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SUMMER

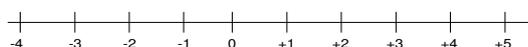
2008

## Ethical Aspects of Advance Care Planning

*On 12 November 2008, the Caroline Chisholm Centre for Health Ethics ran a conference on Advance Care Planning. This is the Director's talk from that conference.*

Good morning, and thank you for coming to our conference. My task in this presentation is to set out the ethical distinctions which underpin both the law in this area and also the practical decisions that are made every day by patients or their representatives in consultation with their health care professionals. In other words, my task is to set out the foundational ideas and distinctions which inform this whole area of decision making. My hope is that reflecting on these foundational ideas will help to make each of us just a bit more proficient as we engage with practical cases. In my presentation, I want to do four things. Firstly, I want to set out the ethical framework which underpins this area of decision making. I've called this section 'Killing versus Allowing to Die.' Secondly, I want to explore how this ethical framework can best be followed in Advance Care Planning. Thirdly, I want to offer some practical comments from an ethical perspective about how to go about Advance Care Planning. Fourthly, I'll offer some brief comments on the topic of Assisted Nutrition and Hydration. This is a matter about which there has been ongoing deliberation in Catholic ethics. For all of us, it's an issue which deserves careful, ongoing reflection.

### Killing versus Allowing to Die



Trying to End Someone's Life	Trying to Preserve Someone's Life	
<b>Euthanasia</b>	<b>Ordinary or Proportionate Care</b>	<b>Extraordinary or Disproportionate Care</b>
an action or omission which of itself and by intention causes death, with the purpose of eliminating all suffering		FUTILE or TOO BURDENSOME: <ul style="list-style-type: none"><li>. physically too painful</li><li>. psychologically too distressing</li><li>. socially too isolating</li><li>. financially too expensive</li><li>. too burdensome in any other way</li></ul>

Let us now look at the ethical framework which guides us in this area. I've presented this as a diagram, which I hope is useful. First of all, if it's a concept you're familiar with, think of a line graph with positive numbers on one side and negative numbers on the other side. The numbers do not have exact meaning, except that larger numbers

correspond to more and more extensive interventions. So, the negative numbers represent 'trying to end someone's life,' whereas the positive numbers represent 'trying to preserve someone's life.' The name for efforts to end someone's life is of course euthanasia. Meanwhile, within efforts to preserve someone's life, we distinguish two different categories. There is what is called 'ordinary or proportionate care,' and there is what is called 'extraordinary or disproportionate care.' We'll expand on the meaning of these terms shortly, but first let us note what the diagram reveals. What we are aiming for in end-of-life care is ordinary or proportionate care. This means that we must at one end distinguish ordinary or proportionate care from euthanasia, and we must at the other end distinguish ordinary or proportionate care from extraordinary or disproportionate care.<sup>1</sup> That's the ethical framework which guides us in the sorts of cases we are considering today.

Let's talk first about distinguishing ordinary or proportionate care from euthanasia. Euthanasia is defined as "an action or omission which of itself and by intention causes death with the purpose of eliminating all suffering."<sup>2</sup> We'll take that definition apart to ensure that we understand it. First of all, the phrase "of itself and by intention" reveals the two things which are necessary to constitute euthanasia. There must be both lethal intent and lethal means – the intention to kill, and some intervention which is lethal. Indeed, it is this intention to kill which sets euthanasia apart and makes it different from allowing to die. If we refuse extraordinary treatment, ultimately it is our illness that kills us. But in euthanasia, it is a person who kills – either the doctor in medically-mediated

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euthanasia, or the patient in Physician Assisted Suicide. Some people might object that this focus on causality and intention seems very obscure and therefore not of great moral significance. But neither of these claims is true. As regards its significance, allowing to die is like watching someone drown far out at sea, someone so far away that we cannot reach them in time to save them from drowning. But because of this intent to kill, euthanasia instead is like holding their head under the water. Or again, allowing someone to die is like watching someone fall from high up on a cliff, whereas euthanasia instead is like pushing them off the cliff. It's therefore a crucial moral difference. And sometimes, it's not so obscure either, for in some cases the only possible explanation for the treatment given would be an intent to kill. The definition also notes that euthanasia can be either an action or an omission. An action is easy to understand: it's an overdose of morphine or a suicide pill or whatever. But there can be euthanasia by omission too. There are some things that we really should do to preserve our lives. In some circumstances, treatments like assisted ventilation during surgery or fluids for hydration after surgery are not extraordinary means which can legitimately be forgone, but rather ordinary or proportionate care which cannot rightly be refused. To refuse such ordinary care, therefore, is euthanasia by omission. Indeed, this is a particular concern for Advance Care Planning: we must ensure that our plans do not lead into euthanasia by omission. We must ensure that our plans for ordinary or proportionate care do not cross the line and instead become euthanasia. Finally, to complete our study of the definition, the phrase "with the purpose of eliminating all suffering" distinguishes euthanasia from other forms of killing. When someone kills with the purpose of eliminating suffering, that is euthanasia. But when someone kills Granny to inherit her property, that's just ordinary, old-fashioned murder.

So at one end, we must ensure that our Advance Care Planning does not lead into euthanasia, especially euthanasia by omission. But at the other extreme, we distinguish ordinary or proportionate care which cannot be refused, from extraordinary or disproportionate care which may be forgone. Here, we can refuse treatment which is either futile or too burdensome. Treatment is futile if it provides no benefit to a particular patient. I think we are wise to have a very restricted understanding of futility. There can be many benefits from treatment. These include slowing down the progress of a disease, sustaining the patient's life, or relieving the patient's distress or discomfort. Treatment can only be futile if it offers none of these benefits at all.<sup>3</sup> On the other hand, we should have a much more extensive concept of how something can be too burdensome. There are at least three things to consider here.<sup>4</sup> First of all, we should consider the state of the patient, and what resources they have to endure burden. For example, a patient who until now has enjoyed good health, who is young and fit and robust, can reasonably endure more burden than another patient who is old and frail and perhaps worn down by chronic disease. Secondly, we must consider what benefits are

possible from the treatment, and how likely these are. But above all, we must consider the burdens of treatment. Such burdens can be physical, psychological, social, or financial. Eventually, we may decide that a particular treatment is physically too painful. In the fifteenth to eighteenth centuries, before the use of anaesthesia, the usual example of something being physically too painful was amputation. Nowadays, the third or fourth round of chemotherapy might be another example. Or again, we might decide that something is psychologically too distressing. For example, in the early tradition, in a world very different from our own, it was held that a woman who felt great distress at the thought of a male doctor examining her private parts could legitimately refuse that treatment as too burdensome. That might be an odd example for us, but it does illustrate how extensive our understanding of burden should be. Or to offer a modern example, I knew a patient who refused an amputation which may have saved her life not because it would be too painful but because she was already frail, and because she was too distressed at what a burden it would be to lose a leg and to face extensive rehabilitation. We might also decide that something is socially too isolating. The tradition considered a case where moving from home to the European Alps might save someone's life. But if moving from home would isolate the patient from his family, the tradition allowed him to stay home and accept death.<sup>5</sup> Nowadays, much the same decision might be made by an elderly woman from a country town who decides not to go to the capital city for treatment but to stay at home to spend her time with her grandchildren and to care for her sick husband for as long as she can. We might also decide that something is financially too expensive. The tradition insisted that we were not obliged to bankrupt ourselves just to extend our lives a short time. Nowadays, in some circumstances, we might also have to consider whether a particular treatment makes excessive demands on healthcare resources. Treatment might also be too burdensome in other ways – for example, a patient might judge a particular treatment either morally or spiritually repugnant. In any of these circumstances, the treatment is too burdensome and therefore extraordinary or disproportionate. It can therefore be legitimately refused.

Note that there is an inescapably subjective dimension to these determinations. What one person finds too painful, another endures without complaint. What one person finds too isolating, another might even find quite enjoyable. Treatment which one person judges too expensive may seem to someone else to be good value for money. This is why the best person to make these judgements has always been the patient.

Finally, having discussed the sorts of decisions which can legitimately be made, let me note the sort of decisions which must not be made. We might decide that treatment is futile, but we must never decide that someone's life is futile.<sup>6</sup> No matter how frail or disabled someone is, treatment must never be omitted because either the patient or their representative or their medical team has decided that this life is no longer worth living. To act on

such a decision would be euthanasia by omission.

## Advance Care Planning

But let us turn to Advance Care Planning. At least two features of modern medicine have made this necessary. Firstly, there is the enormous power of modern medicine to keep people alive. Thus, people legitimately fear that they might be kept in a painful or distressing or isolating state. Secondly, so many more people now die having lost decision-making capacity.<sup>7</sup> At a time when we would like to have a say about our treatment, more and more of us are no longer capable of doing this.

Advance Care Planning has grown out of this circumstance. The earliest form of this was what is variously called a living will or an Advance Care Directive. For example, Queensland has such a document.<sup>8</sup> It lists various situations, and asks the patient to specify what they would or would not want. Thus, it considers such situations as being “in the terminal phase of an incurable illness,” or being “permanently unconscious (in a coma),” and so on. And it asks the patient to specify whether in that situation they would or would not want various interventions such as cardio-pulmonary resuscitation, assisted ventilation, artificial hydration, artificial nutrition, and so on. An Advance Care Directive only applies after the patient has lost decision-making capacity. In some jurisdictions, a Directive can have the force of law and be legally binding.

More recently, there has been another approach to Advance Care Planning. Following this approach, someone appoints a friend or family member to be what is variously called a health care proxy, or a substitute decision maker, or a health care representative. They may also write something to guide their representative. However, they rely above all on the representative, with the written statement not as a binding declaration but simply as a guide. Again, this health care representative becomes involved only after the patient has lost decision-making capacity.

Nowadays, the vast majority of ethicists recommend a patient representative over an Advance Directive. Most ethicists agree that good outcomes are more likely to be achieved with a representative, and therefore that this is a better approach than the Advance Directive. There are at least eight difficulties with an Advance Directive which make it a less successful mechanism than a health care representative:

First of all, with Advance Directives, there is an almost exclusive focus only on treatments. For example, the directive we looked at asked the patient to specify in various situations whether or not they would want cardiopulmonary resuscitation, or assisted ventilation, or artificial hydration, or whatever. Indeed, this is a focus on treatment very much in the abstract. As we’ve noted, considerations about whether or not treatment might be too burdensome usually consider the current state and resources of the patient, the actual benefits that might come from the treatment, and a realistic assessment of the

burdens which can really only be made when you know all the circumstances of the case. This should not be a simply medical decision about treatment in the abstract. It should instead be a truly human decision which considers every relevant circumstance, not just treatment in isolation. You may have to ponder this point for a while to really appreciate the difference between the abstract decisions which are made in Advance Directives, and the much more richly contextual decisions which really should be made when we decide either to choose or forego treatment. I know that as I’ve thought about this, I’ve come to recognize that this almost exclusive focus in Advance Directives on treatments alone and treatments in the abstract is a serious problem indeed.

A second difficulty is that it is almost impossible to foresee all possibilities. Let me offer an example. Someone with a terminal illness has decreed in an Advance Directive that they do not want artificial hydration. But then they go to hospital for minor surgery, perhaps the insertion of a ureteral stent to allow them to urinate more easily and so to relieve abdominal pain. But after such surgery, re-hydration is a normal part of post-operative care. If the Advance Directive was legally binding, and if this problem was not picked up beforehand, a patient might be deprived of treatment which would not involve much burden at all and which would provide significant benefit.<sup>9</sup> We cannot foresee every possibility. To rule out some treatments in an Advance Directive, especially one which is legally binding, might in some circumstances deprive us of treatment which would make our life easier. It might leave us more disabled and in greater distress. This could be a serious problem indeed.

A third issue concerns informed consent. For consent truly to be informed, we need three things. We need knowledge, understanding and freedom – knowledge or the factual information about a situation, understanding or the capacity to make sense of this, and the freedom to decide either one way or the other. When someone fills out an Advance Directive, they certainly have freedom. But do they have knowledge and understanding? And if really they do not, is their consent really informed consent? Nowadays, before treatment or before research, we go to great lengths to inform the patient - to ensure that their consent is truly informed. Especially when I reflect on that, I am struck just how deficient Advance Directives really can be. Do Advance Directives really express informed consent? It is a worrying question.

A fourth issue is that Advance Directives do not always reflect changes of mind. People do change their minds over the course of an illness. When an illness begins, we might imagine that some future possibilities would be quite intolerable. But then our illness does progress, and our views change as we learn that even in difficult circumstances life can still be very sweet. Certainly, an Advance Directive can be changed to reflect our new choices, but this is not always done. Especially as a patient’s health deteriorates, they may have many other priorities apart from updating their Advance Directive.<sup>10</sup> But if an Advance Directive is not updated and a patient

**N**loses capacity, the Directive may trap them in views and choices which have long been superseded.

**A** fifth and very serious concern is that in certain circumstances an Advance Directive may require what is effectively euthanasia by omission. In these circumstances, a certain treatment really would be ordinary or proportionate means. Be it assisted nutrition and hydration or short-term assisted ventilation or whatever, it is neither futile nor overly burdensome. In these circumstances, refusal of that treatment enforced by an Advance Directive really would be euthanasia by omission. Perhaps the patient knew this, and really had suicidal intent. Or perhaps the patient did not recognise this, and really would not have wanted euthanasia by omission if they had been fully informed. Either way, the omission of treatment which could be of benefit and which would not be overly burdensome might be enforced by an Advance Directive.

A sixth concern is that Advance Directives hold great potential to become litigious. After the patient has lost capacity, someone in the family or the health care team believes that the Advance Directive clearly applies in a certain way in the current circumstances. Someone else disagrees. Perhaps they believe that the patient while still competent changed his mind, and therefore that the Advance Directive should no longer apply. Or perhaps they believe that the Directive does not apply in these circumstances, that it is really about something quite different. Or perhaps they're concerned that the strict application of the Directive in these circumstances would be euthanasia by omission. Either way, because these literally are issues of life and death, it all ends up in court. As someone moves towards death, there will always be disputes. Sometimes, these disputes do end up in court. But there is something about Advance Directives which are written down and which are legal documents which all too readily leads to disputes and legal arguments and court cases and quarrels and bitter feelings. There must be a better way than this.

A seventh concern is that Advance Directives work against real dialogue. In end-of-life care, as in just about everything else in life, things work best when we are able to speak together, to dialogue, to negotiate, and to come to consensus. This is what patients and families and health care professionals do over the entire course of a final illness. But an Advance Directive can cut across this. Rather than an ongoing dialogue which truly can discern what is best, there is simply a decision which may or may not be all that wise. I think that dialogue and the relationships that should exist between patients, families and health care professionals can be greatly diminished by Advance Directives.

A final concern is that Advance Directives tend to undermine the professional culture of health care. At the heart of health care is the relationship between the health care professional and the patient. The patient does not know what health care he or she needs; the health care professional must investigate and advise them. But the health care professional cannot simply decide for his or

her patient: the health care professional advises but ultimately the patient must decide. There is great mutuality in this relationship, and it is this relationship which truly makes health care a profession. But this relationship can be greatly damaged by Advance Directives. What must be done is no longer discerned by the patient and health care professional in dialogue. Instead, it can be that the patient is simply telling the health care professional what to do. The doctor, the nurse, the allied health worker is no longer treated as a true professional who is in dialogue with his or her patients. Instead, they are treated as a mere technician, not as a professional but as someone who simply has the technical skills to provide what a patient demands. If you believe as I do in the great profession of health care, this is indeed of great concern.

Catholic Health Australia and the Australian Catholic Bishops Conference have produced two fine documents to advise both patients and health care professionals about Advance Care Planning.<sup>11</sup> As I have done, these documents recommend not an Advance Directive but a patient representative. For example, Section 3 of the guide for patients is about appointing a representative. And Section 4 explains how you can guide your representative while avoiding documents that might be too directive. In the same way, the model statement on the back page of this guide clearly states that this statement "is intended to guide but not direct my representative." In this part of my presentation, I have tried to explain this clear preference for the patient representative over the Advance Directive.

## **Practical Comments**

Let me now offer three practical comments from an ethical perspective. Firstly, I highlight the importance of ongoing conversation among the patient, their family and friends, and their health care professionals.<sup>12</sup> Particularly because these are matters of life and death, this sort of conversation can be very difficult. It may require all our wisdom to create an appropriate situation, and all our courage to use it. But this ongoing conversation is very important. We need to understand what decisions have been made and, even more importantly, the reasons for these decisions. We need also to understand the patient's fears and wishes. All this will guide us if and when we speak for them. Myles Sheehan is a Jesuit priest who is also a medical doctor, a gerontologist with a particular expertise in end-of-life care. He suggests that a key question to ask the patient is how hard they want us to push: "if the situation is ambiguous or looks poor," how hard do they want us to try to maintain life?<sup>13</sup> Another important question is when the time comes and if circumstances permit, would they want their organs donated for transplantation? All this information should of course be noted in the patient's medical record. It can also help family and friends to keep their own records too.

Secondly, let me comment on the standard we should use if we become a health care representative. Should we apply the standard of best interests, and seek to identify

objectively what the best thing to do is? Or should we make a substituted judgement, and seek to discern what this patient would want, even if that might not be in their objective best interests?<sup>14</sup> For a while, there was ongoing ethical debate about this matter. Eventually, the law in many jurisdictions asks for something of a compromise. It asks us to identify the patient's best interests keeping in mind their fears and wishes. There is a certain wisdom in this compromise. By itself, substituted judgement is too open to abuse. A family might really want Granny dead as soon as possible so they can get their inheritance. They choose the course of action most likely to achieve this, and claim it's what they think Granny would want. And because the standard is substituted judgment, it is difficult to challenge them. By contrast, a best interests determination gives us an objective standard, which makes it easier to challenge outrageous decisions.

But on the other hand, in many ways we do seek to make a substituted judgement. Indeed, it can be helpful to alert the family that this is their role. For it can be a far easier thing not to *decide* for the patient, but to *speak* for them. A friend of mine tells a story. A middle-aged woman had been asked to give permission for her elderly mother's ventilator to be turned off. She had sat for over an hour and was clearly struggling, so my friend, a hospital ethicist, was sent to speak with her. The lady explained her dilemma: If the ventilator is turned off, her mother will die. How could she possibly make such a decision? My friend explained that she didn't have to decide for her mother, that all she had to do was to speak for her mother. If her mother could speak, what would she say? Almost without thinking about it, the lady replied, "Oh, that's easy. Mum wouldn't want to be kept alive like this." And then she stopped, and realised what she'd said. "Is it as easy as that?" she asked quietly. "Yes it is," my friend replied. "You don't have to decide for your mother. You only have to speak for her." "Well, why didn't someone tell me that?" the lady protested. "I've been sitting here struggling for an hour because no one told me what I really should be doing." For above all, we are the patient's representative, and our task is to re-present the patient, to make the patient present when they can no longer speak for themselves.

My third practical comment is about conscientious objection, particularly in the context of a binding Advance Directive. As a health care professional, we are concerned about the choice which has been decreed. Let us say it involves treatment which has been refused. We are concerned that this decision really is against the patient's best interests, that they will be deprived of worthwhile benefit which does not involve significant burden. We might even be concerned that this refusal constitutes euthanasia by omission. What do we do? We speak with the family. Perhaps before they lost capacity, the patient changed their mind, and the Advance Directive no longer applies. We look closely at the Directive, and at the concrete situation. Perhaps there are significant differences between the Directive and the concrete situation, differences which mean that the Directive does not rightly apply in this situation. In some

circumstances, we might seek legal counsel and the intervention of the courts. But if none of these things change the decision and we still have serious concerns, we may have to withdraw from the case. We cannot leave the patient without care, so they will have to be transferred to the care of another. But as health care professionals or even in some cases as health care institutions, we should not and cannot be forced to go against our professional judgement. If all else fails, in some circumstances, either an individual or even an entire institution may have to exercise conscientious objection and withdraw from a case.<sup>15</sup>

## Assisted Nutrition and Hydration

Let me briefly address Assisted Nutrition and Hydration or ANH. This might be an IV line inserted into a vein, or a nasogastric tube which runs down the food pipe. But for long-term feeding, it is usually a PEG tube which is inserted through the abdominal wall into the stomach. I want to discuss the Catholic understanding of ANH which guides both Catholics and Catholic health care institutions. This is important because this Catholic understanding differs from that which informs Victorian law. I offer five points:

Firstly, let us consider the sort of case where someone already has a PEG tube inserted. Victorian law regards the provision of ANH through a PEG as medical treatment – medical treatment which could simply be refused.<sup>16</sup> By contrast, Catholic teaching recognizes ANH not as medical treatment but as ordinary care. 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*."<sup>17</sup> So once a patient has a PEG, Catholic teaching regards the provision of ANH through the feeding tube not as medical treatment but rather as a natural part of care.

Secondly, Catholic teaching holds that in normal circumstances ANH is ordinary or proportionate care. Thus, John Paul continued that the use of ANH "should be considered, in principle, *ordinary* and *proportionate*, and as such morally obligatory"<sup>18</sup> as long as it gives nourishment and/or relief from suffering. According to Catholic teaching, then, for a patient with a PEG, ANH is not as a general rule extraordinary or disproportionate treatment which might legitimately be refused. Rather, as a general rule, PEG feeding is ordinary or proportionate treatment which should not be refused. Indeed, to refuse or withhold such ordinary treatment may well be euthanasia by omission.

Thirdly, "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, either because they would not be metabolised adequately, or because their mode of delivery would be gravely burdensome."<sup>19</sup> In his pronouncement, John Paul included the phrase "in principle," which means "in general" or "barring exceptional circumstances." But there can be exceptional circumstances. Especially as death approaches, a patient's

digestive system may shut down, so the ANH feed simply sits in the patient's stomach and is not digested. Or, again especially as a patient is dying, ANH might become gravely burdensome because of painful infection around the feeding tube or a serious risk of pneumonia from aspiration of the PEG feed into the lungs. So while ANH is in principle ordinary or proportionate, there can be legitimate exceptions when ANH can and should be refused or withheld.

Fourthly, the *insertion* of a feeding tube is a medical act. Thus, the Australian bishops have stated, "To insert a feeding tube is a medical decision subject to the normal criteria of medical intervention."<sup>20</sup> In many cases, loss of appetite is a normal part of the dying process. Especially as death approaches, it may well be both futile and far too burdensome to insert a feeding tube.

Fifthly, let me offer some practical examples. As death approaches, it may well be legitimate to withhold ANH "if, for example, food and fluids can no longer be absorbed or excreted by the body, or if withdrawal of food and fluid would not hasten death and the tube causes significant discomfort." "Or in the final stage of a progressive illness a person may refuse a feeding tube put into the stomach... if maintaining nutrition in this way would cause significant physical discomfort and is not going to prevent their imminent death. Or in the same circumstances they might consent to the insertion of such a tube but say that, if the tube becomes infected, which is usually associated with localised pain, then they would want it withdrawn and not replaced."<sup>21</sup> But on the other hand, there are many other cases where ANH should not be either refused or withheld. If ANH would sustain someone's life without causing significant discomfort, refusal or withholding of this treatment may well be euthanasia by omission. This might particularly be the case if this decision was made by another person who decided that the life of a disabled patient was no longer worth living.

Well, we've come to the end of the presentation. We can refuse treatment if it is futile or too burdensome. In any other circumstance, refusal of treatment may well be euthanasia by omission. If the patient loses capacity, the best way to continue to discern what should or should not be done is not through an Advance Directive but through a health care proxy or representative. To do this well requires ongoing conversation and discernment. And this same discernment applies to Assisted Nutrition and Hydration, which should not be refused except in exceptional circumstances.

**ENDNOTES**

<sup>1</sup> "Some people are more concerned about the danger of undertreatment... Others are more concerned about the danger of overtreatment... We must acknowledge both of these concerns... If we focus on only one of these dangers we may fall into the opposite danger without being aware of it." For this, see Department for Christian Responsibility and Citizenship, Catholic Bishops' Conference of England and Wales, *The Mental Capacity Act and 'Living Wills': A Practical Guide for Catholics* (London: Catholic Truth Society, 2008), 17-18.

<sup>2</sup> John Paul II, *Evangelium Vitae (The Gospel of Life)*, #65,

Holy See, [http://www.vatican.va/holy\\_father/john\\_paul\\_ii/encyclicals/documents/hf\\_jp-ii\\_enc\\_25031995\\_evangelium-vitae\\_en.html](http://www.vatican.va/holy_father/john_paul_ii/encyclicals/documents/hf_jp-ii_enc_25031995_evangelium-vitae_en.html)

<sup>3</sup> *A Guide for People Considering Their Future Health Care & A Guide for Health Care Professionals Implementing a Future Health Care Plan*, Catholic Health Australia: <http://www.cha.org.au/site.php?id=666>

<sup>4</sup> Congregation for the Doctrine of the Faith, *Declaration on Euthanasia*, Part IV, Holy See, [http://www.vatican.va/roman\\_curia/congregations/cfaith/documents/rc\\_con\\_cfaith\\_doc\\_19800505\\_euthanasia\\_en.html](http://www.vatican.va/roman_curia/congregations/cfaith/documents/rc_con_cfaith_doc_19800505_euthanasia_en.html)

<sup>5</sup> Scott Sullivan, "A History of Extraordinary Means," *Ethics & Medics* 31, no. 9 (September 2006): 1-2; no. 10 (October 2006): 3-4; no. 11 (November 2006): 3-4.

<sup>6</sup> *Code of Ethical Standards for Catholic Health and Aged Car Services in Australia* (ACT: Catholic Health Australia, 2001), Part II, #1.14.

<sup>7</sup> cf Daniel P. Sulmasy, "'Advance Directives' as an extension of the tradition of forgoing extraordinary means of care," *Bioethics Outlook* 19, no. 2 (June 2008): 1-12 at 6-7.

<sup>8</sup> <http://www.justice.qld.gov.au/files/Guardianship/advancehealthdir.pdf>

<sup>9</sup> Bernadette Tobin, "More talk, less paper!" *Bioethics Outlook* 19, no. 3 (September 2008): 1-7 at 4.

<sup>10</sup> Brigid Vout, "Advance Care Planning Programs and Catholic Healthcare," *Bioethics Outlook* 15, no. 4 (December 2004): 1-16 at 10.

<sup>11</sup> *A Guide for People Considering Their Future Health Care & A Guide for Health Care Professionals Implementing a Future Health Care Plan*, Catholic Health Australia: <http://www.cha.org.au/site.php?id=666>

<sup>12</sup> A very useful resource for health care professionals and pastoral carers is Josephine M. Clayton, Karen M. Hancock, Phyllis N. Butow et al, "Clinical practice guidelines for communicating prognosis and end-of-life issues with adults in the advanced stages of a life-limiting illness, and their caregivers," *Medical Journal of Australia* 186, no. 12 (18 June 2007): S77-S108 or [http://www.mja.com.au/public/issues/186\\_12\\_180607/cla11246\\_fm.html](http://www.mja.com.au/public/issues/186_12_180607/cla11246_fm.html)

<sup>13</sup> Myles N. Sheehan, "On Dying Well," *America* 183, no. 3 (29 July - 5 August 2000): 12-15 at 13-14.

<sup>14</sup> *End-Of-Life Issues*, Part 2, Catholic Health Australia, <http://www.cha.org.au/site.php?id=666>

<sup>15</sup> *A Guide for Health Care Professionals Implementing a Future Health Care Plan*.

<sup>16</sup> *Gardner; Re BWV* [2003]

<sup>17</sup> John Paul II, "Address to Participants in the International Congress on 'Life-Sustaining Treatments and Vegetative State: Scientific Advances and Ethical Dilemmas,'" #4, Vatican, [http://www.vatican.va/holy\\_father/john\\_paul\\_ii/speeches/2004/march/documents/hf\\_jp-ii\\_spe\\_20040320\\_congress-fiamc\\_en.html](http://www.vatican.va/holy_father/john_paul_ii/speeches/2004/march/documents/hf_jp-ii_spe_20040320_congress-fiamc_en.html)

<sup>18</sup> Ibid.

<sup>19</sup> Bishops Commission for Doctrine and Morals, Australian Catholic Bishops Conference, "Briefing Note on the Obligation to Provide Nutrition and Hydration," ACBC, <http://www.acbc.catholic.org.au/bc/docmoral/2004090316.htm>

<sup>20</sup> Ibid.

<sup>21</sup> *The Mental Capacity Act and 'Living Wills'*, 26, 46.

All online resources accessed 13 November 2008.

Kevin McGovern



# Victorian Abortion Law Reform Bill 2008

*This report on the Victorian Abortion Law Reform Bill 2008 particularly considers the fact that it has denied health care professionals any right of conscientious objection. It sees this as part of an international attempt to deny conscientious objection against abortion, and to enforce abortion as an international human right.*

In 2007, John Brumby's Victorian state government announced that it planned to decriminalise abortion and to enshrine the current practices of abortion. With the recent passage of the *Abortion Law Reform Bill 2008*, it has gone further than it promised, and implemented one of the most radical laws in the Western world.

Members of Parliament were granted a conscience vote, and parliament had one of the longest and most emotional debates in its history. Former Premier Joan Kirner and her colleagues had campaigned for over 35 years to overturn the law on abortion. Were some MPs intimidated by their advocacy? Ultimately, the Abortion Bill passed in the Upper House by three votes, 23-17, with no amendments.

## What the Act Allows

As a result, abortion has been legalised on demand up to 24 weeks. After 24 weeks, a woman must seek the approval of two doctors before she can undergo an abortion. All the amendments designed to provide safeguards and some protection and alternatives for vulnerable women were defeated. No recognition was given to the humanity of the unborn child or the need to protect the most vulnerable.

In a controversial move, the Bill denies healthcare professionals the right to conscientious objection and aims to compel them to be involved in the very practice to which they object. Doctors and nurses may be required to participate in a so-called "emergency abortion." Additionally, doctors, nurses, pharmacists and psychologists will now be required to refer women seeking an abortion to someone who is known not to have any conscientious objection to abortion - in other words, to someone they know will perform an abortion. Failure to comply with the legislation may mean that they could face sanctions and deregulation by the Medical Practitioners Board and other professional bodies. They could also face compensation claims for distress and harm caused to the woman. Additionally, doctors may have trouble obtaining professional indemnity insurance if they refuse to comply with the law.

Victoria now has one of the most extreme pieces of abortion legislation in the world. Catholic Archbishop of Melbourne Denis Hart said, "The bill is an unprecedented attack on the freedom to hold and exercise fundamental religious beliefs," adding that "the bill is clearly intended to require Catholic hospitals to permit the referral of women for abortions."<sup>1</sup> Catholic hospitals also defended the rights of their staff and warned that they do not do abortions and that they will not do them. Catholic Health Australia (CHA) speaking for fifteen Catholic hospitals in Victoria said it was ready to fight in the courts for the conscience rights of physicians.<sup>2</sup>

The controversial conscience clause was opposed by a

number of groups and professionals currently involved in the care of patients, including Catholic Health Australia, Doctors in Conscience, the Christian Dental and Medical Fellowship of Australia, and the Ad Hoc Interfaith Committee. The Australian Medical Association (AMA) also opposed that particular section of the bill.

## Right to Conscientious Objection vs Right to Abortion

There have been similar moves overseas to force doctors to act against their conscience. Doctors in the United Kingdom, the United States, Canada, and the European Union have also faced attacks on the right to conscientious objection especially over abortion.

**United Kingdom:** The British Medical Association (BMA) policy-making body reportedly considered removing the right of doctors to conscientious objection through the influence of Dr Evan Harris. Harris is a Liberal Democrat MP and a doctor who is known in the UK as "Dr Death" for his unlimited support of abortion and euthanasia.<sup>3</sup> The proposal would require doctors to carry out abortions or refer women for abortions. Dr Harris has recently been removed from the BMA ethics committee.<sup>4</sup>

**United States of America:** Doctors' rights to conscientious objection have also come under attack in the United States. At the request of the Mayor of New York City Michael Bloomberg and New York Governor Eliot Spitzer, attempts have been made to require students specialising in obstetrics and gynaecology in that city's hospitals to take part in abortion as a routine part of their standard medical training.<sup>5</sup>

In another extreme move, the American College of Obstetricians and Gynaecologists (ACOG) planned to limit the rights of physicians to opt out of this training through conscientious objection to abortion. In a paper circulated by their ethics committee, they said that "physicians who have religious or moral objection to 'standard practices' such as abortion, sterilization or the prescribing of contraceptives are not ethically obligated to provide those services, but do owe patients a timely referral to another doctor willing to deliver them."<sup>6</sup>

Since 1973, the US congress enacted three separate laws aimed at protecting doctors' rights to act in accordance with their conscience.<sup>7</sup> As these rights come under increasing attack, the US Federal Government is moving to provide stronger protection for doctors' right to conscience. Michael Leavitt of the US Federal Health and Hospitals Corporation has proposed a law that would require "certification by health care providers who receive federal funding that they are in compliance with the existing federal law, barring discrimination against physicians, hospitals and their employees who refuse to

participate in abortions, sterilisations or other health care procedures to which they object on religious or moral grounds.”<sup>8</sup> Failure to comply with the legislation could see the institution lose federal funding.

This proposal has not gone unchallenged, with New York Senator Hillary Clinton and Cecile Richard of the Planned Parenthood Federation of America arguing in September in the *New York Times* that “patients might be denied access to these critical services.”<sup>9</sup> Mrs Clinton has the support of 28 other Democrat Senators including Senators Barack Obama and Joe Biden, who co-signed a letter opposing Leavitt’s proposed law.<sup>10</sup>

The United State Conference of Catholic Bishops (USCCB) has given its support to the Leavitt proposal, “saying it is needed because of ‘growing hostility on the part of some professional organisations and advocacy groups to rights of conscience in health care.’”<sup>11</sup>

**Canada:** Physicians’ rights to conscience have been threatened by the College of Physicians and Surgeons of Ontario (CPSO), the regulatory and licensing authority for physicians and surgeons practicing in Ontario. An ethics paper circulated by the College proposed that doctors’ rights to conscientious objection would be severely limited. But under a storm of protest, including opposition from the Ontario Medical Association, the College has amended its proposed policy. However, a similar attack on doctors’ rights has now commenced in the Canadian province of Alberta.<sup>12</sup>

**European Union:** The European Union Network of Independent Experts on Fundamental Rights advises the European Commission and the European Parliament on human rights. It has declared that doctors should be forced to perform abortions even if they have a conscientious objection because the right to abort a child is an “international human right.” In very similar language to that of Victoria’s *Abortion Law Reform Bill*, the EU statements say that “an obligation will be imposed on the health care practitioner exercising his or her right to religious conscientious objection to refer the woman seeking an abortion to another qualified health care practitioner who will agree to the abortion.”<sup>13</sup>

### Imposing Their Values: Autonomy Rules

For years, pro-choice activists have claimed that they were about ‘choice.’ They argued that those of us who oppose abortion do not have to have one or to be involved in one. But, they said, we should not stop someone else from having an abortion – that is, that we “should not impose our morals on others.” But the debate has “moved from ‘Our Bodies, Our Choice’ to ‘My Choice, You Don’t have a Choice.’ Autonomy, the ‘I want’ ethics, trumps the right to life, the right to liberty and the physician’s duty to do no harm.”<sup>14</sup> While demanding rights for themselves, they do not want to extend these rights to others.

How has this happened? In a recently emerging view, some people now see the profession of medicine not as a vocation of service, but merely as one of meeting the demands and needs of the patient, even if those demands

are unreasonable or not in the best interests of the patient. Margaret Somerville explains that in this account “physicians are mere technicians able to provide services that patients want and have a right to access. Physicians have a duty to provide these services and no right to bring their moral or ethical reservations into play.”<sup>15</sup>

Taken one step further, this view could require physicians to accommodate all sorts of bizarre requests from the patient. While this view harms the patient, it also harms to physicians and society. As Margaret Somerville comments:

Treating physicians as mere technicians denies that respect is required for physicians’ freedom of conscience and their ethical and moral values. Quite apart from the serious wrong to physicians that denial inherently constitutes, such an understanding of the physician-patient relationship would do a great disservice, not only to the medical profession and society in general, but also to patients, because maintaining respect in any human encounter, including for patients in the physician-patient encounter, requires that respect be mutual.<sup>16</sup>

Such ideas run counter to the Hippocratic tradition and the Declaration of Geneva. They also conflict with the approach taken by Australia’s National Health and Medical Research Council (NHMRC), which recognises a right to conscientious objection in #5.9 of its *Ethical Guidelines on the Use of Assisted Reproductive Technology in Clinical Practice and Research*, and in #3.6.7 of its *National Statement on Ethical Conduct in Human Research*. In each case, the standard is the same. For example, the ART guidelines state:

Conscientious objectors are not obliged to be involved in procedures or programs to which they object. If any member of staff or student expresses a conscientious objection to the treatment of any individual patient... the clinic must allow him or her to withdraw from involvement in the procedure or program to which he or she objects. Clinics must also ensure that staff and students are not disadvantaged because of a conscientious objection.

### Abortion as a ‘Human Right’?

There is no doubt that abortion advocates and their allies are aiming to have abortion recognised as an ‘international human right.’ Yet despite their efforts, “not a single UN human rights treaty mentions abortion,” and no international agreement recognises any such right. This has not deterred them from working to “determine how the right to abortion-on-demand could be found in universally accepted norms such as the right to life.”<sup>17</sup> Thus, for example, the *Freedom of Choice Act* currently before the US congress would establish abortion as a “fundamental right.”<sup>18</sup> The attacks on doctors’ rights to conscientious objection in Victoria and internationally are clearly also part of this.

Ironically, there is growing evidence that fewer doctors are willing to perform abortions in a number of countries including the United Kingdom, Spain, Italy and the

USA.<sup>19</sup> Campaigns aimed at forcing doctors to cooperate either by performing an abortion or by referring to an abortionist are one way that advocates of abortion are attempting to override this. The American Association of Pro-Life Obstetricians and Gynaecologists sees these new tactics as a “draconian measure(s) more consonant with the actions of a repressive regime than with the tenets of a free society.”<sup>20</sup>

## Freedom of Conscience is Fundamental to Democracy

Attacks on conscientious objection are attacks on freedom of thought and religion. Ultimately, they attack democracy itself, for democracy is built on the foundation of respect for human life and freedom of conscience. We should be concerned about the totalitarian element which has crept into this issue.

Speaking recently at a conference on the Sixtieth Anniversary of the United Nations’ *Universal Declaration of Human Rights*, Cardinal Keith O’Brien of St Andrews and Edinburgh, said that human rights legislation has failed most miserably in defending the most basic right of all: life. “We must continue to promote a culture of life at home, at work and in society, going beyond efforts just to reach legislators,” he insisted, because it is the “underlying values that must change first before the laws will follow, not the other way around. Yes of course the legislative agenda is important and it cannot be neglected but neither should the very pressing social agenda.”<sup>21</sup>

Despite these threats to our freedom, we must continue to hope and work to build a new culture of life and love. We must continue to offer women genuine life giving solutions to unexpected pregnancies, and to heal those affected by past abortions.

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Marcia Riordan



## Fetal Alcohol Spectrum Disorders

*Harms of alcohol consumption are not limited to the consumer. For women, it poses a significant threat to their unborn child. This article discusses one type of alcohol-related harm to the fetus: the fetal alcohol spectrum disorders (FASD).*

### Alcohol and Health

Alcohol plays a significant part in the Australian economy, culture, and lifestyle. It is used extensively as a social and recreational tonic and as a de-stressor or relaxant. Moderate alcohol consumption is

thought to have some health benefit.<sup>1</sup> However, with high levels of alcohol consumption the harms and adverse effects far outweigh these benefits.

In Australia, alcohol is the second largest cause of drug-related deaths and hospitalizations.<sup>2</sup> In terms of conditions contributing to burden of disease, alcohol

ranks seventeenth in Australia and third in the world.<sup>3</sup> The estimated economic cost of alcohol-related social problems in Australia during the year 1998-99 was \$7.6 billion.<sup>4</sup> In accordance with the increasing trend in alcohol consumption over the past decades, it may be concluded that the economic cost to the community has increased substantially since then. Though similar proportions of Indigenous and non-Indigenous adults drink at high risk levels,<sup>5</sup> this is a more significant issue for the Indigenous youth as compared to their non-Indigenous counterparts.<sup>6</sup> The per capita alcohol consumption in Australia for those aged 15 years and above is 9.8 liters of alcohol per person.<sup>7</sup> Drinking at a high risk level is defined as average daily consumption of seven or more drinks for men or five or more for women. High risk drinking has increased generally over the past decade, but more so for women.<sup>8</sup> A national survey in 2004 has shown that a large proportion of women (47%) continue to drink during pregnancy and breast feeding.<sup>9</sup>

### Fetal Alcohol Spectrum Disorders

The hazardous effects of alcohol are not limited to adults and numerous adverse effects of alcohol on the human fetus have been recognized. These varied teratogenic effects resulting from pre-natal alcohol exposure are grouped under the umbrella term of fetal alcohol spectrum disorders (FASD). These include all alcohol associated developmental disorders ranging from fetal alcohol syndrome (FAS), the most severe form of alcohol teratogenesis, as well as the more frequent albeit less drastic effects such as alcohol-related birth defects (ARBD) and alcohol-related neurodevelopmental disorders (ARND).<sup>10</sup> These terms include features ranging from stunted growth, morphological anomalies, and intellectual and behavioural problems. Children with FASD have low IQ, cannot keep up in school, have a tendency towards anti-social behaviour, are unable to interact with the others, and cannot maintain stable employment.<sup>11</sup> They suffer from impulsivity, an inability to relate behaviour to consequences, reduced understanding of societal rules and personal limitations, and an inability to manage emotions and anger. These characteristics increase their risk of criminal behaviour.<sup>12</sup> Such characteristics also make them more vulnerable to exploitation and marginalization. The increase of risky and high risk drinking among women in the reproductive age group has led to an increase in the incidence of FASD.

The effects of alcohol on the developing fetus depend on the stage of pregnancy as well as the quantity and frequency of alcohol consumption.<sup>13</sup>

However, there is no consensus in the literature regarding the level of alcohol that may be hazardous to the fetus. Some studies have reported adverse fetal effects at levels as low as one drink per week, while others have not. This controversy has resulted in divergent guidelines on alcohol consumption during pregnancy around the world. However, it is well-established that the worst outcomes occur with high levels of frequent drinking during the peri-conception period and the first trimester of pregnancy.

### Prevalence of FASD

In Australia, contemporary data on prevalence of FASD is inconsistent. A national active case-finding study was conducted using the Australian Paediatric Surveillance Unit during 2001-2004, and the birth prevalence of FAS was estimated to be 0.06 per 1000 live births.<sup>14</sup> The rate of FAS was significantly higher among Indigenous children as compared to non-Indigenous children. Another study on the Indigenous community in the Northern Territory also found high rates of FAS i.e. 1.7 to 4.7 per 1000 live births.<sup>15</sup> However these estimates of prevalence are likely to be an underestimation as only the prevalence of FAS was reported, while the more common alcohol related birth defects such as ARBD and ARND were not included.

A Victorian study has estimated the prevalence of FAS to be 0.014 per 1000 live births.<sup>16</sup> However this estimate has been based on the previous guidelines from the National Health and Medical Research Council (NHMRC) for alcohol use in pregnancy. These were less restrictive than the U.S. guidelines that recommend complete abstinence. If the latter guidelines are used, the Victorian prevalence of FAS doubles to 0.03 per 1000 live births.

From these studies, it may be concluded that the population groups most at risk are those with socio-economic disadvantage and Indigenous communities. Statistical comparisons have shown that Australian women are three times more likely to drink during pregnancy than their U.S. counterparts.<sup>17</sup> Thus, it may be concluded that despite lack of accurate data on FASD in Australia, due to high levels of drinking in this country, the prevalence of FASD and its associated cost would be at least comparable to the rest of the developed world.

### Determinants of Alcohol Use in Pregnancy

The determinants of FASD are entrenched within the determinants of alcohol use by women during pregnancy. A large number of cases of FASD arise from maternal lack of knowledge of the detrimental effects of alcohol on the fetus and equally from lack

of awareness of pregnancy in the early stages, when the fetus is most susceptible to its teratogenic effects.

## Biology and Behaviour

Biological predisposing factors for the development of FASD include increasing maternal age and increasing birth order, due to chronic alcohol use and increasing consumption with age.<sup>18</sup> Children born to smaller women with less body fat are also at increased risk, which includes under-nutrition in mothers as a risk factor. Adolescents exposed prenatally to alcohol are more likely to develop early-onset alcohol disorders.<sup>19</sup> There may also be genetic factors which predispose to alcohol abuse and FASD.

High levels of alcohol consumption and frequent binge drinking characterise pregnancies that result in FASD. Women tend to reduce alcohol consumption after their pregnancy is recognised. However, this may not be the case for heavy drinkers. As well, women who are likely to abstain after recognition of pregnancy are often not informed enough to make that decision early on. This is attributable to the lack of clear practice guidelines and the absence of ante-natal counselling regarding substance abuse. Women predisposed to risky drinking and thus FASD, often initiate alcoholism at early age and frequently binge drink. Strong associations between concurrent smoking, drug abuse, alcoholism and increasing incidence of FASD have also been reported.

## Environment and Culture

Low socio-economic status, lower levels of education and unfavourable employment conditions have been strongly correlated with alcohol abuse and FASD.<sup>20</sup> These factors are likely to increase the risk of physical and sexual abuse, which have been associated with a higher tendency for alcohol abuse by women. Other risk factors include living with an alcoholic male partner, having unstable relationships, and having alcohol-abusing parents.<sup>21</sup> These women frequently suffer from low self efficacy, high dependency, and have poor social support networks. This induces high risk behaviours, and may lead to unplanned pregnancies during which they continue to drink. Low spirituality and lack of religiosity have also been implicated in substance abuse tendencies. These factors coupled with low education among women leads to continuation of risky drinking during pregnancy, contributing to the risk of FASD.

Societal acceptance of high levels of alcohol consumption and the association of alcohol with celebrations and cultural events may have

desensitised society to its adverse effects. Higher levels of alcohol consumption are now considered acceptable. This results in peer pressure and promotion of a drinking culture. The elements of easy accessibility and media glamorisation, make society increasingly alcohol dependant, contributing to increase in alcohol-related harm especially for women.

## Health System

The health system also contributes to the FASD problem. Surveys of women and obstetricians have revealed that the health system is failing to prevent FASD. In one survey of obstetricians, almost half stated that they did not routinely discuss alcohol consumption during antenatal visits, and a number of health professionals were unable to diagnose to FAS.<sup>22</sup> As a consequence, pregnant women are unaware of safe levels of drinking. Many stated that, given the right information and support, they would have altered their behaviour. The health care system has also fallen short in terms of providing support to families with a FASD child. This is partly due to misdiagnosis and lack of recognition by health workers: the children are often misclassified and are unable to receive the required support.

## Preventative Strategies for FASD

Despite this bleak picture, there is hope for tackling this issue and potential factors have been identified. These include promoting responsible family planning, better education, improved employment, adequate nutrition and responsible drinking among male partners. All this highlights the significance of the social determinants of health and presents opportunities in preventing FASD. However, the most significant role is for obstetricians and other health workers. Routine antenatal management must include alcohol use information, for identification of high risk groups and to provide counselling and support. Further research is also needed to understand the prevalence and determinants of FASD in order to allocate resources for its prevention. It would also be worthwhile to invest in education and training to improve diagnostic acuity among health personnel for recognition of FASD. It is also important to provide support services to those affected by FASD and their families.

From a policy perspective, in 2006, the Australian government published national clinical guidelines, stating that for alcohol consumption “an abstinence-based approach is not recommended.”<sup>23</sup> These guidelines were formulated despite “compelling international evidence that mothers who drink even small amounts of alcohol during pregnancy could unwittingly harm their unborn children.”<sup>24</sup> Currently

These guidelines are under review and the new draft guidelines do recommend an abstinence-based approach,<sup>25</sup> but this process must be expedited and translated into practice in order to prevent further harm.

## Conclusion

FASD is a significant health issue in Australia. It has wide ranging social, economic and medical underpinnings which necessitate action, as it inequitably affects the most vulnerable in society. This is an issue where socio-economic disadvantage is both the cause and the effect. Determinants of FASD encompass a number of the social determinants of health and a multi-sectorial health promotion approach is required to address this issue. In light of current guidelines, best practice for health professionals would be to discuss alcohol consumption routinely with patients presenting for ante-natal care and to follow the abstinence-based approach when advising these women.

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