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# Bioethics, the law and the care of those in need

Victorian Attorney-General the Hon Robert Clark was guest speaker at the 2012 Annual General Meeting of the Caroline Chisholm Centre for Health Ethics. In this extract from his speech, he discusses the relationship between the law and ethics, and the reform of Victoria's laws on guardianship and powers of attorney. While some ethical obligations should not be made into legal duties, he argues that every legal duty is founded upon a moral obligation. The reform of Victoria's laws on guardianship and powers of attorney seeks to make it easier for individuals and their families to provide for their current and future needs, while strengthening the last resort roles of the Office of the Public Advocate and the Victorian Civil and Administrative Tribunal to protect vulnerable people from neglect, abuse and exploitation.

## **Ethics and the Law**

In a pluralist society such as ours, there is room for different understandings about what constitutes just and ethical decision making in the health, disability and aged care sectors. Believers from all traditions and non-believers alike should able to put forward propositions on how the dignity of the human person can best be protected and the promotion of the common good can best be achieved. In our democracy all should be given a fair hearing based on the strengths of the arguments that underlie the propositions that they put forward.

It also seems to me (speaking as a non-Catholic) that when a religious tradition remains true to its moral and ethical standards, it displays an integrity that demands respect from the rest of the community, even those who may radically disagree with one or more of its propositions. Perhaps this is because all of us, whether we are religious or whether we are not religious, can understand what Pope John Paul II said when he wrote in 1993:

No one can escape from the fundamental questions: What must I do? How do I distinguish good from evil? 1

If none of us, including bioethicists, can escape these fundamental questions, then certainly neither lawyers nor legislators are able to. Indeed, Professor Robert George, a recent visitor to Victoria, is well known for arguing, in the tradition of Aristotle and Aquinas, that one of the purposes of law is to make men and women good, or virtuous. In other words, he argues that good law is a necessary though not sufficient condition for the development of virtuous behaviour – good behaviour, of course, being at the core of the domain of the bioethicist.

No doubt there are many ways in which the affinity between law and bioethics can be characterised. I was reminded of their close kinship many years ago when I became involved in considering the difficult issues surrounding the law and ethics of euthanasia. As I

understand it, the position held by Catholic hospitals is that set out in Catholic Health Australia's *Code of Ethical Standards*:

By *euthanasia* is meant any action or omission which of itself and by intention causes death with the purpose of eliminating all suffering. Examples of euthanasia include administering deliberate overdoses of otherwise appropriate medications, and the unjustified withholding or withdrawing life sustaining forms of care. Euthanasia must be distinguished from other care decisions which sometimes risk or have the effect of shortening life but which are not intended to hasten death...<sup>2</sup>

From this it seems that in the Catholic ethical tradition it is *just* to provide palliative medication which may have the effect of shortening life but is intended only to relieve pain, but *unjust* for a doctor to provide a drug with the intention of bringing about death. It is *ethical* to forgo treatment if it is therapeutically futile or overly burdensome<sup>3</sup> but *unethical* to deliberately withdraw effective treatment or care in order to bring about death.<sup>4</sup>

## IN THIS ISSUE

Bioethics, the Law and the care of	
those in need	Pg 1
by Robert Clark	
Fetal Alcohol Spectrum Disorder:	Pg 5
by Kerri Anne Brussen	
<b>Preparing Well for Death</b>	Pg 9
by Kevin McGovern	

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It has struck me in the past how much the centrality of intention in this ethical analysis is reflected in the criminal law. Perhaps this is not surprising since the common law understanding that no criminal liability attaches to an act without a mens rea (or a guilty mind) is said to be traced as far back as St Augustine. Today, the law still draws the critical distinction between the *licit* administration of a drug with the intention of relieving a person's pain and the illicit administration of a drug with the intention of relieving a person of their life. While the area of withholding treatment is now somewhat overlaid by complex statutory provisions, legal commentators still point to the critical distinction between the withholding of reasonable treatment with the intention of bringing about death and the withdrawal of treatment that is futile or overly burdensome.<sup>6</sup>

...every legal duty is founded upon a moral obligation....

Of course, even in this area where the common law has developed over many centuries, legal reasoning does not completely mirror traditional moral, or bioethical, reasoning. In a leading case about manslaughter by omission, *R v Instan*, Lord Chief Justice Coleridge CJ (in 1893) commented on the obligation to provide medical aid and nourishment for a vulnerable person under one's care by saying:

It is not correct to say that every moral obligation is a legal duty, but every legal duty is founded upon a moral obligation.

That the law should not be concerned with proscribing every moral obligation is famously reflected in Thomas Aquinas' citation<sup>8</sup> of that vivid saying from Proverbs Chapter 30, verse 33: "He who violently blows his nose brings forth blood" (a turn of phrase that may not naturally spring to mind today). Indeed, that the law should not be directed at suppressing all vices is nowadays considered trite as a proposition.

Political philosophers today argue convincingly that governments must respect individual freedom and the autonomy of nongovernmental spheres of authority, that the record of big government in the twentieth century shows that it frequently harms those it seeks to help, and that there is a sphere of autonomy and individual freedom of decision-making where it is not wise, prudent, or perhaps even just, for the law to seek to tread.<sup>9</sup>

However philosophers such as Robert George also develop the argument that it is a mistake to suppose that the principle of limited government is rooted in the denial of moral truth. <sup>10</sup> In other words, there is no inconsistency between limited government, tolerance and respect for individual freedom on the one hand, and moral truth on the other.

Indeed it can be said that the rule of law, at least to the extent it is based on the principle that 'like cases should be treated alike,' is itself built on a moral imperative, one

that is reflected in many aspects of anti-discrimination laws. Some philosophers argue that the imperative that 'like cases should be treated alike' is necessary because of the foundational principle that each human being possesses a profound, inherent, and equal dignity simply by virtue of his or her nature as a rational creature. <sup>11</sup> My understanding is that this is a proposition that most Catholic bioethicists would agree with. But even those who disagree with the principle of treating like cases alike are likely to concede that the principle is important because it has the effect of protecting most those most in need of protection.

Perhaps a good example is the criminal law regarding murder or manslaughter by omission which I've mentioned briefly earlier: the law applies equally to all, but has the most profound effect where a person under care is most in need of protection and care. Some of you may recall the scene from Robert Bolt's play about Thomas More, *A Man for All Seasons*, where Bolt postulates More as saying:

This country's planted thick with laws from coast to coast ... and if you cut them down ... d'you really think you could stand upright in the winds that would blow then?<sup>12</sup>

This is a sentiment that has resonated down the years – and certainly has resonated with many lawyers – that the law is there to protect, and those who would like to take an axe to the law risk opening up to the winds of destruction: something that unfortunately we have seen in various countries in various eras. In 2000, now retired High Court Chief Justice Murray Gleeson cited the passage from Robert Bolt's play that I have just referred to when he commenced his *Boyer Lecture series* that year. Chief Justice Gleeson said that this

...imagery of law as a windbreak carries an important idea. The law restrains and civilises power.  $^{13}$ 

He said that in this sense:

The rule of law is meant to be a safeguard, not a menace.<sup>14</sup>

And certainly this something that all lawyers would echo: their commitment to the law is for it to be a safeguard and not a menace.

Chief Justice Gleeson also said in the same lecture, however, the law is "in constant need of improvement." In Victoria, many of us have recently been engaged in considering how to improve laws that are intended to protect those in our community who are in most need of care. I mention in particular two major inquiries that have taken place:

# Reform of Victoria's laws on guardianship and powers of attorney

In 2008, the Parliamentary Law Reform Committee was asked to inquire into law reforms to strengthen the law surrounding powers of attorney, including how to

minimise their abuse. The Committee reported<sup>16</sup> unanimously in late 2010 and made 90 recommendations, including:

- clarifying the powers and duties that representatives have when acting on behalf of another under a power of attorney;
- allowing people who make powers of attorney to appoint a 'personal monitor' to oversee the actions of their representatives;
- empowering the Victorian Civil and Administrative Tribunal (VCAT) to award compensation if a power of attorney is abused; and
- creating criminal offences for people who abuse powers of attorney.

In undertaking that work, the Committee was seeking to balance a range of considerations, many of which are of long standing and many of which resonate in a variety of different contexts. In the context of appointments under Enduring Powers of Attorney, the Committee had to consider, on the one hand, how to empower people to take responsibility for decisions that may affect them and enable others to act and stand up for the person concerned when they no longer have the capacity to do so for themselves; and on the other hand, how to protect people from the risk of abuse by those to whom they entrust their care.

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... and on the other hand, how to protect people from the risk of abuse by those to whom they entrust their care....

It probably does not need me to make the point that the family can be, and fortunately in most instances is, one of the strongest and most nurturing and supportive institutions known to humanity, and that in the vast majority of cases, people are well served when their loved ones are able to take care for and exercise responsibility on behalf of those who have diminished or lack legal capacity. On the other hand, there are always a minority of cases where there is abuse and exploitation be it financial abuse, or denial of care, or even sometimes a desire to see the person concerned no longer on the face of the earth. So in framing its Report, the Committee was mindful of needing to ensure checks and balances, and it put forward its recommendations accordingly.

Many of the same themes and objectives were echoed in the report of the Victorian Law Reform Commission on its review of guardianship and administration law in Victoria, the purpose of which was to try to ensure that the law in Victoria is more responsive to the needs of people with impaired decision-making abilities.<sup>17</sup>

The Commission made more than 440 recommendations, including:

- re-thinking the general principles that should underlie the rationale behind guardianship law and that should be used to interpret guardianship law;
- facilitating greater use of personal appointments of supported and substitute decision makers, so that the Public Advocate can remain a guardian of last resort;
- clarifying the responsibilities of substitute decision makers;
- giving the Public Advocate greater powers to investigate and protect individuals from abuse; and
- reforming VCAT procedures to expedite urgent matters and resolve matters outside of formal hearings where possible.

You can see from these key recommendations that not only was the Law Reform Commission looking to balance the considerations I mentioned earlier, they were also looking to address the context in which a large number of these decisions are now likely to be made here in Victoria and in Australia – namely, the context of an ageing population, growing levels of dementia and what some expect to be one of the most significant intergenerational transfers of wealth ever to have been experienced in human history, as the baby boomers start to hand over what they have built up to subsequent generations. All of these factors create a need for the services of the Public Advocate and the availability of VCAT, as well as giving rise to many challenges in making policy decisions in this area, not only in providing for individual cases, but also as to how the system as a whole can service the range of needs that have emerged.

I might add that, in addition to the needs of the aged, there is a growing recognition of the need to provide more effectively for younger people who have been born with acute disabilities, and for the capacity of their families - in those instances where fortunately they have a family to support them - to be able to continue to give them the greatest possible scope to live independent lives in the community at the point when they move into adulthood and where therefore some of the powers that the law gives to parents cease to apply. That is a dilemma that both the Parliamentary Committee and the Law Reform Commission grappled with and about which there continues to be lively debate.

The Government is grateful for the enormous amount of work and effort that resulted in the recommendations of these inquiries, not only the work put in by members of the Parliamentary Law Reform Committee and the Commissioners of the Victorian Law Reform Commission, and their staff, but also the time and effort volunteered by many individuals, non-governmental groups and advocates for people with disabilities and other disadvantaged groups, including the contributions of a range of Catholic institutions, such as Marillac House, 18 St Vincent's Hospital in Melbourne, 19 and the Plunkett Centre in Sydney. 20

The Catholic Archdiocese of Melbourne<sup>21</sup> in particular provided very substantial submissions covering many

issues including:

- the basic principles that should guide guardianship laws;
- the criteria for appointing substitute decision makers;
- the principles that should guide substitute decision makers (including how to balance so called 'best interest' principles with 'substituted judgement' principles);
- the scope and operation of enduring powers of attorney and whether they should be registered;
- the scope and limitation of so called 'advance directives';
- participation in medical research; and
- how to guard those in need from the abuse or misuse of powers of attorney or guardianship.

... The government intends to give priority particularly to reforms that will make it easier for individuals and their families to provide for their current and future needs, while strengthening and enhancing the last-resort roles of VCAT and the Office of Public Advocate and enabling them to protect needy persons from exploitation....

The government is giving careful consideration both to the Parliamentary Law Reform Commission's Report on Guardianship and to the Parliamentary Law Reform Committee's Report on Powers of Attorney, and looking at how we can draw on both of those reports to improve the law in these areas. We take the view that the recommendations interact and overlap, and that the recommendations from one report cannot be tackled in isolation from those of the other. The government intends to give priority particularly to reforms that will make it easier for individuals and their families to provide for their current and future needs, while strengthening and enhancing the last-resort roles of VCAT and the Office of Public Advocate and enabling them to protect needy persons from exploitation.

When I recently picked up a copy of Catholic Health Australia's *Code of Ethical Standards* I was pleased to see that it sums up the goals of Catholic health care services as being 'Respect for the dignity of the person and the promotion of the common good.'<sup>22</sup> I hope that my colleagues and I who are lawyers and legislators would share these twin goals of respect for dignity and promotion of the common good when we seek to formulate public policy and good laws.

#### **ENDNOTES**

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<sup>2</sup> Catholic Health Australia (CHA), *Code of Ethical Standards*for Catholic Health and Aged Care Services in Australia,

- II.5.20, CHA, http://www.cha.org.au/images/resources/Code% 20of% 20ethics-full% 20copy.pdf
- <sup>3</sup> Ibid., II.1.13.
- <sup>4</sup> Ibid., II.5.3.
- <sup>5</sup> Louis Waller and Charles Robert Williams, *Criminal Law: Text and Cases*, 10th ed. (Chatswood, NSW: LexisNexis Butterworths, 2005), para 1.11.
- <sup>6</sup> Loane Skene, *Law and Medical Practice: Rights, Duties, Claims and Defences*, 3rd ed. (Chatswood, NSW: LexisNexis Butterworths, 2008), paras 10.25, 10.27.
- <sup>7</sup> For *R v Instan* (1893) 17 Cox CC 602, Court for Crown Cases Reserved, see Waller and Williams, 289.
- <sup>8</sup> Thomas Aquinas, *Summa Theologiae* I.II.96, article 2; online at http://www.thomasinternational.org/projects/step/treatiseonlaw/delege096\_2.htm
- <sup>9</sup> Robert George, "Law and Moral Purpose," *First Things* 2008; online at http://www.firstthings.com/article/2007/12/001-law-and-moral-purpose-16 <sup>10</sup> Ibid.
- 11 Ibid.
- <sup>12</sup> Robert Bolt, *A Man for All Seasons* (London: Heinemann, 1960), 39; cited, for example, by Chief Justice Murray Gleeson, "A Country Planted Thick with Laws," Lecture One of the 2000 Boyer Lectures, ABC,

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- <sup>13</sup> Gleeson, "A Country Planted Thick with Laws."
- <sup>14</sup> Ibid.
- <sup>15</sup> Ibid.
- <sup>16</sup> Victorian Parliamentary Law Reform Committee, *Report into Powers of Attorney*, August 2010, Parliament of Victoria, http://www.parliament.vic.gov.au/images/stories/committees/lawrefrom/powers\_of\_attorney/Report\_24-08-2010.pdf
- <sup>17</sup> Victorian Law Reform Commission (VLRC), *Report on Guardianship*, January 2012, VLCR, http://www.lawreform.vic.gov.au/sites/default/files/Guardianship\_FinalReport\_Full%20text.pdf
- <sup>18</sup> Submission by Marillac to the Victorian Law Reform Commission: Review of Victoria's Guardianship and Administration Act, VLRC, http://www.lawreform.vic.gov.au/ sites/default/files/Submission\_IP\_27\_Marillac\_14-05-10.pdf
  <sup>19</sup> Submission on behalf of St Vincent's Hospital (Melbourne) Limited for Inquiry into Powers of Attorney, VLRC, http:// www.parliament.vic.gov.au/images/stories/committees/ lawrefrom/powers of attorney/submissions/POA19 -

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- 20 Submission of the Plunkett Centre for Ethics, VLCR, http://www.lawreform.vic.gov.au/sites/default/files/Submission\_CP\_53\_Plunkett\_Centre\_For\_Ethics\_23-05-11.pdf
- <sup>21</sup> Submission of the Catholic Archdiocese of Melbourne, VLCR, http://www.lawreform.vic.gov.au/sites/default/files/ Submission\_CP\_27\_Catholic\_Archdiocese\_of\_Melbourne\_19 -05-11.pdf
- <sup>22</sup> Code of Ethical Standards, I.1 on p. 2.

#### Hon Robert Clark MLA ₩

The Hon Robert Clark MLA is the Member for Box Hill in the Victorian Parliament. He is also the Attorney-General, the Minister for Finance, and the Minister for Industrial Relations. He undertook tertiary studies at Melbourne University, obtaining a B. Com (Hons) in 1980, an LLB in 1982, and a BA in 1986. Before entering Parliament, Robert Clark was a solicitor practicing in commercial, financial and labour law. He has been a Member of Parliament since 1988.

# Fetal Alcohol Spectrum Disorder: The Hidden Harm

On 29 November 2012, one of the Standing Committees of the Commonwealth House of Representatives released a report on the prevention, diagnosis and management of Fetal Alcohol Spectrum Disorders (FASD) in Australia. This article explores the findings and recommendations of this report. The Commonwealth parliamentary committee noted that FASD is a serious health issue in Australia. It therefore called for a National Plan of Action, education for health professionals, and public awareness campaigns to encourage women not to drink when pregnant or when planning a pregnancy. Other recommendations included better management of FASD within education, disability services, and the criminal justice system.

On 8 November 2011, the House of Representatives Standing Committee on Social Policy and Legal Affairs was asked by the then Minister for Families, Housing, Community Services and Indigenous Affairs, the Hon Jenny Macklin MP, and the then Minister for Health and Ageing, the Hon Nicola Roxon MP, to inquire into and report on developing a national approach for the prevention, intervention and management of Fetal Alcohol Spectrum Disorders (FASD) in Australia. The Committee undertook this inquiry, and issued its report in just over twelve months. Ninety-two submissions were received by the committee, as well as a number of exhibits. Thirteen public hearings and community forums were held. The Committee also visited the Royal Hospital in Melbourne Women's Marninwarntikura Women's Bush Camp in Mimbi, Western Australia.<sup>2</sup> The report is titled *Fetal Alcohol* Spectrum Disorders: The Hidden Harm. It is 187 pages in length, and outlines the Committee's findings and its nineteen recommendations.<sup>3</sup>

Chapter 1 introduces the concept of FASD as well as the Australian and international response to the condition. Chapter 2 examines the science of FASD, and the role of alcohol in our Australian society. Chapter 3 considers the prevention of FASD, including an examination of the issues surrounding health warnings on alcoholic beverages. The difficulties with diagnosing and managing FASD are discussed in Chapter 4. Chapter 5 addresses the lack of data on the prevalence of FASD. The chapter concludes with a discussion on the challenges of managing young adults with FASD and the benefits that could be provided by the legal recognition of FASD.4

# **Chapter 1: Introduction**

FASD is the most significant cause of non-genetic, atbirth brain damage in Australia. FASD encompasses a range of cognitive, physical, mental, behavioural, learning and developmental disorders detected in children and adults as a consequence of exposure to alcohol in the womb.<sup>5</sup> There is no cure, no vaccine and no medical treatment. The only way to eliminate the condition is through prevention.

North America leads the world in recognition of FASD. Diagnostic tools, guidelines, early intervention and screening programs have been available in North America since 1993.<sup>6</sup> On the other hand, many

Australians are unaware of FASD, and the true incidence of FASD in Australia is unknown. Individuals and researchers have been trying to fill a void in government policy for the last twenty years.<sup>7</sup>

Chapter 1 concludes with recommendations 1 to 3. The first recommendation is that this report should form the basis of a National Plan of Action for the prevention, intervention and management of FASD.8 Further, a FASD Reference Group should be established, and the Commonwealth Government should report within 12 months on critical elements of the National Plan of Action, and within five years on the progress towards eliminating FASD in Australia.9

# Chapter 2: FASD and alcohol consumption patterns

Alcohol is a known teratogen with the brain being the most sensitive to harm.<sup>10</sup> Areas of the brain affected are those involved in the cognitive functions that include memory, attention, language, problem solving and decision making.<sup>11</sup> FASD is the umbrella term given to a range of effects, which include cognitive impairment, growth retardation, facial anomalies and developmental abnormalities of the nervous system. Low IQ is found in a small number of people with FASD.

FASD includes: Fetal Alcohol Syndrome (FAS), partial Fetal Alcohol Syndrome (pFAS), alcohol-related neurodevelopmental disorder (ARND), and alcohol-related birth defects (ARBD). For a diagnosis of FAS or ARND, there must be dysfunction in at least three areas of the central nervous system (i.e. academic achievement, communication problems, fine or gross motor problems, or behavioural problems). FAS is distinguished by three distinct facial features as well as structural and functional brain abnormalities. Once other diagnoses are excluded, FAS is the only diagnosis of FASD that can be made without confirmation of pre-natal exposure to alcohol.<sup>12</sup> Two of the three FAS facial characteristics plus brain abnormalities and known pre-natal exposure to alcohol are required for a pFAS diagnosis. ARND is the largest FASD category. Without identifying facial features, a confirmed history of maternal alcohol use is required for diagnosis. FASD is often an "invisible birth defect." 13 Early intervention in childhood can help avoid secondary conditions. 14

Australian attitudes towards alcohol consumption have liberalised over recent decades. A now prominent feature of alcohol consumption in Australia is binge drinking. One in five Australians aged 14 years or older drink at risky levels at least once a month. This is not only a male problem, with a shift observed towards the acceptance of female drinking. FASD is only one of the many alcohol related harms.

In 2010, the National Drug Strategy Household Survey undertaken by the Australian Institute of Health and Welfare reported that 48.7% of pregnant women reduced their alcohol intake but did not abstain completely, while 48.9% abstained (up from 40.0% in 2007). There are four key factors why women continue to drink: (i) in the early weeks they are often unaware that they are pregnant; (ii) they have a lack of awareness of the harms of alcohol on the developing fetus; (iii) they have a dependency on alcohol; and (iv) culturally it is expected that they drink.

# Chapter 3: FASD awareness and prevention

It is not possible to identify a 'safe' level of alcohol consumption during pregnancy. It is therefore pivotal for the prevention of FASD to raise public awareness that FASD can result from even a small exposure to alcohol prenatally. One of the key recommendations in the 2009 Australian Alcohol Guidelines is that the safest option for the developing fetus is that the mother does not drink alcohol.<sup>16</sup>

This has not always been the advice provided. The 1987 guidelines provided no advice to pregnant women. In 1992, the advice was not to drink while pregnant. In 2001, this advice was modified to include limits on an acceptable amount of alcohol during pregnancy. After a substantial literature review, a public consultation, and both national and international peer review, the 2009 Guidelines again advise that women should not drink any alcohol while pregnant. At the same time, it should also be stressed that not all neonatal exposure to alcohol results in a child with FASD. <sup>17</sup>

Sadly, many people within the Australian community are not aware of this advice. Further, some health professionals – including some doctors and some midwives – are not aware of the current guidelines and therefore wrongly advise women that even moderate drinking is safe during pregnancy. There is a great need for ongoing education both within the general community and within the health professions about this issue. Pregnant women want clear advice, and they expect to receive this from their health professionals. <sup>19</sup>

Advice must be provided not only to pregnant women but also to women's partners and families and to the general community. As alcohol is central to socialisation in many groups, it is very difficult for a pregnant woman to abstain while her family and friends pressurise her into drinking. FASD is not just a pregnant woman's issue. It is also an issue for her partner, her family and all of society. How, for example, might men support their pregnant partners to abstain from drinking during

pregnancy? How might we as a society communicate this challenge to men?<sup>20</sup>

The chapter reports on some significant community-led initiatives within some Indigenous communities to combat alcohol problems by creating dry communities or developing alcohol management plans. The Liliwan Project is a community-led strategy to address FASD in the Indigenous community of the Fitzroy Valley in Western Australia. It received international recognition by the United Nations for making a difference in that community.<sup>21</sup>

Recommendations 4 to 9 are listed next. They include that by 1 January 2014, all health professionals should be educated to provide the advice that the safest option during pregnancy is not to drink; and a mechanism should be in place to record the alcohol consumption of all pregnant women as a basis for future research and advice. By 1 July 2013, an FASD awareness campaign should have begun, and by 1 October 2013, all pregnancy and ovulation kits should carry a message advising women not to drink if they are planning a pregnancy. The Commonwealth Government should also work with the State and Territory Governments to devise strategies to lessen the impact of FASD both in Indigenous communities and for alcohol dependent women.<sup>22</sup>

... It is not possible to identify a 'safe' level of alcohol consumption during pregnancy....

Chapter 3 continues with a discussion on the marketing of alcohol. In 2009, the World Health Organisation stated, "If the price of alcohol goes up, alcohol-related harm goes down. Younger drinkers are affected by price and heavy drinkers are more affected than light drinkers." A number of studies have verified this information.<sup>23</sup>

Voluntary labelling indicating the various harms of alcohol (not just those linked to FASD) has been in place in Australia since late 2011. This voluntary approach will continue for another two years. However, fewer than one in six alcohol products carry warnings. While supporting warning labels, most submitters were critical of the voluntary scheme. Labels were thought to be hidden and designed for minimum exposure. <sup>24</sup>

Chapter 3 concludes with recommendations 10 to 14. They include that by 1 March 2013, a suitable format and design for health warnings be determined and implemented by 1 January 2014 along with an awareness campaign. Two studies should be commissioned and completed by 1 October 2013. The first is to examine price, availability and the effect on consumption patterns. The second is to examine market strategies including the impact of the advances in technology and the links to sport. From the first study, the committee recommends the development of an Alcohol Sales Reform Plan to reduce the harms caused by irresponsible alcohol consumption. <sup>25</sup>

A number of submissions to the Committee were received from parties who had a commercial interest in the alcohol industry. Many of these tried to deflect and minimise some of the harms caused by alcohol. For example, the Winemakers' Federation of Australia suggested in their submission to the inquiry that drinking in moderation during pregnancy poses "no significant risk of harmful effects." They suggested that this view should inform future guidelines, and therefore that future campaigns "should avoid alarmist statements about the impact of low levels of alcohol... with the goal of scaring women into abstinence." <sup>26</sup> Is this an acceptable view?

# **Chapter 4: Diagnosis**

FASD is incurable. With an early diagnosis of FASD, however, outcomes are enhanced by appropriate interventions, and some symptoms are partially remediated by timely interventions.<sup>27</sup>

Many obstacles to diagnosis were noted:

**Stigma**: The diagnosis of FASD is an acknowledgment of maternal alcohol consumption.<sup>28</sup>

Current capacity of health professionals to diagnose FASD: FASD is poorly recognised in Australia and is often missed or the diagnosis is delayed, partly attributed to health professionals' reticence in asking about alcohol consumption during pregnancy.

Complexity of FASD: FASD encompasses a number of diagnoses and can be a challenge to diagnose correctly, particularly those conditions lacking the typical facial features.

Lack of nationally consistent diagnostic tools and guidelines: A set of guidelines for diagnosing FASD is available in North America. Australia does not have such a guideline available, even though in 2008 health professionals endorsed the need for such guidelines. In 2010, the Australian FASD Collaboration undertook the FASD Project which developed a standardised system to screen and diagnose FASD. Completed in 2011, the outcome is now under review by the Department of Health and Ageing.<sup>29</sup>

Lack of diagnostic services in Australia: Globally there are a number of clinics specifically for the diagnoses of FASD, with the majority being found in North America. Australia is lagging behind in offering such a service.<sup>30</sup>

A diagnosis of FASD should be followed up by a management plan so that all required services can be accessed. Both the Lililwan Project and a model of care developed by the Department of Health in Western Australia provide good examples of how services might be provided in remote areas.

Chapter 4 concludes with recommendations 15 and 16. They recommend that by 1 October 2013, a trainer and user manual and a diagnostic instrument for FASD should be available for use, and by 1 July 2014, a national FASD strategy for diagnostic and management services should be implemented.<sup>31</sup>

# **Chapter 5: Management needs**

The lack of consistent screening and diagnostic tools make it problematic to measure the prevalence, to develop management strategies, and to raise awareness of FASD.

Some of the challenges are:

**Carers**: Cognitive disability and FASD are not part of the list of eligible conditions for government support.

Action: Eligibility criteria should be changed to include FASD and cognitive disability on the list of recognised disabilities to allow access to various governmental benefits. A further problem is that 'impairment' is not defined in legislation. It has also been suggested that FASD should be included in the Commonwealth Government's Better Start for Children with a Disability Initiative. The National Disability Insurance Scheme might also provide some support for those with FASD.

**Education**: Parents find themselves educating school staff about FASD. Children often do not complete school after being labelled as wilful, obstructive and defiant.

Action: The government needs to recognise the condition as a disability. Outcomes would also be improved by the provision of funding for support and the education of teachers in how to teach children with FASD.

Criminal Justice System: Legal Aid NSW commented that it was FASD-associated behaviours that linked people with FASD to the criminal justice system. As FASD is not a registered disability, people are not linked to specific support systems, particularly in remote areas. Terminology utilised by the courts subjected people with FASD to unfair treatment within the criminal justice system.

Action: In North America, FASD is taken into account when sentencing. Ashurst Australia suggests that the law needs to include the term cognitive impairment in legislation to allow for fairer treatment of those with FASD within the criminal justice system.

**Identifying FASD** as a disability: The formal recognition of FASD as a disability is seen as the key to unlocking support for those with FASD and to raising the profile of the disease. In 2011, the Standing Committee on Aboriginal and Torres Strait Affairs requested that FASD be added to the List of Registered Disabilities. However, this request was denied.<sup>32</sup>

Recommendations 18 to 19 conclude chapter 5, and are the last recommendations of the inquiry. They recommend that educational material be developed to raise awareness of FASD; that this material should be monitored by the FASD Reference Group; and that FASD is listed in the List of Recognised Disabilities for the Better Start for Children with a Disability Initiative. Lastly, the eligibility criteria for access to support services and diversionary laws should be amended to allow for the cognitive impairment of those with FASD.<sup>33</sup>

## ■ Conclusion

world to ensure that Australians can lead as healthy life as possible. For example, Victoria led the globe with the introduction of compulsory seat belts in 1970.<sup>34</sup> After neonatal screening was introduced into USA in the early 1960s, it became part of the Australian program in 1968.<sup>35</sup> Australia was the first country in the world to legislate for plain packaging of cigarettes in 2011. 36 So why have those affected by FASD had to wait so long for recognition of their condition and appropriate support? Perhaps a recent front-page article in the Melbourne Age offers a hint. It is titled, "I grew up thinking if I didn't drink, I would be really boring."37 For better or for worse, alcohol is a significant part of Australian culture. Even so, it causes a great many harms, including the harm of FASD. We need to acknowledge that not drinking is also an acceptable social practice.

## **ENDNOTES**

<sup>1</sup> House of Representatives Standing Committee on Social Policy and Legal Affairs, FASD: The Hidden Harm (Canberra: Commonwealth of Australia, 2012), http://www.aph.gov.au/ parliamentary\_business/committees/

house\_of\_representatives\_committees?url=spla/fasd/report.htm

<sup>2</sup> Ibid., 5-7, 149-52.

<sup>3</sup> Ibid., xvii-xxii

<sup>4</sup> Ibid., 6-7.

<sup>5</sup> Ibid., 1.

<sup>6</sup> Ibid., 2-3. This difference between North America and Australia is quite significant. An Information Package written by the then National Organisation for Fetal Alcohol Syndrome and Related Disorders (NOFSARD) and presented at a meeting on 3rd July 2008 to the then Health Minister Nicola Roxon details the history of FASD, the rationale for early diagnosis, a community consultation report as well as case histories. It also explains why FASD did not make it onto the Australian political agenda almost twenty years ago when it was recognised internationally as a major cause of cognitive impairment in children. For this, see National Organisation for Fetal Alcohol Syndrome and Related Disorders, "Information Package," http://www.nofasd.org.au/research-library/reports NOFSARD is now the National Organisation for Fetal Alcohol Spectrum Disorders (NOFASD). It is the national peak organisation representing the interests of individuals and families living with FASD.

<sup>7</sup> The Hidden Harm, 3-5.

<sup>8</sup> In response to this report, the Australian Government released its action plan on 6 August 2013. The focus is rightly on prevention, with new funding of \$20 million over four years for initiatives which include prevention activities within the general community, and targeted activities directed towards women with problematic alcohol use and remote Indigenous communities. For this, see Australian Government, Responding to the Impact of Fetal Alcohol Spectrum Disorders in Australia: A Commonwealth Action Plan, Commonwealth Department of Health, http://www.health.gov.au/internet/main/publishing.nsf/ Content/0FD6C7C289CD31C9CA257BF0001F96BD/\$File/ Commonwealth-Action-Plan.pdf. One Australian FASD organisation described this action plan as "a step in the right direction" which nonetheless "falls well short in addressing the recommendations from the FASD Inquiry." For this, see Foundation for Alcohol Research and Education (FARE), "Australian Government Action Plan to reduce the impact of

Fetal Alcohol Spectrum Disorders (FASD) 2013-14 to 2016-17," FARE, http://www.fare.org.au/2013/08/australian-Australian government health policies have often led the government-action-plan-to-reduce-the-impact-of-fetal-alcoholspectrum-disorders-fasd-2013-14-to-2016-17/

> The Hidden Harm, 9-10. While the Commonwealth Department of Health website reports on the development of an action plan, it does not report on the implementation of any of the other recommendations from The Hidden Harm.

<sup>10</sup> Teratogens can disturb the development of an embryo or fetus. They may cause a birth abnormality or disrupt the pregnancy.

11 The Hidden Harm, 21.

<sup>12</sup> Ibid., 27. The three facial features are: small eye slits, a smooth philtrum and a thin upper lip.

<sup>13</sup> Ibid., 27-8.

<sup>14</sup> Ibid., 30-1.

 $^{\rm 15}$  Australian Government, Australian Institute of Health and Welfare, 2010 The National Drug Strategy Household Survey Report (Canberra: Australian Institute of Health and Welfare, July 2011), 73, http://www.aihw.gov.au/publication-detail/? id=32212254712

<sup>16</sup> National Health and Medical Research Council, Australian Guidelines to Reduce the Health Risks from Drinking Alcohol (Canberra: Commonwealth of Australia, 2009), 67.

<sup>ì7</sup> The Hidden Harm, 50-1.

<sup>18</sup> Ibid., 52-3.

<sup>19</sup> Ibid., 56.

<sup>20</sup> Ibid., 60-1.

<sup>21</sup> Ibid., 62-3.

<sup>22</sup> Ibid., 67-71.

<sup>23</sup> Ibid., 73.

<sup>24</sup> Ibid., 80.

<sup>25</sup> Ibid., 87-90.

<sup>26</sup> Ibid., 52.

<sup>27</sup> Ibid., 91-4.

<sup>28</sup> Ibid., 96. Anecdotal evidence suggests that a diagnosis of Attention Deficit/Hyperactivity Disorder, Autism Spectrum Disorder or general developmental delay is preferred to a diagnosis of FASD.

<sup>29</sup> Ibid., 102-3.

<sup>30</sup> Ibid., 95-106.

<sup>31</sup> Ibid., 111-3.

<sup>32</sup> Ibid., 115-47.

<sup>33</sup> Ibid., 147-8.

34 Centres for Disease Control, "Driver Safety-Belt Use --Budapest, Hungary, 1993," MMWR 42(48) (1993): 939-941, http://www.cdc.gov/mmwr/preview/mmwrhtml/00022331.htm 35 Monash Children's, "Chronology of Monash Children's," Monash Children's, http://www.monashchildrens.org.au/page/ About\_Us/Our\_History/Chronology\_of\_monash\_childrens/ <sup>36</sup> Australian Government, Department of Health and Ageing, "Plain packaging legislation receives the Royal Assent," Australian Government, http://www.yourhealth.gov.au/internet/ yourhealth/publishing.nsf/Content/tobacco-label-passedleg The Tobacco Plain Packaging Act 2011 (Cth) requires that all tobacco products sold in Australia after 1 December 2012 are in plain packaging. A High Court challenge by tobacco companies was unsuccessful. For this, see Mark Metherell, "Big tobacco loses High Court battle over plain packaging," Sydney Morning Herald, 15 August 2012.

<sup>37</sup> Julia Medew, "I grew up thinking if I didn't drink, I would be really boring," The Age (Melbourne), 16 March 2013.

All on-line resources accessed 16 December 2013.

Kerri Anne Brussen &

# **Preparing Well for Death**

How might we prepare well for death? And how might we help other people also to prepare well for death? Spiritual guide Henri Nouwen suggests that we should strive to recognise that we are children of God, brothers and sisters of one another, and parents of the generations to come. This article explores what he means.

Henri Nouwen was a Catholic priest who wrote more than 40 books about spirituality. He is recognised as one of the great spiritual guides of the twentieth century.

Nouwen was born in The Netherlands on 24 January 1932. After postgraduate studies in both psychology and theology, he taught in the United States at Yale (1971-1981) and Harvard (1982-1985), becoming a successful and famous academic through his classes, public talks and writing. However, a deep restlessness within him and a great yearning for community meant that Nouwen sought something more. He considered – but eventually rejected – becoming either a contemplative monk or a missionary in South America.

... Nouwen is particularly attractive as a spiritual guide because he articulates with great honesty and courage the struggles which we all experience in our spiritual journeys....

In August 1986, after a lengthy period of discernment, Nouwen at the age of 54 joined the L'Arche community called Daybreak in Toronto, Canada. Along with other able-bodied people, he lived with and cared for people with intellectual and physical disabilities. Nouwen also nurtured the spiritual growth of the community's members, each day providing some form of reflection, prayer service or activity. Many in the community were neither Catholic nor Christian, so Nouwen was challenged to craft his message in a way that spoke to everyone.

Over the years, Nouwen spent some time away from the community for writing, speaking engagements and other projects. However, he remained a member of the Daybreak community until his death. On one such trip away, after several, unexpected heart attacks, he died in The Netherlands on 21 September 1996. His body was returned to Canada where he is buried in Sacred Heart cemetery near the Daybreak community.<sup>1</sup>

Nouwen wrote throughout his life. He believed that "what is most personal is also the most universal." For this reason, he shared deeply in his writings about his own spiritual journey, his feelings and emotions, and his own struggles. He is particularly attractive as a spiritual guide because he articulates with great honesty and courage the struggles which we all experience in our spiritual journeys.

Nouwen had been greatly affected by the death of his mother in 1978, reflecting on this in *In Memoriam* and *A Letter of Consolation*. *Our Greatest Gift: A Meditation on Dying and Caring* is his thirty-first book. It was

written on a sabbatical from Daybreak in January 1993.<sup>3</sup> At this time, other events in Nouwen's life invited him to resume his reflections on death. Moe Gould, an elderly and much-loved disabled member of the Daybreak community, died in December 1992. Nouwen's sister-in-law Marina San Giorgi was dying of cancer. His friend Rick was dying of AIDS. Nouwen's father was turning 90, and Nouwen himself was in his 60s. Deeply aware of dying and of death, Nouwen asked: How might we prepare well for death? And how might we help other people also to prepare well for death?

To prepare well for our own death, Nouwen suggests that we should reflect on three truths about ourselves. We should strive to see that we are "children of God, sisters and brothers of all people, and parents of the generations yet to come." (*Our Greatest Gift*, 45) To help others prepare well for their deaths, Nouwen suggests that we should try to help them see these same three truths about themselves. In the next section of this article, I will summarise Nouwen's book and explore these three truths which he invites us to reflect upon. Then, in the final section of this article, I will offer my own comments about Nouwen's vision.

Before moving on, however, I express my hope that this brief reflection will inspire many people to read Nouwen's book. In this spiritual gem there are many insights and many powerful images which are not captured in this brief reflection.

## Three Truths about Who We Are

Our Greatest Gift is a short book of just over 22,000 words. Essentially it contains 2 parts, each with 3 chapters. The first part is about preparing well for our own death. (Nouwen calls it Dying Well.) The second part is about helping others to prepare well for their deaths. (Nouwen calls it Caring Well.) In each part, the first chapter is about seeing ourselves as children of God; the second is about recognising that we are brothers and sisters of all people; and the third is about discovering that we are parents of generations to come. I will draw on all these chapters to discuss these three themes in turn:

We are children of God: When we are children, we are very dependent on the care of others. We become more independent as we become adults. (We are probably never as independent as most of us would like to think.) When we are sick or injured, however, or when we are old and frail, we become more dependent again. (Old age is sometimes called our second childhood.)

Nouwen challenges us to become children again – that is, to accept and even to embrace our growing

dependence. It is when we are most dependent and when we are in greatest need that many of us receive the greatest help. It may be the stranger who helps us when our car breaks down late at night. It may be the friend or family member who listens to us and cares for us when it feels as if our world is falling apart. In 1990, Nouwen was hit by a car, and almost died. In that time of great dependency, he experienced the care of doctors and nurses who literally saved his life.

... Nouwen challenges us to become children again – that is, to accept and even to embrace our growing dependence....

Nouwen also challenges us to see the care which each of us receives in so many ways as a sign or a channel of God's care for us. Most of us have some sense of God, but Nouwen challenges us to recognise – and to dare to believe in – a loving God who watches over us, who cares for us, who looks after us in every way. To be a child of this loving God is to experience a deep sense of safety. Whatever happens, God will see us through. When some things happen in our lives, they seem like disasters. To be a child of God, however, is to dare to believe that God will bring new life even from the disasters we experience. From this perspective, too, even death is transformed. It is stripped of all its power to frighten us, for surely our loving God will bring us to new life even through death.

Most of us baulk at being dependent and becoming like a child. We fear being seen only as a nuisance or a burden. Even more deeply, we fear being rejected and abandoned. To care for someone in their need is therefore to help them to accept and even to embrace their dependence. As they rely on us, our care invites them to rely even more deeply on God, whose care for them is more profound and more complete that our own care could ever be. Quite simply, then, our care for other people in their need helps them to see – and to accept – that they are children of God. It helps them as God's children to place their trust and hope in God.

We are brothers and sisters of all people: Nouwen recognises two movements in our lives. The first is the process whereby we become different from other people. Thus, for example, Nouwen became a world famous writer. It is good that we make something of ourselves and that we make a difference in the world, and we rightly feel great satisfaction in what we have achieved. As we age, however, and especially as we move towards death, in our own eyes our achievements diminish in importance. We discover that, despite all our differences, we remain essentially the same as everyone else. As Nouwen observes, "We were all born powerless, and we all die powerless, and the little differences we live in between dwindle in the light of this enormous truth." (Our Greatest Gift, 24)

We all die. However, Nouwen does not see this either as a source of despair or as something which we must reluctantly accept. In his religious vision, we all come from God; we live in this world for a relatively short time; and then we return to God when we die. And in that context, those who have already died – and those who are now preparing for death – take away our fear and fill us with hope.

Nouwen writes about visiting his mother's grave:

When I stand before that simple grave... I know that I am not alone. My mother is there, and she speaks to me. There is no apparition, no mysterious voice, but there is the simple, inner knowledge that she who died more than fourteen years ago is still with me.... I hear her say that I must be faithful to my own journey and not be afraid to join her someday in death. (*Our Greatest Gift*, 68)

Nouwen writes also of all those who are now dying: "the people dying all over the world because of starvation, oppression, illness, despair, violence and war." As they surrender to death – as they die trusting that God will bring them to new life – they too "become our teachers." (Our Greatest Gift, 27)

... We prepare for our own death by deepening our sense of connection to all people – and in particular our sense of connection with those who have died and those who are now dying.....

A good death is therefore a death in solidarity with all people living and dead. We prepare for our own death by deepening our sense of connection to all people – and in particular our sense of connection with those who have died and those who are now dying. As carers, we help others prepare for their death by helping them deepen their own sense of connection to all people. We might, for example, affirm someone's hope that when they die, they will be reunited with the people they love who have gone before them – that they will see Mum again, or that they will be reunited with a cherished spouse who has died.

We are parents of generations to come: Nouwen distinguishes between the action and the passion of our lives. The action of our lives is what we do. On the other hand, the passion of our lives is what happens to us, and how we respond to this. Above all, it includes the way in which we undergo the final journey of dying and of death – not how we die in a physical sense, but how we die in an emotional or spiritual sense.

Nouwen also makes the somewhat unsettling suggestion that the legacy which we leave behind will depend less on our action and more on our passion. It is through this legacy that we become parents of the generations to come. And Nouwen suggests that this will happen less through our action and more through our passion.

He uses his close friend and secretary Connie Ellis as an

example. A kind, energetic and vibrant person, Connie helped many people (including Nouwen) in many different ways. In 1992, however, extensive treatment for a large brain tumour left Connie very frail, and with little prospect of significant improvement. "She who had always been eager to help others now needed others to help her." (Our Greatest Gift, 82)

Nouwen suggests that Connie will become a parent of the generations to come more through her response to her illness than through anything she did before that:

In her growing dependence, she is giving more to her grandchildren than during the times when she could bring them in her car to school, to shops, and to sports fields..... In fact, in her illness, she has become their real teacher. She speaks to them about her gratitude for life, her trust in God, and her hope in a life beyond death....She who lived such a long and productive life gives what she couldn't give in her strength: a glimpse of the truth that love is stronger than death. Her grandchildren will reap the full fruits of that truth. (*Our Greatest Gift*, 89-90)

... Believing that our legacy will come less through our action and more through our passion, Nouwen counsels that preparing well for death requires us to shift our focus from action to passion....

Believing that our legacy will come less through our action and more through our passion, Nouwen counsels that preparing well for death requires us to shift our focus from action to passion. When we are dying, our focus should not be on what we might still be able to do. Instead, our focus should be on our dying – and on dying in such a way that our passing brings inspiration and hope to others. Our focus should change "from doing to being." (*Our Greatest Gift*, 38)

In the same way, "to care for the dying is to help the dying make that hard move from action to passion... from wondering how much they can still accomplish" to dying well so that the manner of their dying is perhaps their greatest legacy. (Our Greatest Gift, 87)

Before moving from this summary of Nouwen's book, I should note that it contains one more major section. It is titled 'The Grace of the Resurrection.' In it, Nouwen notes that the resurrection of Jesus Christ – and our own hope for resurrection because of this – is the very cornerstone of the Catholic and Christian faith. He also admits that he has said very little about the resurrection in this book. I will return to this point in the next section of this article.

#### **Comments**

Let me offer two observations about Nouwen's vision:

Christian inspiration, universal message: My first

observation is somewhat paradoxical. While the inspiration for Nouwen's message is profoundly Christian, the message itself reaches beyond Christianity. Let me expand on each of these points:

Early in his book, Nouwen explains how he came to his insights:

I stay close to my own heart, listening carefully to what I have heard and felt. I also stay close to the hearts of those whose joys and pains are touching me most at this time in my life. Most of all, I stay close to the heart of Jesus, whose life and death are the main sources of understanding and living my own life and death. (*Our Greatest Gift*, 10)

Nouwen follows this process consistently, with each chapter reporting what he has seen in his own life, what he has observed in others' lives, and what he has learnt from the story of Jesus. For example, above all else it is the story of Jesus which teaches Nouwen that our lives are fulfilled more by our passion than by our action:

Jesus moved in his life from action to passion.... In the Garden of Gethsemane... he was handed over to those who resented him and his words.... From that moment, initiatives.... Jesus no longer took Everything was done to him. He was arrested, put in prison, ridiculed, tortured, condemned and crucified.... The mystery of Jesus' life is that he fulfilled his vocation not through action but through.... being the passive subject of what others did to him." (Our Greatest Gift, 84-85)

Learning in this way about our own lives from the life of Jesus is obviously profoundly Christian. *Gaudium et Spes*, one of the important documents from the Second Vatican Council, endorses this sort of reflection when it states that "Christ... fully reveals humanity to itself."

All this being said, Nouwen's message reaches beyond Christianity. It is his reticence about the Christian doctrine of the resurrection which makes this possible. Christians will surely have in mind their hope of resurrection as they reflect on Nouwen's insights. People from other faiths have different beliefs about the afterlife. Even so, from these different perspectives, they will still recognise the truth of Nouwen's insights about preparing well for death. In Australia and in many other countries around the world, there are also many people who do not belong to any organised religion. However, many in this vast group also have some sense (perhaps even a very deep sense) of a divine being who watches over us. Many hold some hope - however unclear the details may be – that they will live beyond death and that they will be reunited with those they love. Nouwen's insights about preparing well for death will speak to them too. Those who do not believe in God will see truth in Nouwen's call to see ourselves as brothers and sisters of all people, and as parents of the generations to come.

I noted earlier that at Daybreak Nouwen was challenged to craft his message so that it spoke to everyone. I wonder if this is the reason that his insights speak now to so many people.

Our greatest legacy is still before us: In end of life care nowadays, Dignity Therapy highlights the importance of leaving a legacy. Often, people look back over their lives to identify their legacy. Nouwen however challenges us to see that our greatest legacy is still before us. In November 1992, just before he wrote *Our Greatest Gift*, Nouwen visited his friend Rick who was dying of AIDS. This is what he said:

Rick, don't be afraid.... Please trust that the time ahead of you will be the most important time of your life, not just for you, but for all of us whom you love and who love you. (*Our Greatest Gift*, 42)

... Nouwen challenges us to see that our greatest legacy is still before us....

... Please trust that the time ahead of you will be the most important time of your life....

Very significant things do happen as people prepare for death. And if we do grasp the opportunities that come to us as the end of our life approaches, if we do prepare well for death, and if we do die well, that may well be our greatest legacy.

## **Conclusion**

As the Twenty-Third Psalm says, all of us walk in the valley of the shadow of death. But if we dare to believe that the Lord is our Shepherd, there is indeed nothing that we shall want. Even the shadow of death becomes not a thing of fear but a reminder of promise and of hope. It is truly *Our Greatest Gift*.

#### **ENDNOTES**

I took material for this short account of Nouwen's life from Deidre LaNoue, "A Literary Biography of Henri Nouwen," in *The Spiritual Legacy of Henri Nouwen* (New York: Continuum, 2001), 12-56; and "A Remarkable Life: The Henri Nouwen Story," (US) National Institute for the Renewal of the Priesthood, http://www.jknirp.com/noubio.htm

<sup>2</sup> Henri Nouwen. *With Open Hands*, trans. Patrick Gaffney

<sup>2</sup> Henri Nouwen, *With Open Hands*, trans. Patrick Gaffney (Notre Dame, Indiana: Ave Maria Press, 1972), 7.

<sup>3</sup> On page 49 of *The Spiritual Legacy of Henri Nouwen*, Deidre LaNoue wrongly states that *Our Greatest Gift* was written in 1994. She also confuses other dates. For example, she states that Moe Gould died in December 1993, whereas Nouwen reports that Moe died on 31 December 1992. For this, see Henri J. M. Nouwen, *Our Greatest Gift: A Meditation on Dying and Caring* (New York: HarperCollins, 1995), xi.

<sup>4</sup> Vatican Council II, *Pastoral Constitution on the Church in the Modern World (Gaudium et Spes)*, #22; Holy See, http://www.vatican.va/archive/hist\_councils/ii\_vatican\_council/documents/vat-ii\_const\_19651207\_gaudium-et-spes\_en.html

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Kevin McGovern ₩

# Caroline Chisholm Centre for Health Ethics

Suite 47, 141 Grey Street, East Melbourne Vic 3002

Tel (03) 9928 6681 Fax (03) 9928 6682 Email: ccche@svpm.org.au

www.chisholm.healthethics.com.au

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**Director/Editor:** Rev. Kevin McGovern Dip Ap Sc (Optom) (QIT),

STL (Weston Jesuit School of Theology)

**Research Officer:** Mrs. Kerri Anne Brussen B App Sci (RMIT),

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BA (Mathematics and Economics) (Punjab University)