offers little if any benefit in advanced dementia, as a general rule a feeding tube is not inserted into these patients.

The United States (US) *Ethical and Religious Directives for Catholic Health Care Services* (ERD) is their

equivalent to the *Code of Ethical Standards for Catholic Health and Aged Care Services in Australia*. On

17 November 2009, the US bishops voted (219 for, 4 against) to change Directive 58 of the ERD. The new directive reads:

In principle, there is an obligation to provide patients with food and water, including medically assisted nutrition and hydration for those who cannot take food orally. This obligation extends to patients in chronic and presumably irreversible conditions (e.g. the ‘persistent vegetative state’) who can reasonably be expected to live indefinitely if given such care. Medically assisted nutrition and hydration becomes morally optional when they cannot reasonably be expected to prolong life or when they could be “excessively burdensome for the patient or [would] cause significant physical discomfort, for example resulting from complications in the use of the means employed.” For instance, as a patient draws close to inevitable death from an underlying progressive and fatal condition, certain measures to provide nutrition and hydration may become excessively burdensome and therefore not obligatory in light of their very limited ability to prolong life or provide comfort.¹

Catholic teaching about what is variously called medically assisted nutrition and hydration (MANH), clinically assisted nutrition and hydration (CANH), or tube feeding with a PEG (percutaneous endoscopic gastrostomy) is contained above all in two statements. The first is a speech given by Pope John Paul II in 2004. In 2005, a few months after the death in Florida of Terri Schiavo, the US bishops wrote to Rome asking questions about tube feeding. The second important source for this teaching is the response to these questions by the Congregation for the Doctrine of the Faith (CDF).² Both these statements are referenced in Directive 58, with the quote coming from the CDF.

Australia’s *Code of Ethical Standards* sets out the teaching in this way:

Nutrition and hydration should always be provided to patients unless they cannot be assimilated by a person’s body, they do not sustain life, or their only mode of delivery imposes grave burdens on the patient or others. Such burdens to others do not normally arise in developed countries such as Australia.³

There have been at least three statements by entities associated with national bishops’ conferences which have discussed these matters helpfully. In Australia in 2004, the Bishops Committee for Health Care and the Bishops Committee for Doctrine and Morals, together with Catholic Health Australia (CHA), issued a *Briefing Note on the Obligation to Provide Nutrition and Hydration*. In the United Kingdom, there have been two useful guides from the Department for Christian Responsibility and Citizenship of the Catholic Bishops’ Conference of England and Wales. Issued in 2008, the first is titled *The Mental Capacity Act and ‘Living Wills’: A Practical Guide*. Issued in 2010, the second is titled *A Practical*

Guide to the Spiritual Care of the Dying Person.⁴

Some concern about the new Directive 58 has been expressed in the US media. In this, various opinions were cited. Noting that the directive “applies to all patients receiving care in Catholic-run hospitals,” a bioethicist named Jacob Appel called this “the most significant Church intervention into the lives of non-adherents since the Inquisition.” Thomas G. Weinandy, Executive Director of the Secretariat for Doctrine and Pastoral Practices at the United States Conference of Catholic Bishops, said that if a patient or their family refused a feeding tube “and the reason they don’t want it is they basically want to die, then the Catholic institution would explain to them they can’t cooperate with that and they would have to go to another institution.” Carol Keehan, Executive Director of the Catholic Health Association of the United States (CHAUSA), believed that the policy “would come into play infrequently.” Initially alarmed by the directive, a palliative care physician named Porter Storey read it carefully and was relieved that “it won’t stop him from providing appropriate end-of-life treatment.”⁵ In this context, it is appropriate to re-examine Catholic teaching about tube feeding. This teaching can be summarised with four points. The first three apply to someone who already has a PEG or feeding tube inserted into their stomach.

General Rule

1. Tube feeding is not a medical act, but a natural means of preserving life.

In 2004, Pope John Paul II stated that “the administration of water and food, even when provided by artificial means, always represents a *natural means* of preserving life, not a *medical act*.”⁶ I can explain this best using a personal anecdote. After treatment for throat cancer, my father was fed through a PEG for the last four years of his life. (My father’s advice, which he wished he had followed, was: don’t smoke.) While he was unable to swallow normally, my father’s life was both substantially normal and enjoyable to him. Inserting the feeding tube was a medical act. Preventing or treating infection around the gastrostomy sometimes involved medical care. When a tube fell out (every six months or so), replacing it with new one was also a medical act. However, the point is that my father’s meals were not a medical act. I might be having a salad for lunch; my father might be having Ensure or Ensure Plus. However, preparing both meals was simply food preparation in the kitchen which I as someone who does not have medical training was easily able to do. Eventually, I used a knife and fork, while my father used his feeding tube. However, in both cases, our meal was not a medical act but simply “a natural means of preserving life.”

2. In principle, tube feeding is an ordinary and therefore morally obligatory means of preserving life.

Catholic teaching holds that each person has a moral responsibility to use those means of sustaining our lives that are effective, not overly burdensome and reasonably available (‘ordinary’ or ‘proportionate’ means). On the

other hand, each person has the right to refuse any treatment that is futile, overly burdensome or morally unacceptable ('extraordinary' or 'disproportionate' means).⁷ Within this ethical framework, tube feeding "should be considered, in principle, *ordinary* and *proportionate*, and as such morally obligatory."⁸ In most cases, tube feeding preserves life while imposing comparatively few burdens. Barring exceptional circumstances, it would be wrong to refuse, withhold or withdraw tube feeding. This obligation to provide proportionate care extends to people who are profoundly disabled, including those with brain injuries and those in post-coma unresponsiveness or the vegetative state.

We should note that most secular ethics and the law in some jurisdictions (including England and some states in both the US and Australia) hold a contrary view about all this. They hold that tube feeding is a medical act. Because tube feeding is a medical act, they also hold that a patient (or his or her representative) is free to refuse tube feeding at any time. This position is based not on any distinction between proportionate and disproportionate treatments, but rather on a principle of autonomy which holds that a patient (or their representative) must authorise all their medical treatment, and therefore that they must also be free to refuse any treatment.

In Australia, this matter was first considered in detail in a 2003 case before the Victorian Supreme Court, *Gardner; re BWV [2003] VSC 173 (29 May 2003)*. The case considered whether tube feeding could be withheld from an elderly woman with dementia who had not appeared conscious for about three years and who had no real prospect for any improvement of her condition. The judgement made at least five arguments to permit this. Firstly, Osmolite, the product for tube feeding, was medically formulated, and should therefore be considered a drug. This means that its administration must be a medical act. (#76) Secondly, Osmolite is discussed in the doctor's standard guide to pharmaceuticals, the MIMS Annual. The judgement argues that this confirms that Osmolite is a drug. (#78) Thirdly, tube feeding should only be done under medical supervision, which therefore makes it a medical act. (#77) Fourthly, tube feeding cannot be palliative care, which is defined as care "to alleviate pain or suffering when a patient is dying." (#80) Finally, this interpretation seems to be consistent with the intentions of the parliamentarians who formulated the relevant legislation, the Victorian *Medical Treatment Act 1988*. (#45-71, 84-86)⁹

In my opinion, all of these arguments are flawed. Firstly, the fact that Osmolite is medically formulated does not make it a drug any more than medical advice about a balanced diet changes my meat, fruit and vegetables into drugs. Secondly, inclusion in the MIMS Annual does not make something into a drug, for salt is discussed in the MIMS Annual. In any case, the MIMS Annual describes Osmolite not as a drug but as a food. Thirdly, many procedures such as washing, feeding and exercise are performed in hospitals under medical supervision without themselves becoming medical acts. Fourthly, the

definition of palliative care is incorrect. Not restricted to the time when a patient is dying, its purpose is to palliate or cloak the harmful effects of disease. This is precisely what tube feeding does for a patient when their disease leaves them unable to eat and drink in the usual way. Finally, the intentions behind a law might be relevant to a determination of what is legal, but they are not directly relevant to the deeper question of what is ethical or truly right. There has been considerable protest about this judgement and its argumentation.¹⁰ Even so, the ruling remains in place.

A similar interpretation of tube feeding is found the South Australian *Consent to Medical Treatment and Palliative Care Act 1995*, and the 2009 judgement of the Western Australian Supreme Court about the case of Christian Rossiter.¹¹ In the common law tradition, these interpretations of tube feeding – along with similar interpretations overseas – may also influence court rulings about tube feeding in the other states and territories of Australia. Catholic ethicists are concerned that, when tube feeding is an ordinary or proportionate means of preserving life, its refusal, withholding or withdrawal may well constitute euthanasia by omission.

Exceptions

3. Tube feeding may be refused, withheld or withdrawn if it will not sustain life or if it imposes excessive burdens.

John Paul stated that tube feeding is proportionate and morally obligatory "in principle." The Australian bishops explained that "in saying that the provision of nutrition and hydration is in principle obligatory, the Pope allows for those cases in which the provision of nutrition and hydration would not be appropriate." The Congregation for the Doctrine of the Faith (CDF) identified three sorts of cases in which this might happen:

Firstly, it may be that "in very remote places or in situations of extreme poverty, the artificial provision of food and water may be physically impossible." In these cases, the CDF added, "*ad impossibilia nemo tenetur*," that is, 'no one is obliged to do the impossible.' Cases like this are probably common in a poor or developing country. They would be rare in Australia.

Secondly, there are cases where "due to emerging complications, a patient may be unable to assimilate food and liquids, so that their provision becomes altogether useless." For example, especially as death becomes imminent, a patient's stomach may effectively shut down, so that the tube feed simply sits in the patient's stomach and is not absorbed.

Thirdly, there are cases where tube feeding "may be excessively burdensome for the patient or may cause significant physical discomfort." This is especially a concern when death is near. For example, as death approaches there is a natural process of dehydration. By interfering with this, tube feeding may cause bloating and significant discomfort. It may also increase respiratory secretions, making it more difficult for a dying patient to catch their breath or to cough, and perhaps requiring suction. Especially if a dying patient has a partial bowel

obstruction, tube feeding may cause them to vomit repeatedly, with the attendant risks of aspiration pneumonia and other respiratory complications. Extra fluid from tube feeding may sharply increase the flow of urine, which may require catheterisation of an incontinent, dying patient. Indeed, when death is near, a feeding tube might be removed altogether if the removal of tube feeding will not hasten death and the tube is causing significant discomfort around the insertion site.¹²

Because of the difference between Australian law and Catholic ethical standards, there is a slightly greater potential for disagreement about tube feeding between patients and their representatives (who may decide to refuse tube feeding according to Australian law) and health professionals in Catholic facilities (who must follow Catholic ethical standards). What is helpful in these situations? Firstly, each case must be decided on a case-by-case basis. CHA offered this advice after the BWV judgement; Ron Hamel, Senior Director of Ethics at CHAUSA, repeated this advice when the new Directive 58 was issued. Secondly, because misdiagnosis can occur, it is prudent for clinicians to seek a second opinion about these cases. Thirdly, it is useful to seek an opinion from a Catholic ethicist about what Catholic ethical standards truly do require. (At the Chisholm Centre, we are always pleased to provide such opinions.) Fourthly, especially if disagreement is becoming protracted, it is wise to speak with the local Catholic Bishop sooner rather than later. The Bishop can advise about Catholic ethical standards; with the health professionals and the patient and his or her representatives, the Bishop and his advisors can also seek to discern a mutually acceptable way forward. Fifthly, dialogue among all parties is extremely important. This should seek to hear and at times address concerns and fears about tube feeding. It should include honest appraisal of the benefits and burdens of tube feeding. And it should seek to discern a mutually agreeable way forward. Finally, after a Catholic facility has made known its moral objection to a refusal of tube feeding, there may be some isolated cases in which that facility together with the local Bishop might agree to continue to provide care to this patient. This might happen particularly if the facility has provided long-standing care to the patient, or if the patient or his or her representatives seem somewhat ambivalent about refusing tube feeding, and there is hope that continued care in a Catholic facility might help to persuade them to agree to tube feeding.

Inserting a Feeding Tube

4. Inserting a feeding tube is a medical act which may be judged either proportionate and obligatory, or disproportionate and not obligatory. Because tube feeding usually offers little if any benefit in advanced dementia, as a general rule a feeding tube is not inserted into these patients.

Our first three points pertained to someone who already has a feeding tube inserted. Our final point concerns the insertion of a feeding tube. The Australian bishops have stated, “To insert a feeding tube is a medical decision

subject to the normal criteria of medical intervention.” In many cases – like that of my father – insertion of a feeding tube will preserve life while imposing relatively few burdens. According to Catholic teaching, in these cases insertion of a feeding tube is proportionate and obligatory.

Whether to insert a feeding tube is often a consideration in advanced dementia. Dementia is a terminal condition. Along the way, often near the end, a patient may lose the ability to feed themselves. They are then hand-fed by another, which may take an hour or more. When their consumption even from hand-feeding declines, the insertion of a feeding tube may be considered. Certainly, each case must be decided on a case-by-case basis. However, as a general rule a feeding tube is not inserted. This is because the medical evidence is that in these circumstances a feeding tube provides few if any benefits while at the same time imposing significant burdens. Let me make this point by reviewing three recent articles:

Alan Sanders offers the highest standard of medical evidence, a systematic review of the peer-reviewed literature on tube feeding in advanced dementia. Drawing on over eighty different studies, Sanders concludes that tube feeding “is not likely to prevent or relieve aspiration pneumonia, increase patients’ nutritional status (including prolonging life), or reduce feelings of hunger and thirst better than hand feeding for such patients.” He cautions that “administered in inappropriate circumstances” tube feeding “can also cause significant suffering and in some cases shorten life.” At the same time, “hand feeding also has the advantage of providing sensory-deprived patients a small experience of food and human contact.” Decisions about tube feeding should therefore be made on a case-by-case basis, always considering “the needs of individual patients and their ultimate good.”¹³

Johanna Valiquette also offers a systematic review. She too concludes that in patients with advanced dementia tube feeding usually does not improve nutritional status, reduce the risk of lung infections, nor prolong life. She notes a number of burdens including “cognitive and functional deterioration and distress occurring from the hospitalisation to place the PEG tube” and “the discomfort of the procedure itself along with the usual risks of infection and other complications.” On the other hand, “spoon feeding provides the enjoyment of food as well as the comfort of socialisation that accompanies mealtime.” While “patients should be evaluated on a case-by-case basis,” we should note that “PEG tubes have proven of very limited medical efficacy for most patients with end-stage dementia, while causing significant burdens.”¹⁴

John S. Howland offers a counter-example. He reports the case of an elderly woman who had had dementia for about five years. A feeding tube was inserted after her weight fell by 8 kilograms. Several months later, she had gained 6 kilograms, and recovered her ability to “verbalise and respond to staff.” “In addition to her tube feeds, she began taking small amounts of ‘comfort foods’ (ice cream, puddings, cake) by mouth, which she appeared to enjoy.”¹⁵ Cases like this remind us that there

B cannot be a universal rule against tube feeding in advanced dementia, but only a general rule which allows for exceptions. In advanced dementia, decisions about inserting a feeding tube must be made on a case-by-case basis.

B Drawing on all this evidence, the English and Welsh bishops comment that tube feeding “may cease to be indicated in the last days of life when nutrition and hydration will have little or no effect in sustaining life or earlier than this in some conditions, such as dementia, where steady weight loss despite CANH is recognised as part of the late stages of the illness.”¹⁶

The Chisholm Centre regularly receives inquiries from Catholic families asking if church teaching requires them to have a feeding tube inserted into an elderly relative with advanced dementia. They are usually pleased to learn that tube feeding is not obligatory when there are few benefits and significant burdens. The Centre also hears regularly from Catholics who ask what they are able to say in an Advance Care Plan. While they should not refuse all tube feeding, they are also pleased to learn that they can refuse disproportionate tube feeding. Because this information can reduce burden and suffering at the end of life, the Centre is always pleased to respond to any of these inquiries.

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¹⁴ Johanna Valiquette, “PEG tubes in end-stage dementia,” in *Incapacity and Care: Controversies in Healthcare and Research*, ed. Helen Watt (Oxford: Linacre Centre, 2009), 106-121 at 113, 117, 120.

¹⁵ John S. Howland, “A Defense of Assisted Nutrition and Hydration in Patients with Dementia,” *National Catholic Bioethics Quarterly* 9, no. 4 (Winter 2009): 697-710 at 702.

¹⁶ *Spiritual Care of the Dying Person*, 27.

All on-line documents accessed 23 November 2010.

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