
Bioethics Outlook

Plunkett Centre for Ethics

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“Medically Assisted Death”

Lessons from Canada

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On February 6, 2015, responding to a challenge from the Canadian Charter of Rights and Freedoms, the Supreme Court of Canada (SCC) unanimously struck down Criminal Code prohibitions against ‘medically assisted death’ (MAD), assisted suicide and euthanasia, for a competent adult who clearly consents and has a grievous and irremediable medical condition (including an illness, disease or disability) that causes enduring suffering which is intolerable to the individual.¹ The decision was not restricted to terminal illness or dying and was breathtaking in its scope. It rejected distinctions between withdrawal and withholding of futile or harmful interventions and assisted death; found no ‘slippery slope’ risks to the vulnerable; and guaranteed that no physician would be compelled to participate.

In this rare situation of the legalization of assisted death through a national judicial decision, a stay of sixteen months was granted for the complex tasks of crafting federal and provincial legislation and professional regulation. The federal government modified eligibility to patients with a “reasonably foreseeable natural death” and three unresolved issues were sent for further study: advance directives, particularly for persons with dementia, the eligibility of “mature minors” and the psychiatric illness as the sole medical condition. On June 17, 2016, Bill C-14 *Medical Aid in Dying* (MAID) came into effect in Canada.

¹ *Carter v. Canada (Attorney General)*, 2015 Supreme Court of Canada

This SCC decision was the culmination of a thirty year journey of failed legislative attempts to legalize MAD. It has brought Canada far from its founding Judaeo-Christian beliefs. Medically assisted death is the medicalization of human suffering and a rejection of the Paschal Mystery, the suffering, death and resurrection of Jesus Christ, the central belief of our faith.² It is a cry from our world for a new art of living and of dying and a call to all Christians to respond to the suffering among us with real and active mercy and compassion.

While the political strategies and cultural environments differ, there is a relentless intensity to the legalization of MAD across the developed nations of the world. There are a number of important lessons for Australia and other countries from the Canadian experience, including challenges to the notion of a *good death*, Catholic/Christian understanding of suffering and the duty to care, challenges for medical morality and for the doctor-patient relationship.

Lesson:

The Challenge to the Christian Understanding of A Good Death

In a simpler time, with limited medical options, death came quickly to most persons. The Christian imagination shared a vision of a *good death* in Saint Joseph. This “righteous man”, who lived a selfless life of fidelity to God’s call, is comforted and cared for by his loved ones, Mary and Jesus, as he breathes his last. It is a scene of great sadness and loss, but also one filled with a deep peace, and trust in the faithfulness of God.

In medieval times, Christians addressed the challenges of living in preparation for dying through the *ars moriendi*, the *art of dying*.³ This art leaned heavily upon two fundamental features of the culture: shared faith in the birth, death, and resurrection of Jesus, and the importance of families and community in their social organization. Care for the seriously ill and the dying were family and community activities. They accompanied the patient in prayer, sharing life stories and weeping together. While there were very few cures, care and healing happened!

² Rolheiser, R. (2015). *The Passion and the Cross*. Toronto, ON: Novalis.

³ O’Conner, M.C. 1966 *The Arts of Dying Well: The Development of the Ars Moriendi*. New York: AMS Press.

The simple time of Joseph and Mary, and the medieval *art of dying*, may seem irrelevant to our experiences in the death-denying, death-defying world of modern technologically-driven medicine. But in formal research⁴ and contemporary writing⁵ patients and families still describe the key features of a *good death* that are seen in the death of Joseph. Today, the personal, spiritual and communal challenges of serious illness and dying have become more difficult as the technology and systems dominate care. The ultimate challenge to the Christian understanding of a *good death* is presented by the legalization and normalization of MAD.

Pope Francis has noted that we need to:

“Remain steadfast in the journey of faith, with firm hope in the Lord. This is the secret of our journey! He gives us the courage to swim against the tide. Pay attention, my young friends: to go against the current; this is good for the heart, but we need courage to swim against the tide. Jesus gives us this courage!” (Pope Francis, 28 Apr 2013)

Medically assisted death presents an urgent opportunity to swim against its powerful tide before a technically controlled death becomes the only understanding of a *good death*. Most Catholics are unaware of the challenge. They will need spiritual buoys and lifelines to assist in this difficult swim, for MAD is not a gentle and predictable tide, but a dangerous riptide, carrying swimmers into the depths before they even know they are at risk. There is an urgent need to deepen the understanding of Catholics to the magnitude of this challenge, to promote prophetic resistance to the inappropriate use of technology in response to suffering, and to foster prophetic witness from all in the family of the faith in care of the sick and suffering.

Lesson:

Medically Assisted Death is not Medical Aid in Dying

Canada’s Bill C-14 is titled deceptively, *Medical Aid in Dying* (MAID), in a tragic irony fostering hospital policies regarding their “MAID Service”. But, MAD is about controlling the moment of death, not about the process of dying. Modern palliative care emerged to improve the care for the dying through the relief of pain and other distressing physical symptoms and

⁴ Steinhauser, K.E., Christakis, N.A., Clipp, E.C., McNeilly, M., McIntyre, L., & Tulsky, J.A. 2000. Factors considered important at the end of life by patients, family, physicians, and other care providers. *JAMA*, 284(19), 2476-2482.

⁵ Gawande, A. (2014). *Being Mortal: Medicine and What Matters in the End*. Toronto, ON: Doubleday Canada.

assistance with the spiritual, emotional and familial needs at end of life. It is a philosophy of care that is provided in hospices, special hospital units and in the home and community.⁶ From the faith perspective,

“Palliative care is an expression of the properly human attitude of taking care of one another, especially of those who suffer. It bears witness that the human person is always precious, even if marked by age and sickness. The human person, in fact, in whatever circumstance, is a good in and of himself and for others and is loved by God. For this reason, when life becomes very fragile and the end of the earthly existence approaches, we feel the responsibility to assist and accompany the person in the best way.” (Pope Francis, Address to the Pontifical Academy of Life, 5 March 2015)

Tragically, many have misunderstood the role and efficacy of palliative care and Canada legalized MAD before delivering on many promises of a comprehensive, national hospice and palliative care program.

Even more tragic is the reality that MAD is occurring in hospice and palliative care units, compromising their alternative philosophy of care and compassion.⁷

Lesson:

The Role of Religion in Public Discourse Has Changed Profoundly

Sadly, this decision was made by the Supreme Court on a rights and freedom challenge. Arguments against the use of a medical ‘fix’ to end human suffering have become unintelligible to a secular society where individual rights and choice trump all other considerations.

Notions such as the sanctity of life, salvific suffering and trust in God have lost their meaning in public discourse. Church credibility as protector of the vulnerable has been damaged by the clergy abuse crisis.

⁶ Byock, I. 2013. *The Best Care Possible*. New York, NY: Avery.

⁷ Dugdale, L.S. (2015). *Dying in the Twenty-First Century: Toward a New Ethical Framework for the Art of Dying Well*. Cambridge, MA & London, UK: MIT Press.

Lesson:

Persons Request MAD Because of Suffering, Not Pain

While the media has filled us with vivid images of persons in intractable pain requesting assisted death, the reality is quite different. Persons rarely request assisted death for pain but rather, for psychological distress and care needs, including uncertainty about the future, desire to control the death, fear of dependence, feelings of loss of dignity, fear of abandonment, and guilt at being a burden to others.⁸

Oregon research found that “...no physical symptoms at the time of the request were rated higher than a median of 2 (of 5) in importance.”⁹ While research into difficult pain and other serious symptoms is needed, requests for MAD are about human suffering.

Medically assisted death moves death from a natural, human event in the home and community to a medical act. It is the medicalization of human suffering but because there is no prescription for suffering, death becomes the ‘treatment’. For Christians, it is a rejection of the Paschal Mystery, the suffering, death and resurrection of Christ. Jesus’ suffering is real but it is also life-giving and redemptive. We do not seek suffering and have a duty to relieve it but believe that through our pain and suffering, we can become sharers in the redemptive work of Christ. It is our firm belief that euthanasia is a false solution to the drama of suffering, a solution unworthy of man. Indeed, the true response cannot be to put someone to death, however “kindly”, but rather to witness to the love that helps people to face their pain and agony in a human way. (Pope Benedict XVI, Angelus, 1 Feb 2009)

Lesson:

Doctors Accepted to Be Agents of Death Because of a Shift from a Moral to a Market Model of Medicine

While both the SCC decision and Bill C-14 stated explicitly that no individual doctor would be forced to participate, the Canadian medical profession accepted to provide both euthanasia and assisted suicide. This represents a profound departure from the 2,500 year Hippocratic

⁸ Emanuel et al 2000. Attitudes and Desires Related to Euthanasia and Physician Assisted Suicide Among Terminally Ill Patients and Their Caregivers, *JAMA* 284: 2460-2468.

⁹ Ganzini et al 2008. Why Oregon Patients Request Assisted Death: Family Members Views. *Journal of General Internal Medicine* 23:154-157

tradition which prohibited doctors from prescribing deadly drugs.¹⁰ A focus on virtue and duties provided ethical guidance until the 1803 when medical professionalism developed and produced the first Code of Ethics. The history acknowledged the moral core of medicine which brings the advances of science to the vulnerable sick and suffering and commits to maximizing benefit and minimizing risk and harms. It recognized conflicts of interest in earning a living from serving the sick and the limits of medicine.

Since the 1980's, medical ethics has been replaced by bioethics, dominated by the *prima facie*, principles-based approach of Beauchamp and Childress.¹¹ Erroneous prioritizing of respect for autonomy over beneficence, non-maleficence and justice have promoted a consumer model of the physician-patient relationship.

As medicine and health care have become big business, their commercialization and commodification have contributed to acceptance of this market model where the patient becomes a customer who 'knows best'. This is embodied in the SCC decision where the doctor is simply a provider of information, an assessor of competence and a technical expert in achieving death. There is no role for clinical judgment.

With the loss of a normative vision and philosophy of medicine, educating new doctors for professionalism becomes a serious challenge.¹² Compounding all this is the pervasive power of technology in medicine and in society and widespread belief in a technical 'fix' for all human issues. While medicine can relieve much pain and related physical distress, there is little appreciation today of the limits of medicine in responding to emotional, psychological and spiritual suffering.¹³

Lesson:

Conscience Has Become 'a dirty word'

Related to this secularization of society and rejection of the moral core of medicine the Canadian journey has revealed deep misunderstandings and divisions about the notion of

¹⁰ Miles, S.H. 2004 *The Hippocratic Oath and the Ethics of Medicine* New York, NY: Oxford University Press

¹¹ Beauchamp, T. L., Childress, J.F. 1994. *Principles of Biomedical Ethics* (4th ed.). New York, NY: Oxford University Press.

¹² Pellegrino, E., Thomasma, D. 1981. *A Philosophic Basis of Medical Practice: Toward a Philosophy and Ethic of the Healing Professions*, Oxford University Press, New York.

¹³ Cassell, E. 1991. *The Nature of Suffering and the Goals of Medicine*. Oxford, NY: Oxford University Press.

conscience. In the Catholic understanding, conscience is formed and sustained in communities and is a necessary component of the moral life.¹⁴ In response to the legalization of MAD, the Ethics Network of the Catholic Health Alliance of Canada and others worked diligently to try and protect individual and institutional conscience in the legislation. Hours were spent on a nuanced understanding of the moral *principle of cooperation*, non-complicity in providing the required “effective referral” and the duties of care and non-abandonment of conscientiously objecting doctors.¹⁵ None of this was taken into account in professional regulation because of prevailing legal and philosophical attitudes.

These attitudes have been explored in a special issue of *Bioethics*.¹⁶ The research reveals that most secular sources claim conscience as a private and religious claim that has no place in the physician-patient relationship. The issue of conscience is understood only as refusals of treatment and not as the core of moral reasoning. So, the conscience debate is presented as one of conflict between the physician’s right to conscience protection versus the patient’s right to access to legally sanctioned medical interventions.¹⁷ Conscientious objectors are seen as unethical and not doing their fair share in delivering this service and “...conscientious objection legislation in health care violates the central tenet of professional role morality in the field of medicine: the patient comes first.”¹⁸

The harshest judgment is that persons who are not prepared to offer legally permitted, efficient, and beneficial care to a patient because it conflicts with their values, should simply not be doctors.¹⁹ Despite the literature on the experience of moral/ethical distress when forced to act against conscience and insights on the “moral residue”²⁰ of this distress which

¹⁴ Sulmasy, D. What is conscience and why is respect for it so important? *Theoretical Medicine and Bioethics*, 2008;29:135-149

¹⁵ Pellegrino, 2002 The Physician’s Conscience. Conscience Clauses, and Religious Belief: A Catholic Perspective, *Fordham Urban Law Review* 30 (1) 221-244.

¹⁶ McLeod, C., Downie, J., 2014 *Let Conscience Be Their Guide? Conscientious Refusals in Health Care* Special Issue *Bioethics* 27 (8):16-23.

¹⁷ Hardt, J.J. 2008, The conscience debate: resources for rapprochement from the problem’s perceived source, *Theoretical Medicine and Bioethics*, 29:151-160

¹⁸ Stahl, R.Y., E.J. Emanuel, 2017 Physicians, Not Conscripts-Conscientious Objection in Health Care. *NEJM* 376: 1380-1386.

¹⁹ Savulescu, J., U.Schuklenk 2016 Doctors Have No Right to Refuse Medical Assistance in Dying, Abortion or Contraception. *Bioethics*, 31: 162–170.

²⁰ G. Webster & F. Baylis, 2000 in S.Rubin & L. Zoloth *Margin of Error: The Ethics of Mistakes in the Practice of Medicine*:217-230.

makes erodes sensitivity to the moral and spiritual issues of illness and dying, none of the lessons about the seem to be taken into account.

The Most Important Lesson:

There is An Urgent Need to Reclaim the Duty of Care and Companionship of All the Baptized

*“An evangelizing community ...has an endless desire to show mercy, the fruit of its own experience of the power of God’s infinite mercy...An evangelizing community gets involved by word and deed in people’s lives; it bridges distances, it is willing to abase itself if necessary and it embraces human life, touching the suffering flesh of Christ in others. An evangelizing community is also supportive, standing by people at every step of the way, no matter how difficult or lengthy this may prove to be.” (Pope Francis, *Evangelii Gaudium*, 2013,no.24)*

In a sad irony, MAD became legal in Canada as Catholics celebrated the Year of mercy. Today, those of us opposed to MAD are accused of failure to be compassionate and merciful to the suffering. We are not blind or deaf to situations of great suffering for individuals and families, in health crises and in life itself. We believe we need to witness to care and accompaniment, not the intentional ending of life. Responding to the challenge we need the courage to reclaim the spiritual and corporal works of mercy and to fully respond to *“the suffering flesh in others”*.

With medical advances and an increasing number of health professionals, we have come to expect that all the needs of the sick and dying will be provided by professional and public services. We have forgotten that, as disciples of Christ, we are all called to proclaim the Good News, comfort the afflicted and heal the sick. Some will be called in parish and diocesan ministries for particular needs. But all of us are called to be agents of mercy. *“Suffering flesh”* is found in the acutely and chronically ill, those with disability, the elderly, persons who suffer isolation and loneliness, the dying and the bereaved. Suffering is also found in their families and other caregivers. Society’s focus on acute high-technology health care to the detriment of the full continuum of health need is deeply problematic. These changes have occurred at the same time as social disintegration, increased mobility, and changing family and community dynamics. The family of the faith must assume new duties of care and companionship.

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The fight over Charlie Gard:

We can evaluate his treatment, not his life

Bernadette Tobin

Are Julian Savulescu and Peter Singer right when they claim that Pope Francis has "sided" with the parents of Charlie Gard? ¹ I do not think so.²

Eleven-month old Charlie suffers from a rare form of mitochondrial disease. It affects almost every organ in his body. He cannot move or breathe unaided. As his condition deteriorated, his doctors came to the view that, as further treatment would be ineffective, they should stop trying to keep him alive and, with palliative care, allow him to die.

His parents said that they "would not fight for the quality of life he has now." But, doing what just about any parent would do, they searched online for treatments which, even if they would not cure Charlie, might even slightly improve his condition.

His mother found a treatment (called "nucleoside") used on patients with a less severe mitochondrial condition. A doctor in the United States, contacted by Charlie's parents, said that hypothetically it could be beneficial, though that was unlikely. Charlie's own doctors considered providing this treatment themselves. They would have needed the authorization of the hospital's ethics committee because it would have been experimental. Ultimately, they decided against doing so.

Through some kind of misunderstanding, the parents thought that funding was an issue. So, by means of a public campaign, they raised sufficient funds to take Charlie to the United States for treatment. In fact, it seems that if his doctors had recommended it, and the ethics committee had authorized it, the treatment would have been provided in Charlie's own hospital at no cost to his parents.

The doctors subsequently sought a Court's judgment that it would be in Charlie's best interests not to undergo nucleoside treatment and instead to have his ventilation withdrawn and to be provided with palliative care only. The Court found in favour of the

¹ Julian Savulescu and Peter Singer: Charlie Gard: why Donald Trump and the Pope are right. <http://www.abc.net.au/news/2017-07-13/charlie-gard-donald-trump-and-the-pope-are-right/8706390>: accessed 27 August 2017

² Bernadette Tobin. The fight over Charlie Gard: we can evaluate his treatment, not his life. www.abc.net.au/religion/articles/2017/07/14/4702035.htm: accessed 27 August 2017

doctors' decision. Charlie's parents appealed the decision in several courts. Their appeals were unsuccessful. They then wished to take Charlie home to die.

In trying to understand what motivated not only the Pope but also U.S. President Donald Trump to comment on the case, it is helpful to consider two issues: How should decisions be made about life-prolonging treatment? Who should make these decisions?

How should decisions be made about life-prolonging treatment?

On the first. Medical treatment ought to be therapeutic - that is, it ought to heal. So the benefit at which it aims might be cure (if that is possible), or stabilization, or pain relief, or care for the dying. The key question is: "Will the hoped-for benefits of a proposed treatment compensate the patient for the burdens it will likely impose?" Indeed, having one's life prolonged by medical treatment in such a state as Charlie's might in itself reasonably be considered a burden of medical treatment. It seems that Charlie's doctors thought that the only genuine benefit they could offer Charlie was care for him as he died.

So Savulescu and Singer are quite wrong to claim that the issue in question is whether Charlie's life is "worth living" or whether "it is in Charlie's best interests to die."

Charlie's life has the same worth as does anyone else's life - that is what we mean by the equality of all human beings. As I say, the issue is whether the benefits that medical treatment can offer Charlie now, in his circumstances, are enough to compensate him for the burdens the treatment will likely impose on him. Treatments reasonably judged to be overly-burdensome may legitimately be forgone, even in circumstances in which it can be foreseen that the patient will die sooner than otherwise he would have. What doctors have to evaluate is not Charlie's life, but medical treatments available to him.

Nor is the question whether it is in Charlie's "best interests to die." The question is what medical treatment is in his best interests. If the burdens of a proposed treatment are likely outweigh the benefits it promises, then it is not in Charlie's best interests to have to undergo the treatment that is maintaining or prolonging his life. We need to be more sensitive to the complexities of human affairs than to think that only outcomes matter.

Who should make these decisions?

On the second. Generally-speaking, parents bear the often-onerous responsibility of making decisions about the welfare of their children and, in particular, of authorizing medical treatment. But if doctors think that parents are making a serious mistake, seeking either over-treatment or under-treatment, then they have a responsibility sensitively to try to convince the parents of that, and, if necessary, to involve a court. That is why the attitude of the original

U.S. doctor is shocking. He thought nucleoside treatment extremely unlikely to help Charlie, but nonetheless he said he would provide it if the parents so desired and could pay for it!

Are the President and the Pope on the same page? The President tweeted that if the United States could help Charlie, they would be delighted to do so. If that tweet was motivated by a culture of "whatever parents wish for and can pay for, even if it is likely to be ineffective," then it would be an example of medical consumerism at its worst. But if it was prompted by a sense that the parents were being sidelined by medical technocrats, then he and the Pope were of one mind.

For Pope Francis's hope certainly seemed to me to be that the doctors should not, particularly in the last stage of Charlie's life, neglect the desire of his parents to accompany and care for their own child, themselves, until the very end. His hope was expressed just at the time when the parents said that, if Charlie's life-prolonging treatment was to be withdrawn, then they wanted to take their beloved baby home to die.

The Pope's humane hope is entirely at home with a recognition of the sanctity of human life, according to which, though we should never intentionally bring about death, we are not always obliged to prolong life.

But all that was now a week ago. Now the judge is apparently reconsidering the parents' wish that Charlie undergo further treatment. We shall have to wait and see.³

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³ Charlie Gard was transferred to a hospice where he died on 28th July 2017

Rediscovering The Art of Dying

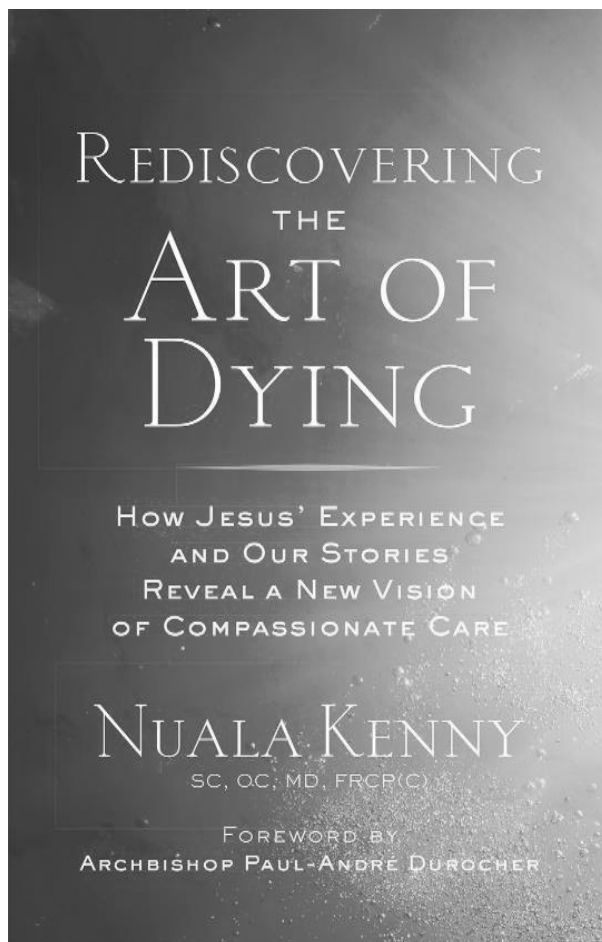
How Jesus' Experience and Our Stories Reveal a New Vision of Compassionate Care

By Nuala Kenny, S.C., O.C., M.D., F.R.C.P.(C)

Drawing on the Passion of Christ, Sr. Nuala Kenny reflects on the inevitable questions we all face regarding health, illness, suffering, and dying. Sr. Nuala Kenny provides a profound spiritual and biblical reflection by linking Jesus's own experience of suffering and death with real-life stories about patients.

This book is for anyone undergoing, or reflecting on illness, suffering, and dying. It is also for families and friends who accompany the sick, dependent and dying, and for caregivers who accompany them. It is sure to guide attitudes, practical decisions, and actions that are central concerns in serious illness and dying, while clearing up misunderstandings that often accompany periods of stress.

Sr. Nuala P. Kenny is a Sister of Charity as well as medical doctor, O.C., M.D., F.R.C.P. Shortly after receiving her MD from Dalhousie University, she became a Fellow of the Royal College of Physicians and Surgeons of Canada, and was certified by the American Board of Paediatrics. Among her many accolades, she was appointed an Officer of the Order of Canada for her contributions to child health and medical education and has received a Queen's Jubilee Medal. She is author of hundreds of papers and two books: among them, *What Good is Health Care? Reflections on the Canadian Experience* (2002) and *Healing the Church*, by Novalis (2012).



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