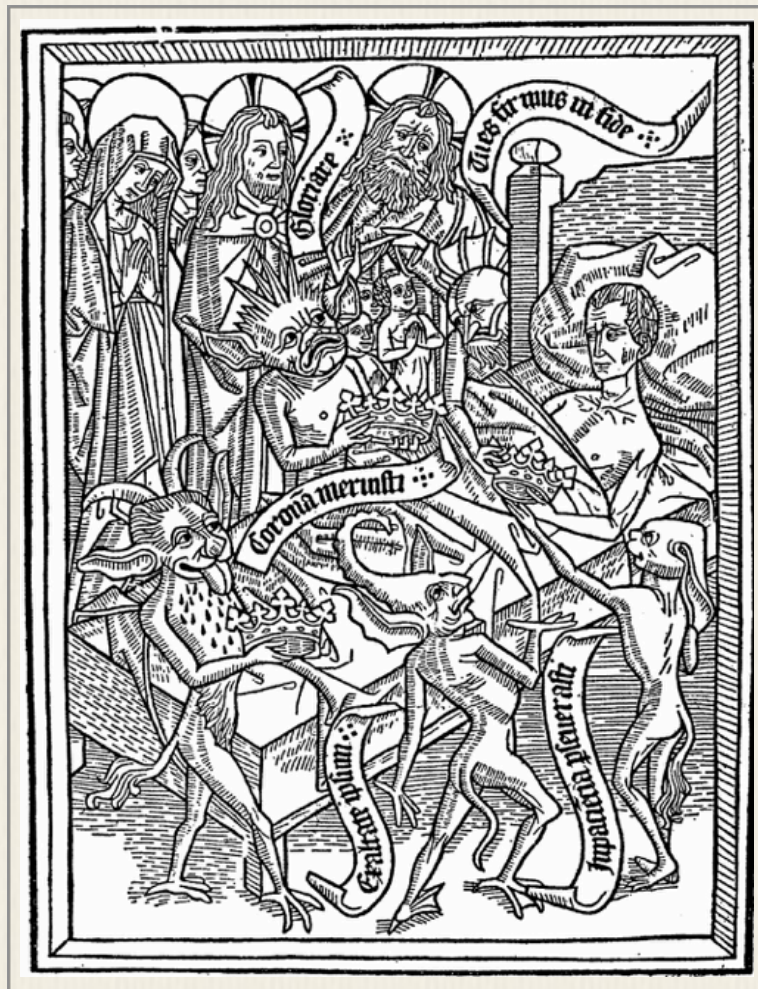

The Art of Dying Well

MEDICAL ASSISTANCE IN DYING (MAID) IN
CANADA

A PUBLIC THEOLOGICAL PRIMER ON CANADA'S
BILL C-14



DR. DAVID PFRIMMER
CENTRE FOR PUBLIC ETHICS - WATERLOO LUTHERAN SEMINARY

The Art of Dying Well

© The WLS Centre for Public Ethics 2016 and Pfrimmer & Associates

Waterloo Lutheran Seminary, Waterloo, Ontario

www.wlu.ca/seminary

All rights reserved. Any form of **not-for profit reproduction is encouraged**, but must acknowledge the source: David Pfrimmer, Centre for Public Ethics at Waterloo Lutheran Seminary, Waterloo, Ontario. No part of this publication may be reproduced **for profit** without the permission in writing from the Centre for Public Ethics.

Preface

There has been a long debate in Canada on euthanasia. The most recent chapter began in 1983 with the Law Commission of Canada recommending “against the legalizing or decriminalizing of voluntary active euthanasia” and not decriminalizing those who aided a terminally ill person to commit suicide.

With Canada’s Supreme Court decision in February 2015 in *Carter v. Canada* (Attorney General), medical assistance in dying has been recognized as a right under Canada’s Charter of Rights and Freedoms for a select group of individuals. In June 2016, the Canadian government passed a new law decriminalizing medically assisted dying and recognizing this right.

Medical assistance in dying means having a medical doctor or nurse practitioner administer a substance that causes death or having them prescribe a substance that a patient self-administers that causes their death. In whatever form, these actions are known as assisted suicide, voluntary euthanasia, or physician assisted dying. Much has been written both in favour and against allowing physicians to assist seriously ill people in dying. Assisted dying raises ethical questions about more than just allowing physicians to aid in bringing an end to a person’s life. It raises questions about the good death and what is involved in the art of dying well.

Many churches and faith communities share similar formal positions opposing euthanasia and medical assistance in dying. However, with this law the state of the national discussion has changed. A recent Anglican Church of Canada’s report “In Sure and Certain Hope” summarized the Canadian situation. The “public debate concerning the legal ban on physician assisted dying is in some ways over.” There are further questions to be studied about how assisted dying might be expanded or not. The debate is therefore not “over.” However, this law marks a decisive departure for Canada in allowing medical assistance in dying for some people.

The unresolved questions will mean that this debate will continue. The Anglican task force suggests churches and faith groups might best work to assure “our energy is best spent at this time ensuring that this practice is governed in ways that reflect insofar as possible a just expression of care for the dignity of every human being, whatever the circumstances.” Faith communities will need a framework for understanding and addressing end of life issues today as this debate unfolds.

Faith communities will need a framework for how to continue to care for people living through those difficult moments now that medical assistance in dying has become the legal.

Discussions about the ethical issues surrounding euthanasia and assisted dying have engaged me over these last 30 years. As I tell my students, the most important theological question we ask ourselves is “How have I changed my mind?” Concerning end of life decisions, most Canadians, including me, have changed our minds to a greater and a lesser degree. This public theological primer is an effort to raise some of the important questions and see if a theological ethical accommodation is possible. I am inclined to think it is possible but in other ways I’m undecided. While this reflects my struggle with these questions, I am grateful to Dr. John Milloy and Mr. Mirko Petricevic, my colleagues at Waterloo Lutheran Seminary’s Centre for Public Ethics for the many conversations and helpful assistance in developing this resource. It remains an unfinished conversation and a continuing discussion. As churches, including my own, wrestle with what the formal statements mean in the light of this new law, I hope these theological and ethical reflections might contribute to the conversation.



Suffering, Death and Hope

I believe in the Holy Spirit, the holy Catholic Church, the communion of saints, the forgiveness of sins, the resurrection of the body, and the life everlasting Amen.

(The third article of the Apostles' Creed)

A few years back following my presentations at a church I was visiting, the pastor called me forward and in front of 300 people said, “I want to present you with this copy of Martin Luther’s death mask.” Ouch! It wasn’t exactly a ringing endorsement!

Only years later when I visited the Market Church in Halle, Germany, where Luther’s death mask is on display, I began to understand. In an age before photography, death masks were relatively common. Luther’s followers wanted to make sure his critics understood that Luther died peacefully and not full of regret for the Reformation and the ensuing religious and social divisions he had unleashed. So they had a death mask made to capture Luther’s peaceful countenance, confirming he died a “good death” with faith in his convictions and his integrity intact. A good death is about honouring a good life.

In the Christian tradition, death is separation from God, from others, and, given our more recent awareness, from creation itself. To be created ‘*imago dei*,’ in the image of God, is to share the essence of our very being with the divine creator. It is not merely to suggest that we occupy a special place in creation. It means, as I have often said, that “no one in anyone without everyone else” and for the faithful, “no one in anyone without God.” This is the basis why churches have been vigorous in their defense of human rights, the protection of marginal and vulnerable people, opposed to the death penalty and to euthanasia and assisted dying. Death is often connected to sin. To some extent the idea of sin today has been trivialized and reduced to merely inappropriate thoughts or actions. More profoundly however, sin is the separation and alienation that divides people, pulling and pushing them apart from each other and from God. It is often those inappropriate thoughts and actions that are symptomatic of this separation and alienation.

In Christianity, the divine paradox is between the sovereign God, the God of power, and the suffering God, the God of love. Christians affirm the sovereignty of the God of life who creates, sustains and causes all life to flourish. However, God takes on a human form in Jesus in solidarity

with human suffering and ultimately death as a suffering God. Elie Weisel in his powerful book *Night* offers an image of the suffering God. He describes the execution by hanging of three prisoners at the Auschwitz concentration camp. One was a child. Weisel heard someone ask as the other prisoners who were forced to witness the ghastly spectacle, “Where is God?” Weisel noted, “From within me. I heard a voice answer: ‘Where He is? This is where—hanging here from this gallows.’” (Wiesel, 2008) Such is the divine paradox, the human expectation of an all-powerful God challenged by the reality of a suffering God.

In Jesus, the incarnation of the suffering God, there is the assurance that this separation or death is overcome conclusively. In Jesus, believers are reunited with the very essence of who we are, those who bear the spark of the divine. This is what allows Paul to write so powerfully about death in his letter to the early Christian congregation in Rome,

“Who shall separate us from the love of Christ? Shall tribulation, or distress, or persecution, or famine, or nakedness, or peril, or sword? ... No, in all these things we shall be more than conquerors through him who loved us. For I am sure that neither death, nor life, nor angels, nor principalities, nor things present, nor things to come, nor powers, nor height, nor depth, nor anything else in all creation, will be able to separate us from the love of God in Christ Jesus our Lord.”

(Romans 8:37–39)

For Christians our individual lives are entrusted to us for the service of God, to our neighbour and to Creation. Suffering and dying become ways to imitate the life of Jesus as disciples and to follow the way of the cross through that suffering to death and the joy the Easter promise of resurrection. In his *Confessions*, Augustine reminds Christians that all life is a joyful journey back to reunion with God, “You have made us for yourself, O Lord, and our heart is restless until it finds its rest in you.” (Augustine, 1960,1.)

As a result of these theological perspectives, Christian piety has accepted suffering and death not as an end but with a hope that transcends suffering and death. Suffering in the words of theologian Douglas John Hall, “... belongs to an order of creation insofar as struggle Is necessary to evoke the human potential for nobility, for love, for wisdom, and for depth of authenticity of being. A pain-free life would be a lifeless life.” Hall is quick to add “But this counsel cannot and must not be exaggerated to the point of celebrating or cultivating pain.” (Hall, 1986,62-3) These theological perspectives have informed much about our theological understanding of death not as an end in itself but as another beginning. These theological views have shaped our positions on assistance in dying. They have made us reticent about hastening or intervening in direct ways that cause death.

Fear of dying is not particularly new for people. Down through the ages, the inevitability of death has been addressed in various ways. For our ancestors, death was more immediate, never far away and a very visible part of daily life. This remains true in many cultures in different parts of the world today. In the more affluent part of the world like Canada, we have been able to sanitize the experience of death, generally confining it to hospitals and long-term care institutions. Many people have very limited exposure to the process of dying. Such lack of experience with dying can

exacerbate modern people's fears and anxieties. Even attending a funeral may not be part of the experiences people have. Nevertheless, talking about our own dying and the death of those we love is an important moment of meaning.

Until the 1600s in Europe, Christian rites and rituals associated with death and dying were the principal ways for understanding and discerning the meaning of death. This European perspective has largely shaped our theological understandings in Canada but not exclusively. As people come to Canada from various parts of the world, they bring with them some of their understandings and meanings. It is also important for us to be attentive to what we can learn from Canada's indigenous traditions as well as those in other parts of the world. Others like the Anglican Church of Canada are doing some important work in this area. However for our purposes here, I will be speaking to some of the more European theological trajectories that have shaped my own Lutheran tradition. They are not meant to be exclusive but hopefully might resonate and contribute to the wider public discussion.

By Luther's time in the 16th century, the dominant urgent issue was the fear of one's own death and our ensuing personal judgment before God. One had to be ready. During the 15th and 16th centuries, an entire body of literature evolved to provide instruction and preparation for dying. The *Ars Moriendi* (Art of Dying) was a body of literature that provided practical advice to prepare the faithful for "a good death." One could not be too careful for the devil lurked everywhere in such moments to tempt believers to abandon the faith and lose their soul in the process. The *Book of the Craft of Dying*, published in 1450, was one of the earliest of these manuals. Among other advice contained within, it also warned of the five temptations used by Satan to deceive the dying. The challenges facing a dying person were the temptation to abandon the faith, to give up to despair, to impatience, to vainglory or complacency, and lastly, the temptation to avarice or attachment to family or property.

As historian Austrā Reinis points out, spiritual care to the sick and dying remained an important focus for the reformers but with some differences. She writes, Martin Luther's *Sermon on Preparing to Die* (1519) became a bestseller, likely because Luther accurately diagnosed and addressed the overriding spiritual concern of devout persons of his day: "despair of eternal salvation, and fear of hell." Susan Karant-Nunn describes how Lutherans retained the *Ars Moriendi* tradition of confession, repentance and the reception of the Eucharist while eliminating the invocation of the saints and the sacrament of penance. Martin Moller wrote a *Manual for Preparing for Death* (1593) that provided these revisions to the art of dying: While people will be held accountable for their life, a Lutheran approach to the art of dying centres on the conviction of a gracious and loving God ready and waiting to forgive people for their failings. Central to the overall *Ars Moriendi* tradition is the understanding that the best preparation for a good death is a good life.

Those who have journeyed alongside dying loved ones know how true these "five temptations" are for people dying today as they were then. Nevertheless, as Globe and Mail writer Erin Ander-

son asks, “Why are we so afraid about talking about death?” Today, many people have not made even the most minimal preparations for a “good death.” Anderson notes,

“An estimated 70 per cent of Canadians have no living will to set out their wishes when they can no longer voice them. Only 47 per cent have designated someone to make decisions on their behalf – and fewer than 44 per cent have spoken to a family member about their end-of-life care. This is why one of the most significant recommendations to emerge from the Royal Society report (on end-of-life care) is that the public and the medical community both need to learn how to clarify these decisions – and learn how to have the “good death” sit-down.” (Erin Andersen, 2011)

Dr. Kenneth Doka of the University of New Rochelle has described one reason that inhibits these conversations: The “end-of-life paradox.” Anxiety about dying peaks not near the end of life but in our 40s and 50s, so ironically “... older adults want to discuss end-of-life directives just when it is most difficult for their children to discuss them.” (Dr. Kenneth Doka, 2015)

One of the essential differences today is how we understand the meaning of death. In the 15th- and 16th-century plagues, wars and starvation made life very difficult, brutish and short. The Black Death across Europe killed some 20 million people, one-third of the population. It was followed shortly thereafter by the Hundred Years War that killed over 3 million people. Death stalked the land. For the predominantly Christian population in Europe, life in this world was understood as a preparation for the better life in God’s world to come.

In the 21st century, the good life is in the present with our focus on economic prosperity, social well-being, personal fulfillment, health and wholeness and more recently the sustainability of our planetary home. Death, far from being a gateway to new life, is often perceived as an end of all the things we love and cherish — our relationships, connection to our communities, our material well-being and personal enjoyment. In the face of such overwhelming loss, the response for many individuals is about retaining personal control or their sense of autonomy. “It is my life and it should be my choice.”

Our understanding of death is further complicated by access to new forms of medical treatment, organ transplantation and advances in technologies that mean death is not merely the cessation of body function, heartbeat and breathing. Today there is a “ragged border between life and death” as Robin Henig notes. “This borderland is becoming increasingly populated, as scientists explore how our existence is not a toggle—“on” for alive, “off” for dead—but a dimmer switch that can move through various shades between white and black.” (Lynn Johnson, 2016) Since the 1960s we have defined death with the traditional cardiopulmonary criteria of breathing and a heartbeat as well as neurological criteria (i.e. “brain death”) of coma or unresponsiveness, the inability to breathe independently and absence of brainstem reflexes. These developments further complicate our considerations about end-of-life decisions because to some extent we have erased the borders between life and death. Ironically the technological paradox is that while such amazing innovations have saved lives, they also exacerbate fear among many that their life may be preserved by these same technologies when their quality of life has deteriorated beyond what they want to bear.

If individual autonomy and the pervasive role of technology dominate and define people in much of their life, it can only be expected that these would loom larger in end-of-life decisions. What is “a good death” in the midst of an understanding of death as the utter loss of all those elements of personal identity and autonomy? Initiating my death becomes my last act of personal control! What is a good death in the midst of technology that has the potential to keep my body functioning after consciousness or brain function have long ceased? Choosing the time of death ensures I will not have to face that technological fate.



New Questions Arising

Historical opposition to suicide, euthanasia and assisted dying has generally served the church and society well in understanding what constitutes appropriate care, medical treatment and support for dying people. Such a deontological ethical approach (obligation-based or rules-based) serves as a “brake” against precipitous actions or enthusiasm in situations of vulnerability, suffering, pain and despair. Doctors and medical staff are charged with healing and the care of the sick and dying. Such opposition has served to preserve the integrity of the physician-patient relationship that depends upon trust and commitment to the patient’s care. As well, it has helped governments charged with safeguarding the well-being of their people, not to be too cavalier in their complicity in the sanctioning ending the life of one of their members. Today there are renewed questions that give this discussion more public traction. The former answers seem insufficient for many people including people in faith communities.

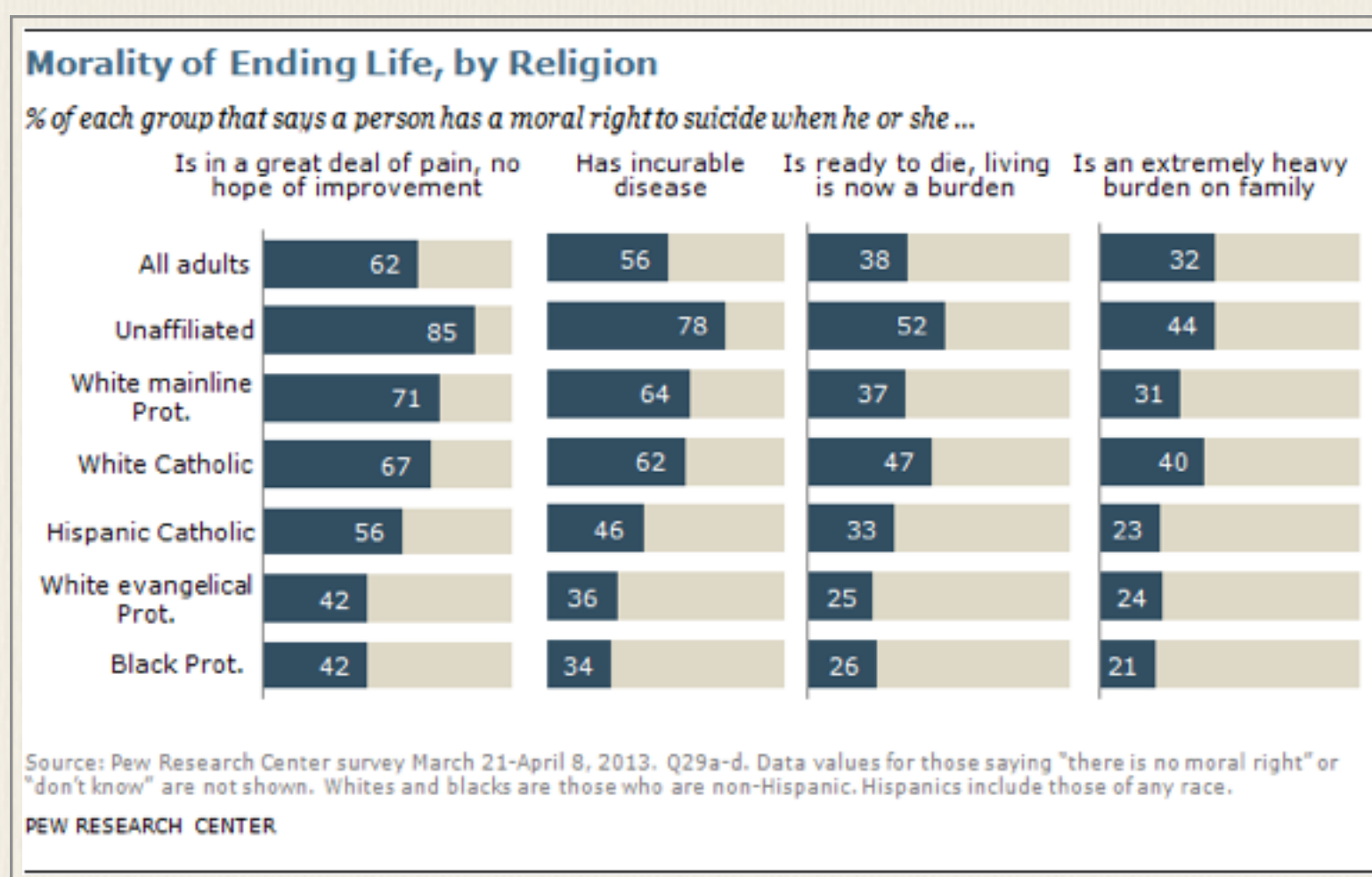
Many people not only in Canada but elsewhere are asking questions about both euthanasia and physician assisted dying. Since the 2014 assisted death of Brittany Maynard, a 29-year-old school teacher with brain cancer, under Oregon’s Death with Dignity Act, “more than half of the U.S. State legislatures have introduced PAS (physician assisted suicide) bills.” (Joseph J. Kotva, Jr., 2016, 28) A number of Canadians have made the trip to Switzerland, including 89-year-old Kay Carter, where assisted dying has been legal since 1942. The Netherlands has allowed euthanasia and assisted suicide since 1984 and it was made legal in 2002. Belgium “legalized euthanasia and physician-assisted suicide in 2002 and, in February 2014, removed the age limit of 18, allowing assisted suicide for children as long as they are terminally ill, suffering unbearably and conscious of their decision, and have the consent of their parents and doctors.” (“Assisted suicide,” n.d.) The U.K. has a law on assisted dying but is continuing with prosecution on a case-by-case basis. Luxembourg has laws similar to Belgium. Colombia does not have a law allowing euthanasia but the Constitutional Court has ruled that a person cannot be prosecuted if “the patient has a terminal illness and gave their consent.” This issue is facing people in many different culturally diverse places.

In the current context with the stories of many people in tragic and extremely difficult circumstances ending their life with medical help, the issue of suicide, euthanasia and assisted dying has

received much more understanding and acceptance than in the past. The strict prohibition against all forms of “assisted suicide” is now open for discussion and modification in the public mind. The current debate began in Canada over three decades ago in 1983. The Law Reform Commission of Canada recommended against legalizing or decriminalizing active voluntary euthanasia or assisted suicide. Subsequently there were numerous court cases, private member’s bills and legislative initiatives culminating most recently in *Carter v. Canada* decision by the Supreme Court of Canada. That decision made Bill C-14 on *medical assistance in dying* (MAID) necessary. This evolution over the past 30 years illustrates how far Canada has changed and how very different the public atmosphere is today on these questions.

Canadian’s views have substantially changed over the course of these debates. A Forum poll released in August 2015 reported “a new high” of 77% of Canadians who “support physician assisted death,” which is up 10% from a similar poll four years earlier. (“Support for assisted suicide increases across four years,” n.d.) In a 2014 Ipsos Reid Poll conducted for Dying with Dignity, an organization that has advocated for greater access to assisted dying,

“... more than eight in ten (84%) Canadians ‘agree’ (51% strongly/33% somewhat) that , as long as safeguards are in place, a doctor should be able to help someone end their life if the person is a competent adult who is terminally ill, suffering unbearably and repeatedly asks for assistance to die. Fewer than one in ten (16) ‘disagree’ (8% strongly/8% somewhat) that doctors should provide this help if asked. (“Most (84%) Canadians Believe a Doctor Should be Able to Assist Someone Who is Terminally Ill and Suffering Unbearably to End their Life | Ipsos,” n.d.)



Eighty-eight per cent of Canadians believe that a patient should have the right to choose physician-assisted dying if they have a terminal illness causing unbearable suffering or they have a serious and incurable illness or condition (87%). (“Support for assisted suicide increases across four years,” n.d.) The following data from the Pew Research Center study show that the views of people of faith in the United States also show support to assisted dying for people in “a great deal of pain” or with an “incurable disease.”

Some observers suggest that the rise in Canadians’ general acceptance of medical assistance in dying, while seemingly opposed to the application of active euthanasia more broadly, underscores a normal deep-seated fear of dying. Interestingly many people are not afraid of death itself but they are afraid of the process of dying. People don’t want to “die a bad death!” At a recent roundtable on palliative care, Dr. Denise Marshall from McMaster University underscored this point: *“Our society is not against death, but against dying. We are a dying-denying society; we want death without dying.”* (Cardus-Pallium Roundtable on Palliative Care, 2016) Currently, there is a different public perception and openness to some forms of assisted dying.

Forum Research president, Dr. Lorne Bozinoff, in commenting on their study noted,

“There has been a great deal of focus on this issue since the Supreme Court struck down Canada’s laws against assisted dying in *Carter vs Canada*. The government has been reluctant to fill the vacuum, but Canadians have spoken out loudly and clearly. They want to control the means and the timing of their own passing.” (“Support for assisted suicide increases across four years,” n.d.)

Certainly Canadian public attitudes have changed. Engaging these new public attitudes will be important for churches and communities of faith if for no other reason than they also represent the views of the members of faith communities themselves. To do this, churches and faith communities will need to recognize the changed legal and legislative context in Canada and more broadly.



Ethical Choices

Changes in the Legal and Legislative Context

Public acceptance of assisted dying has combined with decisions taken by Canadian courts. Assuring access to medical assistance in dying became a more urgent political issue arising from the Supreme Court of Canada's decision in the landmark *Carter v. Canada* case in February 2015. Canada is a nation where the rule of law and respect for human rights is safeguarded under Canada's Charter of Rights and Freedoms. The Supreme Court decision found that insofar as the Criminal Code "prohibits physician-assisted dying for competent adults who seek such assistance as a result of a grievous and irremediable medical condition that causes enduring and intolerable suffering, (the Code) infringe the rights to liberty and security of the person." ((2015) 1 SCR 331," 2015)

The court's recognition of a right under the Charter to medical assistance in dying is for a very specific group of people who meet five conditions. They are (1) competent; (2) have a "grievous and irremediable" condition; (3) are experiencing "intolerable suffering;" (4) are enduring suffering that cannot be alleviated by available treatment or by treatment that is acceptable to the individual; (5) and they consent to the end-of-life procedure. People in these circumstances have a right under the Charter to have timely access to medical assistance in dying to relieve their suffering rather than being forced to prematurely end their own lives before they lose their ability to do so. Canada decriminalized suicide in 1972 although assisting a person to commit suicide remained illegal. Canada's new law removes the criminal penalty for doctors and medical staff involved in providing assistance in dying.

In contrast, recent Supreme Court decisions in the United States have upheld two state laws banning assisted suicide. "However, it allows state legislators to permit and regulate physician-assisted suicide. In effect, the Supreme Court found that while there is no constitutional right to physician assisted suicide, states are free to permit it." (DuBose, 1999, 17) Many states are considering laws to allow greater access to physician assisted dying. However, it is important to note this is not the same as in Canada where a select group of people has a Charter right to access.

Canada's new law received royal assent on June 17, 2016. The new law is a significant change for Canadians. Under the new law patients who are competent to make decisions, who are over the age of 18, and who are "*suffering intolerably and for whom death is reasonably foreseeable*" will be allowed the choice of medically assisted death from doctors and nurse practitioners. Informed and voluntary consent will safeguard vulnerable people against coercion or external pressure to end their lives. The voluntary request will need to be in writing and must be witnessed by two independent people who will not benefit from patient's death. There will be a mandatory 15-day "waiting period – unless death or loss of capacity to consent is considered imminent." ("Government tables doctor-assisted dying bill, sets minimum age at 18," n.d.) While a matter of provincial jurisdiction, the preamble to the legislation calls for "respect for the personal convictions of health care providers" to assure that health care institutions and medical practitioners who conscientiously object will not be forced to offer these services. ("House Government Bill - Bill C-14 - Third Reading (42-1) as passed," 2016) A number of provinces have stated that they intend to allow doctors to opt out of providing this assistance. Nevertheless, safeguarding this exemption in the regulations and in practice remains of some concern to medical practitioners and institutions.

Ethical Choices are Still Necessary

Canadians are adjusting to this availability of medical assistance in dying for some of patients in the difficult circumstances described earlier. There will continue to be contested aspects of medical assistance in dying in Canada whereby advocates will seek to make it more widely available. A parliamentary committee in their 22 recommendations on Bill C-14 argued that the new law should go further. Conversely others will want to restrict it further. It does seem that some form of medical assistance in dying will become a fixture within our medical care system. Churches and faith communities will need to respect the democratic and judicial outcome even if conscientiously they cannot accept the practice itself.

Moral agency still remains an important consideration here. Removing medical assistance in dying from the criminal code and establishing it, as a Charter right for this select group, means that patients and care providers still have to make the moral choice according to their own conscience. It does allow individuals, family and friends in consultation with their medical care providers the moral freedom for ethical deliberation and ultimately the freedom to make a decision. It is worth noting that it is never certain that patients will always make that choice even when it is available. There is also considerable evidence that it is a matter of having the choice is what is important to patients. The Guardian reports that in Oregon, where assistance is available, in 2014 "It is also interesting to note that there are far more prescriptions given out than deaths – just over a third of people who initially get prescriptions change their minds or choose to extend their life." The number of people using the prescriptions continues to rise. Nevertheless, access to a choice may be what is important for some patients even if they do not carry through that choice.

Obligation-based Opposition to Assisted Death

The arrival of the new law also will require Christians and faith communities to revisit their theological assumptions and understandings about the end of life. While we will speak mostly about the Christian tradition here, it is important to note that many traditions ascribe a sanctity to human life arising from a process of ethical deliberation appropriate to their own tradition.

At this point it might be helpful to make the point that there are various ethical approaches or methods that can be used to address ethical questions. Some appeal to a deontological or universal ethics with firmly established natural laws and moral imperatives that are to be applied. Others wrestle with complexity and the ambiguity of the real dilemmas that are perplexing. Some appeal to character or virtue. Still others take a more utilitarian approach focusing on the consequences. Using one ethical method versus another may be like choosing the right gear when driving with a standard transmission on a difficult road.



Adding to the challenge of doing ethics is the various levels of ethical engagement. Many ethicists argue that these decisions involve personal, social and public ethics. Personal ethics involve those individual decisions we make. Social ethics takes place within a system of institutions and dynamics that comprise society. More recently I have argued for public ethics, which gathers people into publics that will address issues.

Historically churches have been more comfortable with a deontological or universal (obligation-based) ethical approach to articulating their opposition to active medical assistance in dying. Simply stated, the argument is that respect for human life is a sacred obligation based on respect for human dignity. Intentionally killing people is intrinsically a violation of that dignity. Therefore assisted death is de facto wrong is not an acceptable practice in society.

There is a general multi-faith consensus opposed to euthanasia and assisted death. The various positions take a similar line of argumentation across traditions. Edwin R. Bose of the Park Ridge Centre has outlined the position of many of the faith traditions. Bose argues that there is "a consensus among Orthodox, Conservative, Reconstructionist and Reform branches of Judaism that assisted suicide and euthanasia are not morally justified" because they "are the equivalent of murder." (DuBose, 1999, 46). Under Islamic law, "God is creator of life; a person does not own his or her life and hence cannot terminate it or ask another to take it." (DuBose, 1999, 51) The arguments are more complicated in some of the eastern faiths. In Buddhism there is a reverence for all life and thus an imperative to "refrain from destroying life." (DuBose, 1999, 67) Hinduism too generally does not sanction assisted dying although there may be some special circumstances when a person can no longer perform their religious rites of purification where it "may be considered acceptable." (DuBose, 1999, 66).

There has been a much stronger consensus among churches against euthanasia and assisted dying. Roman Catholics and evangelical churches have probably expressed the strongest opposition. The Congregation for the Doctrine of the Faith in 1980 reaffirmed the Roman Catholic view that, "Intentionally causing ones own death, or suicide, is therefore equally as wrong as murder. Such action is a rejection of the God's sovereignty and loving plan." (DuBose, 1999, 49). Other Canadian churches took similarly strong views sometimes with a slight variation in the line or theological argument. Many were directly opposed to any changes or expressed such serious reservations that had to be addressed as to make any implementation of new legislation impossible.

The basic theological argument follows similar themes. The Evangelical Lutheran Church in Canada illustrates this as that denomination articulated its argument as follows (my emphasis underlined);

- "The recognition that as Christians we are part of a caring community; a part of the web of human relations we call friends and family, a part of a faith family we call the church; a part of the body of Christ through baptism.
- The recognition that God has created us in God's image and given each of us the gift of life. As Christians we are called on to be thankful stewards of this gift for the well being of all creation, including ourselves. In light of this, as a church, we have affirmed that, deliberately destroying life created in the image of God is contrary to the Christian conscience (p. 6 On Death and Dying).

- The recognition that life in its full Biblical sense includes equally an affirmation of both the biological and the relationship dimension of our being. These two dimensions form an interdependent whole. Quality of life and maintenance of life must both be a concern of Christians.
- The recognition that out of respect for all persons as created in God's image, the carefully and prayerfully considered decisions of individuals regarding their medical treatment needs to be given serious and appropriate recognition. To best make such decisions individuals need to be provided full and accurate pertinent information about the underlying condition to be treated and about the effects of the treatment.
- The recognition that God is present for all through the Resurrection faith of the church, giving hope and meaning through all the dimensions of the life process. This life process includes death and dying (Romans 14:7-10).” (Approved at the Sixth Biennial Convention of the Evangelical Lutheran Church in Canada, n.d.)

When Bill C-14 was passed into law, many churches began to assess how they would respond. Some would try to mitigate the potential negative impact of future changes to the law. The Evangelical Fellowship of Canada opposed euthanasia and assisted dying. After the new law was passed they stated,

"Although we clearly opposed the legalization of euthanasia and assisted suicide, we made recommendations to ensure the practices are as limited as possible, with the strongest possible protections for vulnerable people, and to include conscience protection, so no medical practitioner or institution could be forced to participate, either directly or indirectly.

Still others, notably Roman Catholic institutions said they would not participate. This included many religious hospitals. Many medical care providers and Doctors similarly want to be exempted. The Bishops of Alberta and the Northwest Territories went further arguing in the release of new guidelines "Priests should consider refusing to conduct funerals for people who have chosen a physician-assisted death." ("Assisted death grounds to refuse Christian funeral, bishops say," 2016)



An Ethic of Accompaniment

Do not seek death. Death will find you. But seek the road which makes death a fulfillment.

(Markings, Dag Hammarskjöld 1905 – 1961)

With greater access to medical assistance in dying and with broader public acceptance, churches and faith communities may need to rethink their ethical approaches to this issue. People will be struggling to grapple with not only the specific questions facing family and friends but equally the larger theological questions. There will also be important questions of the appropriate spiritual care to the sick and the dying.

No longer can one assume that people have a deep connection to a particular faith tradition and thereby accept the same assumptions about suffering, dying and death. For those who do have such a strong connection, their expectations about the end of their life have also changed. Those in positions of religious leadership and who provide spiritual care have also changed their thinking and practices. Theological schools are also adjusting their training to some of the new realities. Taken together these changes may result in new considerations about a new set of concerns and needs that must be addressed.

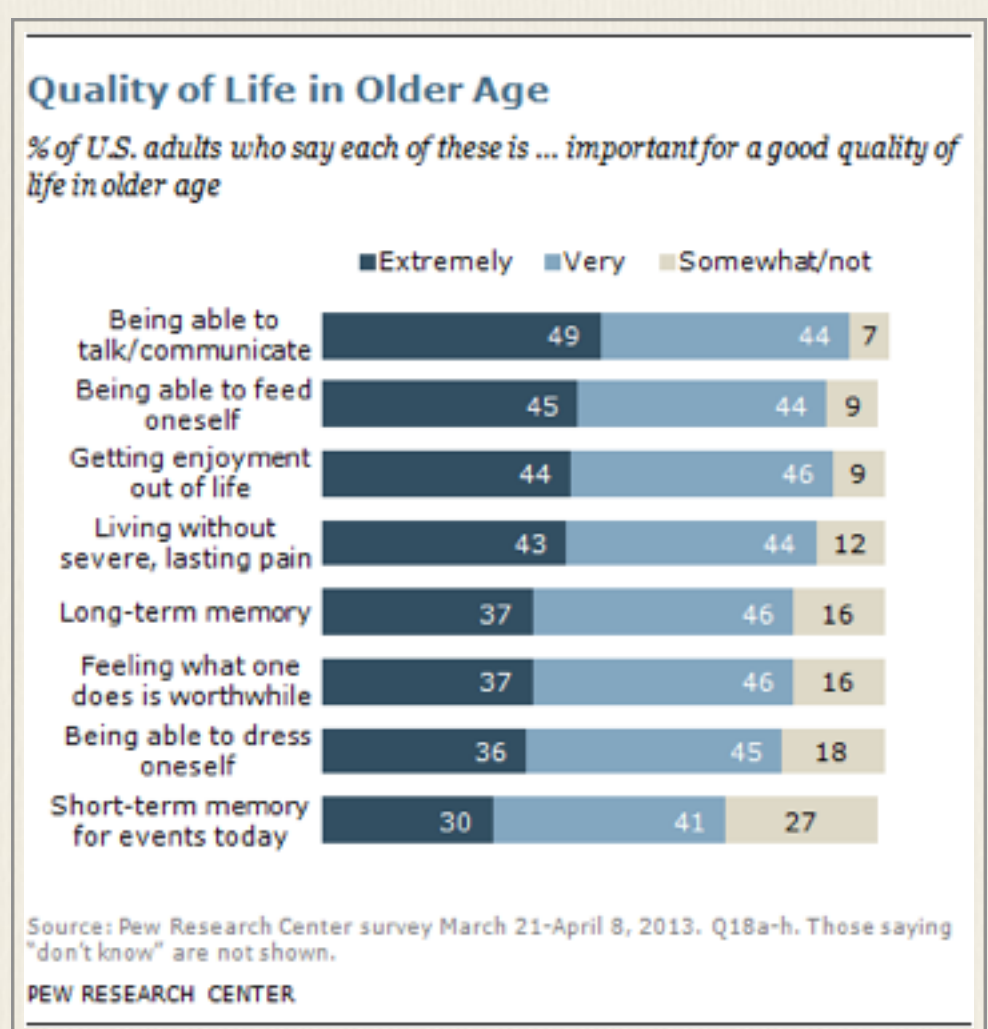
Today dying people understandably share many of the same old “temptations”: feeling abandon or losing confidence in God’s presence; despairing when a prognosis is dire and cure is not forthcoming; impatience with others or pursuit of treatments even if they are futile; and holding destructively onto possessions or demands of family that destroy relationships. The Pew Research Center survey captures some of these concerns about the quality of life. To these dynamics Douglas John Hall points to four conditions “... which constitute, if not suffering as such then the stuff out of which some types of suffering are made.” (Hall, 1986, 57-62) The first is *loneliness*, the feeling of being alone or abandoned. The second is the “*experience of limits*,” things we cannot do or fix. The third is *temptation*, the belief that we might be smart enough to do more than can be done. The fourth is *anxiety* of our own ignorance and dependence. Certainly as jurists and legislators speak today about *irremediable suffering* these constitutive elements speak to a deeper level of suffering that may not be as easily addressed with easier access to medical assistance in dying.

Rising demands for personal autonomy, new medical technologies and treatments, increased fears about the process of dying as well as the continuing needs of an increasingly aging demographic facing the end of their life point to the need for renewed attention concerning what we owe each other in our dying moments. Canadian sociologist Reginald Bibby often notes that while people are becoming more skeptical of what formal religious organizations like churches are offering, “There are certain questions that only the gods can answer!” Today as we explore how to approach end of life considerations, we might want to be guided by the question: How can we accompany this dying person in ways that honour the meaning of their life?

Faith remains significant for many Canadians today. Bibby’s research shows that 65% of Canadians feel their spiritual beliefs are very or somewhat important to them and 41% engage in “spiritual practices” weekly or monthly. (Reginald W. Bibby, 2012, 17) Bibby points out that Canadians are not hostile to institutional religion in principle but they are not buying what they are offering. Bibby goes on to add, “One thing is certain: large numbers of people here and elsewhere will continue to have some needs ‘that only the gods can satisfy.’ Faith and spiritual beliefs will be important in what I call *life moments* like dying and death. Bibby also notes a “particularly important mind-shift” especially among baby boomers, “the movement from deference to discernment.” (Reginald W. Bibby, 2012, 26)

For people of faith and for many others today, discerning and living a life of meaning is what we might describe today as important to our understanding of the good life. This is important to us as we face our own death. It is also important as we accompany dying people, where we become an audience and witnesses to the important life moments and messages that mark the meaning of their life. Likewise, we are companions who point to the markers of meaning in these final stages of life that may be missed or overlooked — relationships with family and children, vocational accomplishments, significant impacts on the life of people, acknowledging the sacrifices made and life enhancing gifts given, and the host of meanings that matter. We honour the rituals of life and the rite of succession for a generation passing the torch to the next generation.

Accompanying the dying in ways that honour the meaning of their life might just offer hope to those facing the loss of everyone and everything they love and know. A fairly consistent desire



of dying patients is to have more control over their life when it seems to lurch out of control. An ethic of accompaniment may recast a more authentic and responsible form of autonomy that gives dying people agency to discover and celebrate old and new meanings in their life. The renowned psychiatrist Victor Fankl has described the value of such life moments of suffering,

‘Whenever one is confronted with an inescapable, unavoidable situation, whenever one has to face a fate that cannot be changed, e.g. an incurable disease, such as inoperable cancer, just then is one given a last chance to actualize the highest value, to fulfill the deepest meaning, the meaning of suffering. For what matters above all is the attitude we take toward suffering, the attitude in which we take our suffering upon ourselves ... suffering ceases to be suffering in some way at the moment it finds a meaning ... man’s main concern is not to gain pleasure or avoid pain but rather to see a meaning in his life.’ (my emphasis added) (Victor Fankl, 1971)

Discovering and affirming meanings may offer what Jack Coulehan has called a “transcendent hope.” (Jack Coulehan, 2013) An ethic of accompaniment must wisely and sensitively cultivate those opportunities for such a transcendent hope that affirms their life as significant and reveals meanings for the person nearing the end of their life.



A Social Ecology of Care

Accompaniment and a Social Ecology of Care

An ethic of accompaniment is about being a companion that seeks to honour the dignity of a dying person with the transcendent hope as they discover their life meaning. This may be laudable but remain an elusive goal in many situations. An ethic of accompaniment places the dying person along with those who love them at the centre of decision-making. This somewhat different approach to *patient-centred care* recognizes the significant active role played by family, friends and web of relationships connected to this person. The Anglican task force makes an important observation about the Supreme Court's Carter decision, noting that it "... consistently reduced the concept of care to the provision of therapy, in terms of medical treatment. It did not pay attention to the broader experience of care in terms of social, emotional, psychological, basic physical, and spiritual care, for example. The meaning of care and the demands it lays upon us need to be broadened." (Taskforce on Physician Assisted Dying, 2016) *An ethic of accompaniment* helps broaden the concept of care. It can help family friends, doctors, medical staff, clergy and care-providers continually recalibrate their role in relation to a dying person, notably as circumstances ebb and flow toward the conclusion of their life. Many companions make this shift intuitively but some do not or cannot without help. Naming an ethic of accompaniment may serve a guiding role.

In proposing an ethic of accompaniment, we might begin by considering what Dr. Bruce Jennings, senior fellow at the Hastings Institute, calls the "ecology" of end-of-life care. Jennings argues "a new orientation is taking shape in end-of-life care that reflects what might be called a 'relational' perspective on the situation, needs and agency of the person at the end of life." Jennings is pressing for an "ecological turn in the ethics near the end of life ... that offer a revised understanding of the goals of end of life care and of ethical standards and communication requirements of end-of-life treatment planning and decision-making." (Bruce Jennings, 2012, 3-4)

New Rochelle University professor Kenneth Doda has made the observation that over the past few decades, end-of-life care has moved from a rescue orientation, where beneficent physicians and people in authority decided what was in the best interest of patients, to an individualistic orientation whereby personal autonomy and individual rights have come to a dominant place. The Carter case and Bill C-14 amendments to the Canadian Criminal Code on the medical assistance

in dying, reflect just this individualistic rights-driven orientation. They were the result of concerted action by groups such as Dying with Dignity, the B.C. Civil Liberties Association and others committed to greater respect for individual rights. Many governments in affluent countries have moved in a similar direction to the one Canada has taken. Dr. Kenneth Doda and Dr. Bruce Jennings have argued that in the next few years there will be a need to shift away from this individualistic orientation toward what they call *a social ecological orientation*. (Bruce Jennings, 2012, 4)

A social ecological approach to end of life care will involve more than just decisions about medical assistance in dying. It will enlist the concerns of a wider network of people. It will focus not just on individual decisions but will consider the impact of decisions on this wider important network of relationships. We know for example that medical staff can experience moral distress where decisions are reached based upon certain convictions but which cannot be implemented. Likewise, anticipatory grief can affect the interaction and the decisions of families and others. While we affirm patient autonomy, as Dr. Doda has observed, “We are very fragile as we face our mortality.” Exercising personal autonomy may not be that straightforward, even among those deemed competent. Beyond these a social ecological approach will need to be sensitive to cultural issues and the various ways ethical decisions are decided. So along with elements from the previous orientations, a social ecological approach adds *the relational principle* that draws in the wider community of people important to the patient.

For churches and faith communities, a social ecological approach is consistent with their theological commitment to understand the essential humanity of people as dependent on and conditioned by their connections to a wider community. For Christians, the community is mutually dependent on one another and the weakest or most vulnerable should receive special attention and have a place. Paul’s first letter to the Corinthians captures this understanding,

“For just as the body is one and has many members, and all the members of the body, though many, are one body, so it is with Christ ... God has so arranged the body, giving the greater honour to the inferior member, that there may be no dissension within the body, but the members may have the same care for one another. If one member suffers, all suffer together with it; if one member is honoured, all rejoice together with it.” (Corinthians 12:12, 24-25)

The Anglican task force has noted the connection of this idea of community with an understanding of the idea of human dignity operative in this kind of ecological framework. Human dignity is linked to relationship and is a product of the demands of human community.

“The point here is not that relationships confer dignity but rather that it is in our experience of those relationships that we are empowered to recognize and give voice to our inherent worth. While this approach to human dignity has much to commend it the danger is that it might be seen as reducing the dignity of those whose capacity for ongoing and sustained relationship is compromised.” (Taskforce on Physician Assisted Dying, 2016)

Churches, faith communities and others will need to press this relational perspective in the face of strong pressures to further entrench an individualistic orientation.

Public Support for an Ethic of Accompaniment and a Social Ecology for End-of-Life Care

End-of-life issues are important for the credibility of governments on a number of levels. In this section we will discuss the responsibilities for governments to safeguard the well-being of their citizens particularly when it comes to the termination of a life. Second we will explore what it might mean for the federal government to develop a national end-of-life care strategy.

One of the primary responsibilities is to safeguard the well-being of its citizens. The federal government has indicated that it will appoint independent bodies to study the questions of whether medical assistance in dying should be available to mature minors, whether those suffering from mental illness would be eligible, and whether advance directives might be considered sufficient to access medical assistance in dying in situations where a person loses the capacity to make such decisions. These were issues raised by various groups and included in the Joint Parliamentary Report, *Medical Assistance in Dying: A Patient Centred Approach*. (“Parliamentary Joint Committees - PDAM (42-1) - Medical Assistance in Dying: A Patient-Centred Approach - Report 1 - Medical Assistance in Dying: A Patient-Centred Approach,” 2016)

Whether we admit it or not, an expanded application of medical assistance in dying implicates the government in the termination of a person's life. In decriminalizing the procedure, expanding the eligibility in ways that fails the ethical test of “last resort” and “lesser harm” may serve to further erode public confidence in government itself. At a recent conference I spoke with an ethicist from the Netherlands. He has reviewed thousands of cases in his homeland where the assisted-dying law is permissive. He commented that families now seem reluctant to send their elderly members to hospitals and institutions because they fear their loved ones might not come back because of such easy application of assisted dying.

Church and faith communities should support government actions that would move in more holistic ecological orientation for end-of-life care. However, an important guarantee in developing such a strategy would be for governments to rigorously resist normalizing medical assistance in dying as a regular treatment of choice. As German churches have noted, legalizing euthanasia implies normalization of a procedure to end the life of a seriously and irrevocably ill person with the approval of the state and society. Social prudence would suggest that the right to medical assistance in dying should be honoured, as it must under the Court's interpretation of the Charter, but only in exceptional situations for those patients as defined in Bill C-14.

The danger of normalizing assisted dying was noted by ethics professor Theo Boer from the Netherlands who reviewed some 4,000 cases of assisted dying on behalf of the Holland's Ministries of Health and Justice. Holland has legalized assisted dying in 1994. Boer notes, “For no apparent reason, beginning in 2007, the number of assisted dying cases started growing by 15% per year. In 2014, the number of cases stood at 5,306, nearly three times the 2002 figure.” (Theo A. Boer, 2016, 24-26) Boer goes on to point out that 12% of all death in the Netherlands (17,000 cases per year) involve palliative sedation. Boer also found through anonymous reporting that

there have been approximately 300 involuntary euthanized deaths annually where the “patient is not judged competent.” “Today, one in 25 deaths in the Netherlands is a consequence of assisted dying.” (Theo A. Boer, 2016, 24-26) In the Netherlands euthanasia and assisted dying has become an accepted practice.

American ethicist Joe Kotva accepts that there are “cases in which doctors cannot sufficiently palliate extreme pain without permanent sedation and in which the patient finds the idea of such sedation a fate worse than death.” He argues that these are exceptions not the norm. “The truth is that cases of truly unimaginable pain are rare.” (Joseph J. Kotva, Jr., 2016, 31) Nor is it pain that most dying patients fear the most. In one Oregon study only 24.7 percent respondents noted pain. An Oregon Public Health Division study, a state where assisted dying has been legal since 1997, reported, “The three most frequently mentioned end of life concerns were; loss of autonomy (91.4 percent), a decreasing ability to participate in activities that made life enjoyable (86.7 percent) and loss of dignity (71.4 percent).” (Joseph J. Kotva, Jr., 2016, 29) Kotva concludes that the experience with assisted dying to date, doesn’t deal with the real concerns of dying people nor does it offer a reasonable basis for making public policies for the general public.

Health Minister Jane Philpott has made clear, “Health care workers ... who follow appropriate safeguards would no longer have reason to fear criminal prosecution.” (“Government tables doctor-assisted dying bill, sets minimum age at 18,” n.d.) Bill C-14 removes the criminal prohibition but many physicians remain uncomfortable with providing assistance in dying. The concern is that normalizing assisted dying may also have an adverse impact on the physician-patient relationship. This relationship is founded on trust and the principles of “nonmaleficence” (not to inflict harm) and “beneficence” (to do good for the other). Trusting medical care providers lies at the heart of health care delivery. Physician assisted dying may compromise this essential foundation of trust in at least two ways. First when a physician provides assistance in dying, it gives the appearance of official sanction as opposed to individual suicide that would have a wider psychological, emotional and social affect on the family and a community. Assisted dying is not just about technical implementation. When a doctor assists a person the process could appear more acceptable than if a person took his or her own life. One can understand why many doctors are uncomfortable with this role and the prospect of being forced to refer people or participate even indirectly in this assistance.

Second, trust in medical practitioners can be eroded over time, as assisted dying becomes a more widely accepted practice. Joe Kotva makes this point regarding the impact on veterinarians who are often involved in euthanizing animals. Kotva notes what is “... worrisome are studies in the United Kingdom indicating veterinarians are more inclined than other healthcare workers to view suicide as a solution to their own problems and that 93% of UK veterinarians favour euthanizing humans. Performing euthanasia appears to change veterinarian’s attitudes toward death. When one intentionally terminates animals that are considered to be part of the family, a natural next step is to alleviate human suffering by death.” (Joseph J. Kotva, Jr., 2016) Care and attention will be needed to monitor and adjust the impact on the medical care providers. Under the new

law, the decision to provide medical assistance in dying is requires a second medical or nurse practitioner. It may be more appropriate to have such decisions and assistance provided by practitioners not directly related to the patient to safeguard the fiduciary responsibility of the physician and nurse practitioners caring for the patient. This warrants further study and consideration.

Those pressing the individualistic orientation to assisted dying will want to expand the conditions and the eligibility so more people in a wider range of circumstances have a right to medical assistance in dying. They may find support in the Canadian courts as they did with the parliamentary joint committee. It is to be hoped that the courts and legislators will be careful here. Joe Kotva makes a strong case that laws are a good teacher. Considering the experience in the U.S. and other jurisdictions, Kotva points to the impact of these assisted dying laws: “Laws are always shaping behaviours and communicating values. Death with Dignity laws is teaching people that this is a good way to die!” (Joseph J. Kotva, Jr., 2016) Governments, the courts as well as other organizations must resist this temptation at normalizing assisted dying as a basis for good public policies on end-of-life care. Assisted death, as the Globe and Mail described it, is a “necessarily imperfect right” that in my estimation should be honoured as an exception to the normal practice of end-of-life care. (“Assisted Suicide A Necessarily imperfect right,” 2015) These may be important questions for consideration for those operating within the rescue orientation or individualistic orientation. However, they would not be the first questions that need to be addressed in moving forward to a social ecological model for end-of-life care.

Second there is a positive proactive role for governments to play in creating an integrated end-of-life system of care for our aging population. Creating and sustaining an appropriate environment, or ecology, for end-of-life care will be an important responsibility that will fall to Canada’s federal government as well as the provinces. To move toward an ethic of accompaniment and developing a social ecology for end-of-life care, governments will have an important role to play in supporting and encouraging a system where various parts of end-of-life care are clearly interrelated in a national end-of-life care strategy. Governments will need to facilitate and convene national plans with clear goals in sustaining the health infrastructure, in mobilizing resources, and safeguarding Canadians well-being, particularly the most vulnerable within the health care system.

A national end-of-life care strategy would most appropriately be developed within the context of a strong public Canadian health care system. One of the key advantages of a publicly administered health insurance system is the ability to coordinate and integrate the delivery of care at various stages of life and situations. Much of the debate has focused on the rights of individuals to access medical assistance in dying. However it is important to remember that citizens, through the instruments and power of the state, have a responsibility to safeguard the well-being of each other, particularly vulnerable members. Outsourcing responsibility for medical care to for-profit agencies or companies would add another level of complexity. It could lead to the erosion of the protections and safeguards to compassionate end-of-life care. A McMaster University study in 2002 on 38 million patients in 26,000 hospitals between 1982 and 1995. The death rate in for-

profit hospitals was 2 per cent higher than in not-for-profit facilities. (Andre Picard, 2002) Governments will need to guard against the commercialization to for profit delivery of end-of-life care, particularly the provision of medical assistance in dying.

Concerns have been expressed about the rising costs in Canada's health care system. The two drivers seem to be the introduction of medical technology and the escalating costs of pharmaceuticals. While the elderly tend to rely on the health care system near the end of their life, there has not been substantial evidence to support the claim that costs would be unsustainable. In fact many seniors are increasingly healthier. Nevertheless, the fear of uncontrollable costs may subtly be used to support the expansion of medical assistance in dying as a form of end-of-life care. Governments will need to find ways to continually affirm the guiding principles of Canada's health care system to assure public trust in the face of creeping privatization.

To this end, the Canadian churches' proposed a Health Care Covenant (see appendix) for the endorsement by all levels of government. It was the very first recommendation of the 2002 Royal Commission on the Future of Health Care in Canada. As Commissioner Roy Romanow noted, "the direction of our health care system must be shaped around health needs of individual patients, their families and communities." (Government of Canada, 2004) Health care reform, and I would argue palliative care planning, needs to be guided by these first principles for a public health care system. The federal and provincial governments should endorse and commit to the Canadian Council of Churches' Health Care Covenant as a guide for any reforms and to safeguard the public's interest in a system that addresses their health needs from birth to death.

Canada needs a national end-of-life care strategy. This plan should outline how the health care system delivers integrated care so that transitions through the various stages have a seamless continuity. An important element of a national end-of-life care strategy will be a palliative and hospice care plan to improve overall access and delivery across the country. In some ways the terms palliative and hospice care has become associated with people who are in the final stages of dying. However, as the Anglican task force rightly points out,

"Although often thought to be synonymous with 'terminal' or 'compassionate' care, palliative care is not confined solely to situations in which curative therapies are no longer possible or desired. Rather, the focus is on relief of distressing symptoms and maintenance or improvement of the quality of life of the sufferer regardless of the prognosis or projected duration of the illness." (Government of Canada, 2004)

My distinction between end-of-life care and hospice/palliative care centres on the nature of the diagnosis. Hospice and palliative care is care aimed at people with a life limiting or threatening illness, that provides relief from pain and suffering and offers treatment, physical support, psychological and spiritual care to them and their families. Cicely Saunders who was the founder of the palliative care movement summarizes a fuller focus of palliative care this way: "You matter because you are you, and you matter to the end of your life. We will do all we cannot only to help you die peacefully, but also to live until you die." (Government of Canada, 2004)

I use the term end-of-life care as a way of avoiding the public misconceptions about palliative/hospice care as only for the terminally dying. In essence, we are all dying from the moment we are born. End-of-life care involves people who are elderly and may be at some risk but who may not yet be diagnosed with a life limiting or threatening illness. I would hope that a national end-of-life care strategy might include additional needed elements not always included in the designation of palliative and hospice care.

Having noted this difference, Canada does need a national palliative and hospice care plan. Churches and faith communities generally believe that patients nearing the end of life should receive good palliative care. (Approved at the Sixth Biennial Convention of the Evangelical Lutheran Church in Canada, n.d.) There have been huge advances in the field of palliative care. Nevertheless, public fears remain about palliative care as a kind of death sentence where a person faces dying in excruciating, unending, tortuous pain. At a recent roundtable on palliative care in Ottawa sponsored by Cardus and Pallium Canada, one participant asked, “How do we nurture a palliative-care movement?” (Cardus-Pallium Roundtable on Palliative Care, 2016) Such a movement they argued might galvanize “a critical mass and then creates cultural receptivity” to broaden the awareness of what is possible and available in palliative care. It is important for a wider public to understand palliative and hospice care as an effective and accessible alternative to assisted dying.

A specific national plan for palliative and hospice care must be given a higher priority. Canada dropped from being ranked 9th in 2010 to 11th in 2015 according to the Economist’s Quality of Death Index. (A Report by the Economist Intelligence Unity, 2015) We were in the middle of the pack of countries when it comes to having a “government-led strategy of national palliative care.” The problem is that Canada’s strategy offers a “broad vision with loosely defined milestones” but no specific targets. “There are limited mechanisms in place to achieve the milestones” and the strategy is prescriptive not mandated. (A Report by the Economist Intelligence Unity, 2015)

Access to palliative care is a significant problem in Canada. According to the Canadian Hospice Palliative Care Association (CHPCA), “Only 16% to 30% of Canadians who die currently have access to or receive hospice palliative and end-of-life care services – depending on where they live in Canada. Even fewer receive grief and bereavement services. (“Fact Sheet: Hospice Palliative Care in Canada,” 2014) The Globe and Mail’s Elizabeth Church reporting on a Canadian Cancer Society study, notes that,

“Thousands of Canadians are suffering unnecessarily each year because they do not have access to palliative care ... It is expected that 75,000 Canadians will die of cancer this year (2016), but about half of them will spend their final hours in an emergency room or acute care bed ... even though studies show that most people want to die at home.” (Elizabeth Church, 2016)

A national effort is needed to make effective and compassionate hospice and palliative care available to all Canadians.

Individuals may want to have their own end-of-life-care plan that they have worked out with family and friends. Such a plan would outline the goals they have for the care they receive, where they would live and possibly at what stage. Such planning would mean writing or updating their will, signing and discussing power of attorney and substitute decision-making and yes, then developing advanced directives should they become necessary. Some may even wish to prearrange their funeral and the kind of ceremony to commemorate their life. These actions can make it easier for family but they also provide an important occasion for the “good death” conversation.

In announcing Bill C-14, the federal government has pledged to invest another \$3 billion over four years and to work together with the provinces under the Health Accord to improve palliative services. This is laudable but Canada will have to move much more concretely to develop a national end-of-life care strategy that includes commitments a national plan for hospice and palliative care. If health care is a right and if, as the Carter decision has made clear, medical assistance in dying is a right under certain conditions, then with the right to health care, which is central to a Canadian self-understanding, the right to end-of-life and palliative cares should be honoured too. Governments need to locate further discussions about extending medical assistance in dying in this broader setting of a national end-of-life care strategy to avoid having assisted dying become by default one of Canada’s primary strategies.

A national end-of-life care strategy should be based on an ethic of accompaniment and a social ecological orientation to end-of-life-care as opposed to a narrower individualistic orientation. This plan will need the leadership of the federal government in partnership with provinces, health care institutions, professional associations, community organizations, churches and faith communities, and a host of other stakeholders who are already providing services and addressing these issues. A consultative process might be useful in the development of such a national plan. This Canadian national end-of-life care strategy will need to:

- Integrate the provision of health and hospital care with long-term care institutions and programs for the seamless provision and transition through care;
- Include and coordinate other national strategies like those proposed for cancer, dementia and Alzheimer’s disease with end of life care;
- Implement a Canadian national hospice and palliative care strategy that helps mobilize additional resources and services to dramatically increase access by Canadians. The aim of this element is to enable patients to experience hospice and palliative care as a more seamless process with Canada’s health system;
- Provide greater investments in preparing and educating professional people and expanding the number of health care specialists in relevant fields such as gerontology, palliative care, spiritual care and counselling , etc.;

- Give attention to education for professionals such as doctors, medical staff, social workers, clergy and others accompanying the people in the final chapters of their life about end-of-life needs, issues, new research and best practices for care;
- Encourage the development and implementation of academic and other programs that support the moral formation of professions and provide them cross-cultural and cross-disciplinary competency in the area of ethical deliberation;
- Develop appropriate curriculum and programs within schools, community groups and faith communities to prepare people for the dynamics at the end of life, on how to accompany people during these times and to equip people with ways to develop and share with family an advanced end-of-life care plan that would include advanced directives and other tools;
- Establish a coordinated program of research and reporting and communication of the findings on current developments, best practices and other data for future planning.

Many of the elements of a plan may already exist in various organizations and places across the country. The challenge will be to identify them and ways to help their function in a coordinated way. It will also be important as the Quality of Death Index has noted that some specific targets be established to measure progress, and some specific measures be put in place to assess if we are honouring the rights of Canadians to this end-of-life care.

It would be within the context of this broader *national end-of-life care strategy* that further conversations about assisted dying might be conducted. The government, when it announced the legislation, suggested further research and conversations about access to medical assistance in dying. Placing such conversations in the context of an end-of-life care strategy would begin with the questions and issues that matter most to people and families as they near the end of their lives. How do you maintain some control over your life? How do you continue meaningful engagements with each other and your friends? How do we avoid the loneliness and isolation faced by many in care? How can we assure and be responsive to human dignity in the face of suffering and pain? A *national end-of-life care strategy* needs to begin here and address these concerns.

Setting a public stage is critically important in light to the adoption of Bill C-14. Locating the questions of medical assistance in dying within the broader discussion of end-of-life-care allows for a more responsible consideration and possibly greater public convergence as opposed to polarization. The Netherlands has had considerable experience with access to euthanasia and assisted dying. Yet, some are not sure they have taken the right direction. Else Borst, former Dutch deputy prime minister who was in office when the Netherlands passed their euthanasia law, has said, “We did it in the wrong order. We gave into the political and social pressure for euthanasia before the nation had properly arranged for palliative care.” (Theo A. Boer, 2016, 26) To be responsive to the real needs and concerns of people it is important to locate questions of euthanasia and assisted dying in this wider framework of end-of-life-care.



Accompaniment in Practice

While governments have a responsibility, so too do churches and faith communities. Churches and faith communities are significant makers of meaning in these final life moments such as takes place during the end of life. This is not just a responsibility but, in speaking with many religious leaders, particularly chaplains, it is also a privilege to accompany people during these often difficult but meaningful times. The well-known Lutheran theologian and pastor Dietrich Bonhoeffer in advising pastors on the importance of attending the dying, reminded them that they would often experience “... the bitterness of death in its most horrible forms ... that will be balanced by wonderful experiences at the deathbed.” (Bonhoeffer, 1985, 61)

An ethic of accompaniment can offer churches and faith communities a renewed understanding of the meaning-making role they might play in end-of-life care. The rescue orientation of the authoritative clergy with all the answers as well as the individualist orientation of the counsellor as a non-directive non-anxious presence, is giving way to a fuller relational orientation of the social ecological approach. Many clergy, chaplains and spiritual care providers are pioneering a more relational approach.

The leadership in many churches and faith communities are pursuing a fuller relational social ecological approach too. They recognize that churches and faith communities have a public responsibility to provide accompaniment through (1) the provision of *spiritual care* to the dying and their families as well as care providers, (2) the development and provision of *support programs* via alternative services like parish nursing, long-term care facilities, support for hospice care and advocacy with governments on effective assessment, accountability and policies for end-of-life care, (3) ensuring that clergy, chaplains and spiritual care providers have *sufficient and effective training in ethics* in order assist with difficult choices and decisions and to be useful to doctors and medical practitioners and (4) the development of *congregational and community education programs* for discussions about dying and end-of-life planning. Many churches and faith communities make important contributions in this regard already. More can be done to recognize and encourage more initiatives, innovation and creativity in this regard.

An ethic of accompaniment based on a social ecological orientation to end-of-life issues can provide an important framework for churches and faith communities as well as for the wider community. So often people struggle with what they can do or how they can help. There is much being done in this regard. There is a much larger conversation needed but there are at least three areas that merit some attention:

High Standards of Professional Spiritual Care

An ethic of accompaniment in the current medically complex context requires special education and training. Since the 1960s with the arrival of Clinical Pastoral Education (CPE) there have been great advances in the way churches have delivered what was formerly called pastoral care but now is referred to as spiritual care. I have suggested elsewhere that *spiritual care* might best be defined as “*creating a safe space to encounter the essential truths about ourselves.*”

Just showing up or just being present is not sufficient spiritual care. This is a dynamic and increasingly professional field. Churches will need to ensure that their clergy remain current in the knowledge and skills required to provide spiritual care, particularly in a multi-faith context today and when so many are “spiritual-but-not religious.” Denominational judicatories and credentialing bodies may want to develop specific expectations for clergy and care providers, particularly those visiting hospitals. Ongoing continuing and interdisciplinary education for spiritual care professionals in end-of-life care as well as for doctors, nurses, clergy, and lay visitors will be essential. In particular, clergy and religious leaders providing care will need to continually and regularly upgrade their qualifications to keep up with developments and best practices in medical and counseling fields.

Advanced End-Of-Life Care Planning and Education

An ethic of accompaniment requires advanced preparation and formation of companions to provide end-of-life care. It also requires confronting the reality of our own dying and death. Churches may want to create opportunities for people to talk with family and friends about advanced end-of-life care planning. Often the focus has been on advance directives that detail a person’s final wishes should they need a substitute decision-maker. Advance directives can be useful but they alone are not sufficient. As the German Protestant churches have observed,

“Many agree that advanced directives should have considerable weight regarding life-prolonging treatment. An objection against them as absolutely binding, however, is that they do not allow for changes in individuals’ set of beliefs, values and their overall evaluation of life.” (Community of Protestant Churches in Europe, 2011)

Deliberation by substitute decision-makers and family will be important and necessary. Churches can initiate programs and model ways that people can have the necessary end-of-life conversations. They can help mitigate Doda’s *end-of-life paradox* that so often inhibits communication within families and among friends. Churches and faith communities may develop new educational programs to discuss death, the process of dying and ways to ensure people’s wishes.

Making Ethical Choices

An ethics of accompaniment recognizes that end-of-life care involves many important ethical choices. Many of these decisions are decided in quite contested and emotionally difficult terrain amidst complex and diverse circumstances and relationships. Care providers, particularly clergy, need to be prepared to do ethics when they are asked. Doing ethics can be difficult in situations with a wide range of potential stakeholders (e.g. family, children, doctors, nurses, friends, other patients, staff and others), where there are diverse and multiple cultural customs and religious beliefs, where there are various ethical approaches to making decisions, and where there may be no consensus on a clear answer or solution. Clergy, chaplains, and spiritual care providers need to develop and continually improve their knowledge of how to do ethics in these medical contexts. Ethics is an important tool in end-of-life care. However, it is not an intuitive skill but requires intentional training and practice for its appropriate use.

Informed Consent

There are very specific ethical questions raised in the provision of end-of-life care. One of the first is, “Has a patient given informed consent to a particular treatment or plan of treatment?” As the German churches have noted,

“Medical ethics views autonomy in general, and the principle of informed consent in particular, as fundamental... Autonomy in the sense of being free to resist unwanted intrusions in one’s life and body is also a vital concern from a Protestant perspective, as it protects personal integrity and enables responsibility.” (Community of Protestant Churches in Europe, 2011, 58)

While all agree this is important, who facilitates reaching informed consent? While patients may understand the implications, did the patient really understand the implications sufficiently and what about addressing the psychological, social and spiritual dimensions arising from consent? These too are important questions.

Refusing Life-Prolonging Treatment

In some circumstances, a patient may refuse particular life-prolonging treatment. There is a serious dilemma in such moments when patients refuse such treatments. The Evangelical Lutheran Church in Canada has stated: When a treatment will not help improve a patient's underlying condition, will not provide palliative assistance to the patient, or will not prevent death from occurring from that condition, then such treatment need not be supported or continued. German Protestants went even further in suggesting it may be irresponsible to provide some treatments that prolong life.

“Discontinuing or withholding life-prolonging treatment under given circumstances is not only permitted but might even be required as an element of proper care and compassion for a seriously, irrevocably or terminally ill patient.” (Community of Protestant Churches in Europe, 2011, 12)

These can be very difficult and conflicted moments. We have already mentioned the importance of advance directives and the need for people to talk with those they love about their ad-

vance end-of-life care plan. Nevertheless, situations may arise where recognized substitute decision-makers or family have to make decisions where a patient may not be able to. Interpreting that advanced end-of-life care plan or advance directive, will require ethical attention to honouring the wishes, values and beliefs of the person.

Still another potential ethical dilemma will be who makes the final decision to withhold or discontinue treatment that will result in the death of the person? Family and friends who have a good knowledge of the person, their wishes and desires, must be included. In the process there should be full and extensive communication with the family by the doctors and medical staff to make sure they are informed. However, should the family, or the doctor, or an independent third party such as an ethics committee make the final decision? The German churches believe that in the end it should be the doctor's or medical team's decision. They point out "Family members should never be burdened with the final decision to end treatment of a loved one. In addition, particular caution should be exercised by responsible medical personnel in cases of disagreement between family members over the question of continuing treatment." (Community of Protestant Churches in Europe, 2011, 61) This may not be culturally acceptable in Canada. Facilitating and even mediating these decisions will be important to navigate sensitively and thoughtfully.

Medical Assistance in Dying

One major ethical consideration will be how people of faith relate to the availability of medical assistance in dying. This is a central ethical question. As we have previously noted many churches and faith communities have been opposed to all forms of assisted death on ethical grounds. "Assisted Death' whether by physicians or other medical professionals is not supported by Lutherans." (Approved at the Sixth Biennial Convention of the Evangelical Lutheran Church in Canada, n.d.) Many faith communities have strongly expressed similar views. How then can people of faith accommodate the reality of medical assistance in dying while remaining true to their convictions about the sanctity of human life? As well, should people of faith accept assisted dying as morally acceptable for themselves or those they love? As we saw earlier in the Pew Center's research, many of the faithful already accept assisted dying in certain circumstances as morally acceptable.

This is a central question. Can people of faith who may be opposed in principle but sympathetic to the circumstances facing a dying person, participate in the practice of assisted dying? An ethic of accompaniment for the dying will offer only an ambiguous accommodation with medical assistance in dying at best. Those who would seek a clear obligation-based answer with a clear line between the right and the wrong will not find that clear a designation in an ethic of accompaniment. Ambiguity is inherent in the ethical enterprise of accompaniment.

In an ethic of accompaniment choices about medical assistance in dying may require employing the principles of *last resort* and choosing the *lesser of two evils*. There seems to be a tacit practice today that hastens death in many hospitals and institutions in cases where the outcome is inevita-

ble. Lutherans have articulated such an ethic of ambiguity in a number of their public statements, most recently in 1997 ELCIC Resolution,

“Christians should feel free to support in an ambiguous situation, appropriate medical treatment whose primary purpose is palliative care or which seeks to address a patient's underlying condition, but which may also have life undermining side-effects.” (Approved at the Sixth Biennial Convention of the Evangelical Lutheran Church in Canada, n.d.)

In the some traditions such as Roman Catholic social teaching, such ambiguity is addressed by what is called, *the principle of double effect*. Attributed to Thomas Aquinas in his *Summa Theologica* (II-II, Qu. 64, Art.7), the principle of double effect suggests that an action may be taken with the intention to do the good but might result in unintended harm. This could occur where a physician prescribes medication for pain to alleviate the suffering of a patient but in so doing hastens the death of the patient.

A question that might be worth exploring is to what extent might *the principle of beneficence* be applied in such circumstances too? In the exceptional situations we are referring to, does this practice of medically assisted dying enable in any way the doing of good for the dying person? I have often heard from chaplains and local clergy that as they have accompanied the dying, many were concerned about “saying goodbye” or resolving outstanding issues with those they loved, or not being remembered by those they love with the visual memory of anguished or tortured final days. I could envision certain exceptional circumstances where medical assistance in dying might be very affirming in honouring the life of a dying person. This is certainly not a justification for the application of assisted dying. However, it is a consideration for the nature of the care being provided.

Palliative Sedation

Another example of ethically ambiguous end-of-life decisions is palliative sedation, which is used near the end of life to relieve severe symptoms by placing the patient in an induced coma. Ethical support for such actions is based on *the principle of double effect*. The key ethical consideration in these ambiguous situations is the role of intention. The primary intention of the actions by a physician are the care of the patient not the end of the patient's life. Lutherans have appreciated the conflicted nature of such circumstances; “In cases of an irremediable medical condition that causes enduring suffering, medical treatment including the administering of pain medication is justifiable even if this may hasten the dying process.” (Approved at the Sixth Biennial Convention of the Evangelical Lutheran Church in Canada, n.d.) The Protestant churches in Europe have elaborated this important distinction.

“Another and more convincing argument (and more) consistent way of justifying the difference between euthanasia and abstention from treatment, is the distinction between “action” and “omission.” It makes a moral difference whether a specific situation – say a person's death –arises through a person's omission or through a person committing an action.... The point is that we are responsible not only for the results that come about, but also for involvement in how they come about through our action and conduct.” (Community of Protestant Churches in Europe, 2011)

Given the historic opposition by churches and faith groups, what does any accommodation mean in practice for people of faith and institutions? Exemptions based on conscience for medical and nurse practitioners as well as institutions should be put in place by provinces in their laws and regulations and should be monitored to assure they are respected. Conscience is a delicate and necessary safeguard to our freedom in Canada. Yale law professor Stephen Carter makes the important point that dissent — not consent — is foundational to the vitality of democracy. (Carter, 1998) Dissent is not limited just to individuals. We need to respect and appreciate those institutions that serve the public interest as communities of moral deliberation and cultures of conscience. Forcing faith-based hospitals to provide assisted dying moves Canada in the wrong direction. Governments clearly agree at this point in the public debate. Nevertheless, some groups in Canada argue all religious hospitals should be required to provide medical assistance because it is a right, the law of the land, and they receive public money. This would be an unwise direction to pursue in the future.

Accepting some accommodation for the reality of medical assistance in dying in Canada may not be ethically or theologically possible in many religious traditions. However some Christians, Lutherans in particular, may see a very limited possibility. Lutherans for example, approach moral decisions with a variety of ethical methodologies that recognize the inherent reality of ambiguity in human affairs and the paradoxical quality of human nature with all its flaws. The Apostle Paul pointed to this reality in his letter to the churches in Rome, “For I do not do the good I want, but the evil I do not want is what I do.” (Romans 7:19) *In a Lutheran ethical approach, there may be room for a discussion concerning the acceptance of medical assistance in dying in some very tragic and highly exceptional circumstances.*

Canada’s new law that restricts access may go further than a possible Lutheran accommodation may allow. Nevertheless, an ethic of accompaniment that recognizes the “ragged border between life and death,” that acknowledges that there may be limits to the effective application of our palliative care practices in some tragic circumstances, and that places a priority on honouring the dignity and life meaning of the dying, may find some small space to accommodate medical assistance in dying. *This is not to suggest that medical assistance in dying is morally right or normally acceptable. It is just to say that assisted dying may not always be evidently wrong.* Medical assistance in dying may, as a last resort, be the lesser of two evils. It may be an imperfect means to claim some final dignity for those suffering intolerably and for whom death is reasonably foreseeable within their wider web of important, meaningful and significant relationships.

Such a proposed accommodation should receive healthy skepticism from the Lutheran community and others. Acceptance of medical assistance in dying in unique circumstances should remain as an ongoing question and the subject of continuing debate and discussion at all levels of the church’s life. Lutherans have recognized the ethical complexity of many difficult issues. For example, Dietrich Bonhoeffer saw this complexity in the question, “What does it mean to tell the truth?” Bonhoeffer argued, “‘telling the truth’ means different things, depending on where one finds oneself. The relevant relationships must be taken into account.”(Bonhoeffer, 2013) Lutherans

have recognized ambiguous complexity on issues of war and state violence. Moral freedom involves not just the freedom to decide but to make ambiguous decisions of right and wrong knowing God's grace offers forgiveness when our freedom results in outcomes that have tragic or unintended consequences. Martin Luther recognized this important very human conundrum. He wrote, in a 1521 letter to his colleague Phillip Melanchthon, "God does not save people who are only fictitious sinners. Be a sinner and sin boldly, but believe and rejoice in Christ even more boldly. For he is victorious over sin, death, and the world." While no one would argue that people should intend to do wrong, nevertheless, at times we do wrong. In other moments "the good" is not always that self-evident.

Clergy as Witnesses for Patient Consent to Assisted Dying

A specific question for pastors and clergy arises when those requesting medical assistance in dying must make the required written request. The request must be signed in the presence of two independent witnesses. The witnesses should be people who will not benefit from the death of the person making the request (e.g. beneficiaries of an estate or insurance claim). Should clergy or members of faith communities, even those opposed to medical assistance in dying, agree to serve as a witness? In some circumstances it may be appropriate particularly if clergy have been a part of the family conversation with the patient. It would seem that an ethic of accompaniment would allow people to serve in that role without forcing them to compromise their own beliefs and convictions. The focus here is to be a companion to the person you are accompanying not to stand in judgment of their decisions.

Proficiency in Ethics and Teaching Ethics

Clearly these are very difficult and complicated ethical questions. Increasing a social ecology of end-of-life care will need people to address the process of doing ethics in these difficult and contested moments. Clergy and lay leaders will need more training in the area of theological ethics, professional ethics and educational pedagogy to better teach ethics within faith communities. Churches need to think about educational programs to help members understand the nature of the making ethical decisions. This is particularly true for religious leaders. More formal programs of education, training and preparation for clergy in the area of end-of-life-care ethics are needed.



Concluding Thoughts

How marvelous it is
To live threatened with Resurrection!
To dream awake,
To keep watch asleep,
To live while dying
And to already know oneself
Resurrected! (Julia Esquivel)

In our consideration here, I have argued that Canada's new law on medical assistance in dying is an acknowledgement that the context for decisions about death has very much changed. The technological borders between life and death have become less clear. The rise of personal autonomy and an individual orientation to dying have driven a political and judicial process. Clearly there is greater personal acceptance of medical assistance in dying and wider public support for the enactment of new laws on assisted death in Canada, across the United States, in Europe and elsewhere. In Canada the courts have determined that some individuals who are suffering intolerably and for whom death is reasonably foreseeable have a Charter right to medical assistance in dying — and before the new law came into effect, courts even granted permission to some individuals who met the criteria.

These social and political developments have raised a wide number of ethical issues for the public and for faith communities. Christians still hold to their belief that death is a gateway to new life because of the “suffering God” who came in the life, death and resurrection of Jesus Christ. However, increasingly the faithful and the wider public still have important questions of meaning that “only the gods can answer.”

Everyone faces certain “life moments” that raise questions of meaning. In the face of this search for meaning in the moments of dying, I have proposed an ethic of accompaniment based on Bruce Jennings's social ecological approach to end-of-life care. This approach offers a neces-

sary framework for governments to approach the emerging and unresolved questions. It also makes clear the responsibility of all levels of government to develop a national end-of-life care strategy that includes a palliative and hospice care plan within which to situate these questions.

Accompanying the dying family member, friend or colleague is a very special, emotional and powerful moment. The Supreme Court has provided a way forward to accompany a very select group whose members face imminent death so their good life might be honoured. Physician-assisted death is an exception under very specific conditions — not a prescription. What is the nature of a good death? It is a question that has, and will, force us all to think differently. Honouring life in the midst of dying unfortunately remains ambiguously messy and confusing.

Faith and spirituality play an important role particularly in these life moments. An ethic of accompaniment provides faith communities a framework to develop an accommodation — if possible — with the reality of legislated access to medically assisted dying in some tragic and exceptional circumstances. Is there a theologically acceptable place for medically assisted death? This debate will continue.

As well, an ethic of accompaniment may help churches and faith communities to determine and evaluate their pastoral practices with those nearing the end of their lives. Does opposition to medically assisted dying prevent someone from accompanying someone who has made that choice? I am not sure it does, nor does it have to.

Churches and faith groups will need to address a number of important and, at times, discomfoting questions. The following summarizes some of these questions. No doubt there will be others that emerge.

1. Given the theological and historic opposition by churches to euthanasia and assisted dying, what are the implications for churches and communities of faith today?
2. Is there a theologically acceptable place of medically assisted death?
3. What is a “good death” in a world where the boundaries between life and death are less clear?
4. How can people of faith maintain respect for human dignity and understand the nature of human suffering in circumstances where medical assistance in dying is a reality and a publicly accepted option for dying patients?
5. How do people in a variety of roles address question of conscience when medical assistance in dying is a right under Canada’s Charter of Rights and Freedoms?
6. How do we understand spiritual care in a pluralistic multi-faith or even no-faith context where meaning is the significant question for people dying today?
7. What are the wider social and government responsibilities necessary to safeguard the dignity and well-being of people in public care?

8. What would a national end-of-life care strategy need to include?

These are questions that will need wider discussion within faith communities among members, within the leadership and those addressing public policy, and for those providing spiritual care.

A good death is about honouring a good life. For Christians and for people of faith, a “good death” is a death after having fully lived a faithful life. For people more generally, it is a life lived with integrity to their ultimate convictions and their deepest held values. It is never a perfect life but rather an honourable one. The *Evangelical Catechism* offers wise practical advice for Christians and others about preparing for the end of our mortal days.

“All life beginning at our Baptism into God’s family is preparing for death. How can we prepare for death?

Preparing for death by;

- use every moment, hour, and every day wisely
- allow time for work, planning, conversation, reflection, play, rest, and sleep
- pay attention to what our conscience tells us
- deal with conflict in a prompt and constructive way
- forgive others and ask them to forgive us
- be willing to part with everything we have for the sake of others
- give thanks for each day that God gives us
- be reminded of the hope of the resurrection of Jesus Christ

(Evangelical catechism, 1982)

In his novel, *My Name is Asher Lev*, Rabbi Chaim Potok tells of a Hasidic Jewish boy in New York City walking down the street with his father. They come across a dead bird by the roadside. “Why do we have to die?” asks young Asher Lev. To which his father responds, “Unless a life can be lost, it is not valued.” (Potok, 2009) If our life went on endlessly, it would lack a sense of meaning and purpose. Years ago the movie *Groundhog Day* made just this point. Every day Bill Murray, playing the movie’s main character, lived that day exactly as he had lived the day before. Over and over again, every day was the same. It was merely a relentless and frustrating repeat of the day before. As we consider the inevitable end of our life, we are called to honour it and to value the gift it has been to us. A good death is about honouring the gift of a good life that has meaning and value for more than just me.



Glossary of Terms

In discussions about assisted dying, there are many terms that are used. The following glossary includes the more precise definition of many key terms. The sources of these definitions are indicated. The Government of Canada's Department of Justice has provided definitions for key terms as intended in Bill C-14. They are also noted.

Advanced state of irreversible decline in capability

(Government of Canada - Department of Justice)

When combined with the requirements that death be reasonably foreseeable and that the person be suffering intolerably, the requirement to be in an advanced state of irreversible decline ensures that medical assistance in dying would be available to those who are in an irreversible decline towards death, even if that death is not anticipated in the short term. This approach to eligibility gives individuals who are in decline toward death the autonomy to choose their preferred dying process.

Advance care planning

(Canadian Medical Association Policy)

A process whereby individuals indicate their treatment goals and preferences with respect to care at the end of life. This can result in a written directive, or advance care plan, also known as a living will.

Advance directives

(Health and Law Institute, Dalhousie University)

Directions given by a competent individual concerning what and/or how and/or by whom decisions should be made in the event that, at some time in the future, the individual becomes incompetent to make health care decisions. An example is a woman who has signed a document that states that, should she fall into a persistent vegetative state, she does not wish to receive artificial hydration or nutrition. Or, as another example, a man who has signed a document that states that, when he is incompetent, he wishes his wife to make all health care decisions on his behalf. There are two kinds of advance directives: "instruction directives" and "proxy directives."

Assisted suicide

(Health and Law Institute, Dalhousie University)

The act of intentionally killing oneself with the assistance of another who provides the knowledge, means, or both.

Common law

(Health and Law Institute, Dalhousie University)

Law developed over the years by judges when making decisions in court. These decisions are relied upon by other judges in making decisions in later cases. This is to be distinguished from acts and regulations.

Competent

(Health and Law Institute, Dalhousie University)

Capable of understanding and appreciating the relevant information as well as the nature and consequences of the decision to be made.

“Dying with dignity”

(Canadian Medical Association Policy)

A death that occurs within the broad parameters set forth by the patient with respect to how they wish to be cared for at the end of life. It is NOT synonymous with euthanasia or physician assisted death.

Euthanasia

(Canadian Medical Association Policy)

Knowingly and intentionally performing an act, with or without consent, that is explicitly intended to end another person's life and that includes the following elements: the subject has an incurable illness; the agent knows about the person's condition; commits the act with the primary intention of ending the life of that person; and the act is undertaken with empathy and compassion and without personal gain.

Grievous and irremediable medical condition

(Government of Canada - Department of Justice definition)

A grievous and irremediable medical condition is defined in the Bill as having all of the following characteristics:

- A serious and incurable illness, disease or disability;
- The person is in an advanced state of irreversible decline in capability;
- The illness, disease, or disability or state of decline causes the person enduring physical or psychological suffering that is intolerable to them and that cannot be relieved in a manner that the person considers acceptable to them; and

- The person's natural death has become reasonably foreseeable due to all of their medical circumstances, without requiring that a prognosis has been made as to the length of time that they have remaining.

Guardian

(Health and Law Institute, Dalhousie University)

An individual with the right and duty of protecting the person, property, or rights of someone who is not mentally capable or is otherwise unable to manage his or her own affairs.

Incompetent

(Health and Law Institute, Dalhousie University)

The characteristic of a person which renders them incapable of understanding and appreciating the relevant information as well as the nature and consequences of the decision to be made.

Independent physicians and nurse practitioners

(Government of Canada - Department of Justice definition)

With respect to the independence of the first medical or nurse practitioner from the second one, the Bill provides that they could not be connected to each other in any way that could impair their objectivity, such as by being in a business or mentoring relationship with each other. They would also need to be independent of the patient, in the sense that they could not be a beneficiary under his or her will, or be otherwise connected to the patient in a manner that could affect their objectivity.

Independent witness

(Government of Canada - Department of Justice definition)

An independent witness would be a person who would not be a beneficiary under the patient's will or otherwise benefit from their death. Persons responsible for the patient's personal care, the health care treatment team and those responsible for any facility where the patient resides or is being treated, would also not be considered independent witnesses. A family member could witness a patient's request if none of these circumstances apply to them.

Informed consent

(Government of Canada - Department of Justice definition)

Informed consent is a medical term that means that a person has consented to a particular medical treatment after having been given all of the information they need to make that health care decision. Information that is necessary to be provided includes their diagnosis, their prognosis, available forms of treatment and the benefits and side-effects of those treatments. It also requires that the person be mentally competent or capable, i.e., that they be able to understand the relevant information and the consequences of their choices.

Informed consent

(Health and Law Institute, Dalhousie University)

The consent of a patient or a patient's substitute decision-maker after being fully informed by the health care provider of the treatment options for the condition including known effects, material risks, discomforts, and side-effects of different methods of treatment and the likelihood of their occurrence; success and failure rates of different methods of treatment; alternative goals of treatment, and reasonably accessible alternative treatment means of pursuing such goals; and the prognosis if the patient remains untreated.

Injunction

(Health and Law Institute, Dalhousie University)

A court order for the purpose of requiring a party to refrain from doing a particular act or thing. A preventive measure, an injunction guards against future injuries rather than affording a remedy for past injuries.

Instruction directive

(Health and Law Institute, Dalhousie University)

An advance directive that establishes what decisions are to be made on behalf of an incompetent individual.

Legislation

(Health and Law Institute, Dalhousie University)

Law made by elected members of government, also referred to as "statute" or "Act."

Mature minors

(Government of Canada - Department of Justice definition)

Minors (below 18 or 19 depending on applicable provincial laws) who have the intellectual capacity and maturity to understand the information relevant to their medical decision and appreciate the consequences of such decision.

Medical aid in dying (MAID)

(Canadian Medical Association Policy)

A situation whereby a physician intentionally participates in the death of a patient by directly administering the substance themselves, or by providing the means whereby a patient can self-administer a substance leading to their death.

Mentally competent or capable

(Government of Canada - Department of Justice definition)

A person is mentally competent or capable when they have the capacity to understand the nature and consequences of their actions and choices, including decisions related to medical care and treatments.

Nonmaleficence

The refraining from inflicting harm on others. In the history of Western Hippocratic medicine, the duty of nonmaleficence has found popular expression in the maxim *primum non nocere* (“first, or above all, do no harm”), widely considered to be the most fundamental moral obligation of health care. The moral obligation of nonmaleficence entails a negative obligation – to not inflict harm – that is often seen as the complementary converse of the obligation entailed by the principle of beneficence – to do good for the other. There has been considerable debate about where the negative duty of nonmaleficence ends and the positive duty of beneficence begins, especially because the former duty has been regarded by most Western societies (at least since the Enlightenment) as prior and clearly obligatory.

Nurse practitioner

(Government of Canada - Department of Justice definition)

Nurse practitioners have the authority to deliver many of the same medical services as family physicians; they can assess, diagnose, prescribe and treat patients. They can act independently in every jurisdiction except Quebec, where they practice under the authority of a physician.

Official guardian

(Health and Law Institute, Dalhousie University)

A government office that may be appointed to, among other matters, act as guardian of an adult who is found unable to manage his or her own affairs. Also referred to as “public trustee” in some jurisdictions or “curator” in Quebec.

Palliative care

(Canadian Medical Association Policy)

An approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification, assessment and treatment of pain and other symptoms, physical, psychosocial and spiritual.

WHO Definition of Palliative Care

(United Nations World Health Organization)

Palliative care is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment

and treatment of pain and other problems, physical, psychosocial and spiritual. Palliative care:

- provides relief from pain and other distressing symptoms;
- affirms life and regards dying as a normal process;
- intends neither to hasten or postpone death;
- integrates the psychological and spiritual aspects of patient care;
- offers a support system to help patients live as actively as possible until death;
- offers a support system to help the family cope during the patients illness and in their own bereavement;
- uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated;
- will enhance quality of life, and may also positively influence the course of illness;
- is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications.
-

WHO Definition of Palliative Care for Children

(United Nations World Health Organization)

Palliative care for children represents a special, albeit closely related field to adult palliative care. WHO's definition of palliative care appropriate for children and their families is as follows; the principles apply to other pediatric chronic disorders (WHO; 1998a):

- Palliative care for children is the active total care of the child's body, mind and spirit, and also involves giving support to the family.
- It begins when illness is diagnosed, and continues regardless of whether or not a child receives treatment directed at the disease.
- Health providers must evaluate and alleviate a child's physical, psychological, and social distress.
- Effective palliative care requires a broad multidisciplinary approach that includes the family and makes use of available community resources; it can be successfully implemented even if resources are limited.
- It can be provided in tertiary care facilities, in community health centres and even in children's homes.

Palliative interventions

(Health and Law Institute, Dalhousie University)

Palliative interventions aim to relieve suffering and improve quality of life for those who are living with or dying from an illness.

Palliative sedation

(Canadian Medical Association Policy)

The use of sedative medications for patients who are terminally ill with the intent of alleviating suffering and the management of symptoms. The intent is not to hasten death although this may be a foreseeable but unintended consequence of the use of such medications. This is NOT euthanasia or physician assisted death.

Parens patriae

(Health and Law Institute, Dalhousie University)

Literally “parent of the country”, parens patriae is the authority of the court to act on behalf of those people perceived to be unable to manage their own affairs.

Physician assisted death (PAD)

(Canadian Medical Association Policy)

A physician knowingly and intentionally provides a person with the knowledge or means or both required to end their own lives, including counselling about lethal doses of drugs, prescribing such lethal doses or supplying the drugs. This is sometimes referred to as physician assisted suicide.

Euthanasia and physician assisted death are often regarded as morally equivalent, although there is a clear practical distinction, as well as a legal distinction, between them.

Physician-assisted suicide

(Government of Canada - Department of Justice)

Where a physician or nurse practitioner gives or prescribes to a person a substance that they can self-administer to cause their own death.

Principle of double effect

(A Handbook of Bioethics Terms, James Tubbs, Jr.)

“A guide for moral reasoning in Catholic moral theology often attributed to Thomas Aquinas. It seeks to explain those circumstances in which it is morally acceptable to perform an action that will predictably lead to a desired good consequence or a effect even though it will also predictably result in an evil consequence or effect (hence the designation “double effect”). Four conditions are generally applied to justify such an action. First, the action itself must be morally good or at least morally neutral (i.e. not intrinsically evil). Second, only the good effect must be morally intended, even though the evil effect may be foreseen. Third, the intended good effect must result directly from the action in question; it must not result from the unintended evil effect. In other words, the evil effect must not be directly produced to then yield the good effect. And fourth, there must be proportionality between the good and the evil effects - that is, the

evil must be outweighed by the good and the predicted outcome....In recent decades some Catholic moral theologians have suggested that the real heart of the double effect doctrine lies not so much in the question of whether the good and evil effects are directly or indirectly intended but rather in the proportionality between good and evil effects (and thus ‘proportionate reason’ for the action in question.)”

Proxy

(Health and Law Institute, Dalhousie University)

A person appointed to make health care decisions on behalf of someone else. One kind of “substitute decision-maker.”

Proxy directive

(Health and Law Institute, Dalhousie University)

An advance directive that establishes who is to make decisions on behalf of an incompetent individual.

Public trustee

(Health and Law Institute, Dalhousie University)

A government office that may be appointed to, among other matters, act as guardian of an adult who is found unable to manage his or her own affairs. Also referred to as “official guardian” in some jurisdictions or “curator” in Quebec.

Reasonably foreseeable death

(Government of Canada - Department of Justice)

"Natural death has become reasonably foreseeable" means that there is a real possibility of the patient's death within a period of time that is not too remote. In other words, the patient would need to experience a change in the state of their medical condition so that it has become fairly clear that they are on an irreversible path toward death, even if there is no clear or specific prognosis. Each person's circumstances are unique, and life expectancy depends on a number of factors, such as the nature of the illness, and the impacts of other medical conditions or health-related factors such as age or frailty. Physicians and nurse practitioners have the necessary expertise to evaluate each person's unique circumstances and can effectively judge when a person is on a trajectory toward death. While medical professionals do not need to be able to clearly predict exactly how or when a person will die, the person's death would need to be foreseeable in the not too distant future.

In terms of the Carter decision, the concept of reasonable foreseeable death is consistent with the factual circumstances of Carter and persons in the situation of Ms. Taylor and Ms. Carter i.e., taking into account all of the patient's medical circumstances, they were on an irreversible trajectory toward death. In all of the medical circumstances of the person, it is fairly clear to the medical practitioner/nurse practitioner (and the second confirming practitioner) that the person is on an irreversible trajectory toward death, even if the practitioner cannot give a specific period of time for the prognosis.

Reciprocity protocol

(Health and Law Institute, Dalhousie University)

A system by which a province or territory recognizes legal documents made in other provinces and territories.

Spiritual Care

Pastoral care traces its origins to the ministry of the pastor in the “cure of perplexed and disturbed souls.” In more recent times there has been an important recognition of the important contribution of psychology and psychiatry to the care and counselling done by clergy. With the arrival of multi-faith and pluralism, the term “pastoral,” which has decidedly Christian accents, has given way to the use of the term “spiritual care.” “Spiritual care” for me, “involves ‘creating a safe space where we can encounter the essential truth about our selves.’” These essential truths are the ones that hold meaning for us and connect us to a web of relationships that define who we are, what we are called to do, and the destination of our mortal life. In more recent times spiritual care has evolved to “spiritual care and psychotherapy” that tries to bridge the historic theological pastoral care approach, the cross disciplinary with psychology/psychiatry and the expectation of public oversight that requires professional certification to allow counsellors to serve the general public.

Substitute decision-maker

(Health and Law Institute, Dalhousie University)

A person appointed to make health care decisions on behalf of someone else. A substitute decision-maker can be appointed by statute or by an advance directive.

Statute

(Health and Law Institute, Dalhousie University)

Law made by elected members of government, also referred to as “legislation” or “Act.”

Terminal sedation

(Health and Law Institute, Dalhousie University)

The practice of combining total sedation with the withholding or withdrawal of artificial hydration and nutrition.

Total sedation

(Health and Law Institute, Dalhousie University)

The practice of rendering a person totally unconscious through the administration of drugs without potentially shortening life.

Unilateral

(Health and Law Institute, Dalhousie University)

Without the knowledge or against the wishes of a patient or patient's substitute decision-maker.

Voluntary euthanasia

(Government of Canada - Department of Justice definition)

Where a physician or nurse practitioner directly administers a substance that causes the death of the person who has requested it.

Withholding of potentially life-sustaining treatment

(Health and Law Institute, Dalhousie University)

Not starting treatment that has the potential to sustain the life of a patient.

Withdrawal of potentially life-sustaining treatment

(Health and Law Institute, Dalhousie University)

Stopping treatment that has the potential to sustain the life of a patient.



Bibliography

2016, L. J. A. (2016, April 1). Crossing Over: How Science Is Redefining Life and Death. Retrieved July 17, 2016, from <http://www.nationalgeographic.com/magazine/2016/04/dying-death-brain-dead-body-consciousness-science/>

A Report by the Economist Intelligence Unity. (2015). The 2015 Quality of Death Index - Ranking palliative care across the world. London, United Kingdom. Retrieved from <https://www.eiuperspectives.economist.com/sites/default/files/2015%20EIU%20Quality%20of%20Death%20Index%20Oct%2029%20FINAL.pdf>

Andre Picard. (2002, May 28). Death rate 2% higher in for-profit hospitals- At least 2,200 more Canadians would die if U.S. system were adopted, study says. The Globe and Mail. Toronto, Ontario.

Approved at the Sixth Biennial Convention of the Evangelical Lutheran Church in Canada. An ELCIC Resolution on Decisions-At-The-End-of-Life.

Assisted death grounds to refuse Christian funeral, bishops say. (2016, September 29). Retrieved October 4, 2016, from <http://www.theglobeandmail.com/news/national/assisted-death-grounds-to-refuse-christian-funeral-bishops-say/article32159903/>

Assisted Suicide A Necessarily imperfect right. (2015, December 19). The Globe and Mail. Toronto, Ontario.

Assisted suicide: Where do Canada, other countries stand? (n.d.). Retrieved July 27, 2016, from <http://www.cbc.ca/news/canada/assisted-suicide-where-do-canada-other-countries-stand-1.2795041>

Augustine, S. (1960). The Confessions of Saint Augustine (Image Books ed edition). New York: Image.

Bonhoeffer, D. (1985). Spiritual care. Philadelphia: Fortress Press.

Bonhoeffer, D. (2013). What Does It Mean to Tell the Truth? In C. J. Green & Michael P. DeJonge (Eds.), *The Bonhoeffer reader*. Minneapolis: Fortress Press.

Bruce Jennings. (2012). From Rights to Relationships: The Ecological Turn in Ethics Near the End of Life. In Kenneth J Doka, Amy Tucci, Charles Corr, and Bruce Jennings (Ed.), *End of Life Ethics: A Case Approach* (pp. 3–22). Washington, D.C.: Hospice Foundation of America.

Cardus-Pallium Roundtable on Palliative Care. (2016). Ottawa, Ontario.

Carter, S. L. (1998). *The dissent of the governed: a meditation on law, religion, and loyalty*. Cambridge, Mass: Harvard University Press.

Carter v. Canada (Attorney General) - SCC Cases (Lexum). (2015, February 6). Retrieved July 27, 2016, from <http://scc-csc.lexum.com/scc-csc/scc-csc/en/item/14637/index.do>

Church report accepts physician-assisted dying as new reality. (2016, June 10). Retrieved August 1, 2016, from <http://cep.anglican.ca/church-report-accepts-physician-assisted-dying-new-reality/>

CMA POLICY SUMMARY - CMA_Policy_Euthanasia_Assisted Death_PD15-02-e.pdf. (n.d.). Retrieved from https://www.cma.ca/Assets/assets-library/document/en/advocacy/EOL/CMA_Policy_Euthanasia_Assisted%20Death_PD15-02-e.pdf

Community of Protestant Churches in Europe. (2011). *A Time to Live, A Time to Die - An aid to orientation of the Community of Protestant Church in Europe on Death-hastening Decisions and Caring for the Dying*. Vienna, Austria.

Division for Church in Society. *A Message on End-of-Life Decisions* (1992).

Dr. Johannes Georg Walch (Ed.). (n.d.). Let Your Sins Be Strong: A Letter from Luther to Melancthon No. 99, 1 August 1521 From Wartburg Segment. In Erika Bullmann Flores (Trans.), *Dr. Martin Luther's Saemmtliche Schriften* (Vol. Vol. 15, cols. 2585-2590). St. Louis: Concordia Publishing House, N.D. Retrieved from <http://www.scrollpublishing.com/store/Luther-Sin-Boldly.html>

Dr. Kenneth Doka. (2015, January). *End of Life Ethics - an Ecological Approach*. Presented at the Lutheran Ethicist's Gathering, Chicago, Ill.

DuBose, E. R. (1999). *Physician Assisted Suicide: Religious and Public Policy Perspectives*. Chicago, Ill.: Park Ridge Center.

EFC_Euthanasia_overview_postmortem.pdf. (n.d.). Retrieved from http://files.efc-canada.net/si/Euthanasia/EFC_Euthanasia_overview_postmortem.pdf

Elizabeth Church. (2016, January 12). Canadians lack proper access to palliative care, study finds. The Globe and Mail. Retrieved from http://license.icopyright.net/rights/printServiceGroup.act?tag=3.8425?icx_id=28122378

End of Life Law & Policy in Canada Dalhousie University. (n.d.). Glossary from Dalhousie University Health Law Institute. Retrieved from http://eol.law.dal.ca/?page_id=216

Erin Andersen. (2011, November 27). Why are we afraid of talking about death? Retrieved July 24, 2016, from <http://www.theglobeandmail.com/life/health-and-fitness/why-are-we-afraid-of-talking-about-death/article534582/>

Esquivel, J. (1982). Threatened with resurrection: prayers and poems from an exiled Guatemalan = Amenazado de resurreccion. Elgin, Ill: Brethren Press.

Evangelical catechism: Christian faith in the world today. (1982) (American ed). Minneapolis: Augsburg Pub. House.

Fact Sheet: Hospice Palliative Care in Canada. (2014, March). Canadian Hospice Palliative Care Association. Retrieved from http://www.chpca.net/media/330558/Fact_Sheet_HPC_in_Canada%20Spring%202014%20Final.pdf

Government of Canada, D. of J. (2016, April 14). Medical Assistance in Dying - Questions and Answers. Retrieved July 22, 2016, from <http://www.justice.gc.ca/eng/cj-jp/ad-am/faq.html>

Government of Canada, H. C. (2004, September 21). Romanow Commission - Health Human Resources Strategy - Health Canada. Retrieved July 22, 2016, from <http://hc-sc.gc.ca/hcs-sss/hhr-rhs/strateg/romanow-eng.php>

Government of Canada, H. C. and the P. health A. of C. (2016a, February 25). Options and decision making at end of life. Retrieved July 22, 2016, from <http://healthycanadians.gc.ca/health-system-systeme-sante/services/palliative-pallatifs/options-decision-making-end-life-options-prise-decisions-fin-vie-eng.php>

Government of Canada, H. C. and the P. health A. of C. (2016b, February 25). Palliative care. Retrieved July 22, 2016, from <http://healthycanadians.gc.ca/health-system-systeme-sante/services/palliative-pallatifs/palliative-care-soins-palliatifs-eng.php>

Government of Canada, H. C. and the P. health A. of C. (2016c, June 16). Medical assistance in dying. Retrieved July 22, 2016, from <http://healthycanadians.gc.ca/health-system-systeme-sante/services/palliative-pallatifs/medical-assistance-dying-aide-medicale-mourir-eng.php>

Government tables doctor-assisted dying bill, sets minimum age at 18. (n.d.). Retrieved from <http://ipolitics.ca/2016/04/14/assisted-dying-bill-sets-minimum-age-limit-at-18/>

Hall, D. J. (1986). *God and human suffering: an exercise in the theology of the cross*. Minneapolis: Augsburg Pub. House.

House Government Bill - Bill C-14 - Third Reading (42-1) as passed. (2016, May 31). Retrieved August 17, 2016, from <http://www.parl.gc.ca/HousePublications/Publication.aspx?DocId=8309978>

Jack Coulehan. (2013). *Suffering, Hope and Healing*. In Rhonda J. Moore (Ed.), *Handbook of Pain and Palliative Care: Biobehavioral Approaches for Life Care*. New York, N.Y.: Springer Science+Business Media. Retrieved from www.stonybrook.edu/bioethics/SufferingHopeHealing.pdf

Joseph J. Kotva Jr. (2016). *Dying in Oregon A critical look at 'death with dignity'*. *Christian Century*, 28–31.

Julia Nicol, Marlisa Tiedermann, Dominique Valiquet. (n.d.). *Euthanasia and Assisted Suicide: International Experiences* [Government of Canada]. Retrieved July 27, 2016, from <http://www.lop.parl.gc.ca/content/lop/ResearchPublications/2011-67-e.htm?cat=social>

Kilner, J. F., Miller, A. B., Pellegrino, E. D., & Center for Bioethics and Human Dignity (Eds.). (1996). *The Center for Bioethics and Human Dignity presents Dignity and dying: a Christian appraisal*. [Carlisle, U.K.] : Grand Rapids, Mich: Paternoster Press ; W.B. Eerdmans Pub. Co.

Kirkey, S. (n.d.). Ontario hospitals allowed to opt out of assisted dying, raising conscientious accommodation concerns. Retrieved August 17, 2016, from <http://www.montrealgazette.com/health/ontario+hospitals+allowed+assisted+dying+raising+conscientious/11979180/story.html>

McIntyre, A. (2014). *Doctrine of Double Effect*. In E. N. Zalta (Ed.), *The Stanford Encyclopedia of Philosophy* (Winter 2014). Retrieved from <http://plato.stanford.edu/archives/win2014/entries/double-effect/>

Most (84%) Canadians Believe a Doctor Should be Able to Assist Someone Who is Terminally Ill and Suffering Unbearably to End their Life | Ipsos. (n.d.). Retrieved August 3, 2016, from <http://ipsos-na.com/news-polls/pressrelease.aspx?id=6626>

Palliative Care | Hospice Care | Palliative Care Canada | Elder Care. (n.d.). Retrieved July 24, 2016, from <http://www.chpca.net/>

Pallium Canada. (n.d.). Retrieved from <http://pallium.ca/>

Parliamentary Joint Committees - PDAM (42-1) - *Medical Assistance in Dying: A Patient-Centred Approach - Report 1 - Medical Assistance in Dying: A Patient-Centred Approach*. (2016, February). Retrieved August 4, 2016, from <http://www.parl.gc.ca/HousePublications/Publication.aspx?DocId=8120006>

Potok, C. (2009). *My Name Is Asher Lev*. Knopf Doubleday Publishing Group.

Reginald W. Bibby. (2012). *A New Day The Resilience and Restructuring of Religion in Canada*. Lethbridge, Alberta: Project Canada Books.

Reinis, A. (n.d.). Luther, Linck, and Later Lutherans on Pastoral Care to the Sick and Dying. Retrieved July 17, 2016, from <http://www.elca.org/JLE/Articles/1086>

St. Augustine of Hippo. (397AD). *Confessions*.

Street, 1615 L., NW, Washington, S. 800, & Inquiries, D. 20036 202 419 4300 | M. 202 419 4349 | F. 202 419 4372 | M. (2006, January 5). Strong Public Support for Right to Die. Retrieved from <http://www.people-press.org/2006/01/05/strong-public-support-for-right-to-die/>

Submission on Physician-Assisted Dying - submission-physician-assisted-dying.pdf. (n.d.). Retrieved from <http://www.united-church.ca/sites/default/files/submission-physician-assisted-dying.pdf>

Support for assisted suicide increases across four years. (n.d.). Retrieved August 3, 2016, from <http://poll.forumresearch.com/post/1365/opposition-down-sharply/>

Susan C Karant-Nunn. (1997). *The Reformation of ritual: an interpretation of early modern Germany*. New York, N.Y.: Routledge.

Taskforce on Physician Assisted Dying. (2016). In *Sure and Certain Hope Resources to Assist Pastoral and Theological Approaches to Physician Assisted Dying (Faith, Worship and Ministry)*. The General Synod of the Anglican Church of Canada. Retrieved from <http://www.anglican.ca/wp-content/uploads/In-Sure-and-Certain-Hope.pdf>

Theo A. Boer. (2016). Rushing Toward Death? Assisted Dying in the Netherlands. *Christian Century*, 24–27.

Thomas Cardina Collins, Archbishop of Toronto. (2016, March 1). Statement from Cardinal Thomas Collins concerning Euthanasia/Assisted Suicide.

Victor Fankl. (1971). *Man's Search for Meaning: An Introduction to Logo Therapy (A Washington Square Press Edition)*. New York, New York: Simon and Schuster.

Warnes, S. (2014, July 18). How many people choose assisted suicide where it is legal? *The Guardian*. Retrieved from <https://www.theguardian.com/news/datablog/2014/jul/18/how-many-people-choose-assisted-suicide-where-it-is-legal>

WHO | WHO Definition of Palliative Care. (n.d.). Retrieved July 24, 2016, from <http://www.who.int/cancer/palliative/definition/en/>

Wiesel, E. (2008). *The Night Trilogy: Night, Dawn, Day*. New York: Hill and Wang.



ELCIC Resolution on End-of-Life Decisions

The Evangelical Lutheran Church in Canada adopted the following resolution at its Sixth Biennial Convention, July 23-27, 1997

MS That the Evangelical Lutheran Church in Canada affirm the following guidelines for assisting persons who are facing the reality of dealing with the often tragic and dehumanizing consequences of a terminal illness or trauma. Therefore we;

- support all appropriate efforts to provide palliative and hospice care to individuals who are experiencing tragic or dehumanizing consequences of a terminal illness or trauma.
- support one another as a caring community which reaches out to those who stand in need in times of death and dying. We support others in the caring community who reach out to those who stand in need in time of dying. In these circumstances Christians are called on to provide assurance of the ever present reality of God's love by providing spiritual care for those both inside and outside the community of the church, helping relieve the pain of suffering, promoting a spirit of compassion and giving comfort to physical needs.
- are not called on to pursue every medical treatment available in every circumstance. When Christians are called on to assist in treatment decisions, it is helpful to assess the recommended intervention in terms of specific purpose and its estimated degree of efficacy. When a treatment will not help improve a patient's underlying condition, will not provide palliative assistance to the patient, or will not prevent death from occurring from that condition, then such treatment need not be supported or continued. Christians should support the full disclosure to those called on to help make treatment decisions, of the pertinent facts of a patient's condition and the effects of all treatments considered.
- do not support the legalization of "physician assisted" death or "mercy killing" in which the purpose of medical treatment or private action is the deliberate taking of a life which has been created in God's image. Such action would too easily allow persons to take advantage of those most vulnerable. Nevertheless, Christians should feel free to support in an ambiguous situation, appropriate medical treatment whose primary purpose is palliative care or which seeks to address a patient's underlying condition, but which may also have life undermining side-effects.

- should seek to provide support and guidance to family, friends, and health care professionals about what treatment and care they would want for the patient in circumstances where the patient may be unable to communicate. Christians should not support any treatment given without the consent of a patient, or if that is not possible, without the witnessed consent of those who have been given authority to speak on behalf of the patient.

- encourage individuals to empower and help alleviate potential guilt of family and friends who may have to make treatment decisions on behalf of the patient by discussing and documenting treatment wishes and the values that inform these wishes.

BACKGROUND INFORMATION

Modern medical science has made remarkable advances in the later half of the twentieth century. These advances have enabled persons to live fuller and longer lives than ever before. Many diseases previously thought to be uncontrollable, have become manageable. Genetic disorders never before diagnosed have been more successfully identified for treatment. The ability to sustain life in the face of life threatening trauma has been dramatically increased.

While this has been a blessing for many, it has also confronted others with a sometimes tragic and dehumanizing prolonged context for dying. Persons facing the ravages of the advanced terminal stages of diseases often find themselves confronting a painful, self negating, radically degenerative future and death, which can be unduly prolonged by the ability of science to simply keep persons alive. It is in such situations, that cut people off from meaningful relationships and rob them of their ability to have any significant input into decisions about their treatment, that individuals find their humanity most undermined.

It is this agonizing reality which has prompted recent proposals by some in Canada, to permit such individuals to obtain, legally, the help of physicians and/or friends in bringing their life to an end. This is a practice often referred to as "mercy killing", "physician assisted death", or "euthanasia". Currently such help cannot be legally given in Canada.

In the face of these proposals and the reality they point to, persons are now seeking to discern what policies and practices might best serve the human dignity of persons who are dying, and when must one draw the line against actions that are morally unacceptable. Should the laws be changed or not? And if so, how far should they go? If not, how should they be more humanely applied? As concerned Christians, how should individuals respond to these proposals and the agonizing reality to which they point? Are there guidelines which Christians can turn to which through prayer and careful reflection will help them address these concerns?

CHRISTIAN CONVICTIONS:

A foundation for Christian guidelines in the matter of euthanasia can be found in the Lutheran Social Statement On Death and Dying adopted by the ELCIC from one of its predecessor bodies. From that document certain affirmations and insights can be drawn which are helpful to

our Christian reflection on issues regarding death, dying, and euthanasia. These affirmations and insights include:

The recognition that as Christians we are part of a caring community; a part of the web of human relations we call friends and family, a part of a faith family we call the church; a part of the body of Christ through baptism.

The recognition that God has created us in God's image and given each of us the gift of life. As Christians we are called on to be thankful stewards of this gift for the well being of all creation, including ourselves. In light of this, as a church, we have affirmed that, deliberately destroying life created in the image of God is contrary to the Christian conscience (p. 6 On Death and Dying).

The recognition that life in its full Biblical sense includes equally an affirmation of both the biological and the relationship dimension of our being. These two dimensions form an interdependent whole. Quality of life and maintenance of life must both be a concern of Christians.

The recognition that out of respect for all persons as created in God's image, the carefully and prayerfully considered decisions of individuals regarding their medical treatment needs to be given serious and appropriate recognition. To best make such decisions individuals need to be provided full and accurate pertinent information about the underlying condition to be treated and about the effects of the treatment.

The recognition that God is present for all through the Resurrection faith of the church, giving hope and meaning through all the dimensions of the life process. This life process includes death and dying (Romans 14:7-10).



A Message on End-of-Life Decisions

This Message was by the Church Council of the Evangelical Lutheran Church in America (ELCA) on November 9, 1992. The is a church partner to the Evangelical Lutheran Church in Canada (ELCIC)

With this message, the Church Council of the Evangelical Lutheran Church in America, upon the recommendation of the Division for Church in Society, addresses some timely aspects of end-of-life situations and encourages further deliberation on the topic throughout this church. This message does not deal with the full scope of these complex matters. It draws upon a relevant social statement, “Death and Dying,” of a predecessor church body as basis for the guidance it offers.¹

THE OCCASION

An elderly woman contemplates in terror the possibility that she might be kept alive for months by means of life-support systems. A son visits a nursing home weekly to see his 95 year-old mother, who is stricken with Parkinson’s disease and who wants to die. Family and friends share the slow, anguishing death of a young man with AIDS. Parents agonize with their pastor over what to do about their daughter who survives in a persistent vegetative state after a car accident.

Increasingly, people know from their own experience similar painful dilemmas. While the achievements of modern medicine have been used to prolong and enhance life for many, they have also helped create an often dreaded context for dying. Costly technology may keep persons alive, but frequently these persons are cut off from meaningful relationships with others and exist with little or no hope for recovery. Many fearfully imagine a situation at the end of their lives where they or their trusted ones will have no say in decisions about their treatment.

In this context, new emphasis is being placed on the rights of patients. Recent federal legislation, for example, requires all health care facilities receiving Medicare or Medicaid monies to inform patients of their right to make medical treatment decisions. This includes the right to specify “advance directives,”² which state what patients wish to be done in case they are no longer able to communicate adequately.

We consider the legislation consistent with the principle that “respect for that person [who is capable of participating] mandates that he or she be recognized as the prime decision-maker” in treatment.³ The patient is a person in relationship, not an isolated individual. Her or his decisions should take others into account and be made in supportive consultation with family

members, close friends, pastor, and health care professionals. Christians face end-of-life decisions in all their ambiguity, knowing we are responsible ultimately to God, whose grace comforts, forgives, and frees us in our dilemmas.

Which decisions about dying are morally acceptable to concerned Christians, and which ones go beyond morally acceptable limits? Which medical practices and public policies allow for more humane treatment for those who are dying, and which ones open the door to abuse and the violation of human dignity? Proposals in various states to legalize physician-assisted death⁴ point to renewed interest in these old questions. ELCA members, congregations, and institutions need to address these questions through prayer and careful reflection.

A CHRISTIAN PERSPECTIVE

Our faith as Christians informs and guides us in approaching personal and public decisions about death and dying today. Among the convictions that orient us are:

- life is a gift from God, to be received with thanksgiving;
- the integrity of the life processes which God has created should be respected;
- both birth and death are part of these life processes;
- both living and dying should occur within a caring community;
- a Christian perspective mandates respect for each person; such respect
- includes giving due recognition to each person's carefully considered preferences regarding treatment decisions;
- truthfulness and faithfulness in our relations with others are essential to the texture of human life;
- and, hope and meaning in life are possible even in times of suffering and adversity a truth powerfully proclaimed in the resurrection faith of the church.⁵

“Whether we live or whether we die, we are the Lord’s” (Romans 14:8). For those who live with this confidence, neither life nor death are absolute. We treasure God’s gift of life; we also prepare ourselves for a time when we may let go of our lives, entrusting our future to the crucified and risen Christ who is “Lord of both the dead and the living” (Romans 14:9).

While these convictions do not give clear-cut answers to all end-of-life decisions, they do offer a basic approach to them.

ALLOWING DEATH AND TAKING LIFE

Withholding or Withdrawing Artificially-administered Nutrition and Hydration

Patients who once would have died because of their inability to take food and water by mouth can today be kept alive through artificially-administered nutrition and hydration. These measures are often temporary and allow many to recover health. At other times, however, they alone maintain life, and they may do so indefinitely. In those cases, is it ever morally permissible to withhold or withdraw such measures?

Food and water are part of basic human care. Artificially-administered nutrition and hydration move beyond basic care to become medical treatment. Health care professionals are not required to use all available medical treatment in all circumstances. Medical treatment may be limited in some instances, and death allowed to occur. Patients have a right to refuse unduly burdensome treatments which are disproportionate to the expected benefits.

When medical judgment determines that artificially-administered nutrition and hydration will not contribute to an improvement in the patient's underlying condition or prevent death from that condition, patients or their legal spokespersons may consider them unduly burdensome treatment. In these circumstances it may be morally responsible to withhold or withdraw them and allow death to occur. This decision does not mean that family and friends are abandoning their loved one.

When artificially-administered nutrition and hydration are withheld or withdrawn, family, friends, health care professionals, and pastor should continue to care for the person. They are to provide relief from suffering, physical comfort, and assurance of God's enduring love.

Refusal of Beneficial Treatment

Patients and health care professionals share a common concern that medical treatment be beneficial. In most situations, they have a common understanding of that benefit. When agreement exists, patients generally are willing to receive treatment. There are situations, however, when patients and health care professionals disagree on what will benefit the patient, or on whether the expected benefit is worth the risks and burdens involved. What is morally responsible in these situations?

Because competent patients are the prime decision-makers, they may refuse treatment recommended by health care professionals when they do not believe the benefits outweigh the risks and burdens. This is also the case for patients who are incompetent, but who have identified their wishes through advance directives, living wills, and/or conversation with family or designated surrogates.

Health care professionals are obligated to inform patients of medical treatment options and what in their best judgment are the potential benefits and burdens of such options. They are also obligated to obtain the consent of patients to provide treatment. Where this consent is not given, they should accept the desired limits of treatment, even when they do not agree with the decision.

A patient's refusal of beneficial treatment does not free health care professionals from the obligation to give basic human care and comfort throughout the dying process which may follow. Family, friends, and pastor need to accompany the person and share the promise of God's faithfulness in life and death.

Physician-Assisted Death

An emphasis on patients' rights, a health care system often unable to respond adequately to catastrophic illness, and the emergence of disease processes (such as AIDS and Alzheimer's disease) that threaten dramatic loss of human capacities are a few of the realities that have converged to create an environment where some patients ask that their life be ended. Is it ever morally permissible for a physician deliberately to act or authorize an action to terminate the life of a patient?

The integrity of the physician-patient relationship is rooted in trust that physicians will act to preserve the life and health of the patient. Physicians and other health care professionals also have responsibility to relieve suffering. This responsibility includes the aggressive management of pain, even when it may result in an earlier death.

However, the deliberate action of a physician to take the life of a patient, even when this is the patient's wish, is a different matter. As a church we affirm that deliberately destroying life created in the image of God is contrary to our Christian conscience.⁶ While this affirmation is clear, we also recognize that responsible health care professionals struggle to choose the lesser evil in ambiguous borderline situations—for example, when pain becomes so unmanageable that life is indistinguishable from torture.

We oppose the legalization of physician-assisted death, which would allow the private killing of one person by another. Public control and regulation of such actions would be extremely difficult, if not impossible. The potential for abuse, especially of people who are most vulnerable, would be substantially increased.

Caring treatment that allows death to occur within the bounds of what is morally acceptable may help reduce the appeal of physician-assisted death. Hospice care offers promise of more humane treatment at the end of life. A more equitable health care system that more effectively responds to catastrophic illness and provides the needed follow-up care should also be a priority for those concerned about end-of-life decisions.

MINISTRY IN PREPARATION FOR THE END OF LIFE

Advance directives are welcome means to foster responsible decisions at the end of life. Yet people are often overwhelmed and frightened when thinking about medical treatment and legal possibilities, and therefore do not take steps to prepare for the end of their lives. People recognize their rights as patients but at the same time feel unprepared to take on the responsibility.

Communities of faith should, can, and often do provide holistic ministry to prepare people for end-of-life decisions. Pastors can help people to deal with their fears and hopes. Congregations can offer opportunities for conversation and deliberation about the end of life. They can invite hospital chaplains, hospice care-givers, social workers, attorneys, or others knowledgeable about advance directives to help them consider the topic's many dimensions.

Church related hospitals, nursing homes, and other social ministry organizations are also encouraged to provide for continuing conversation and deliberation about their ministry at the end of life. The staff of these organizations need to understand the ethical principles that are to guide the care they provide. Ethics committees can play an important role in dealing with unresolved conflicts about treatment decisions.

We rejoice in the faithful and compassionate congregations, pastors, health care professionals, and church institutions who minister with persons who are dying and their families and friends. We give thanks for family and friends who minister to their loved ones. In the midst of often agonizing end-of-life decisions, we are reminded of the God-given mystery of both life and death. May the Holy Spirit grant to us all loving wisdom and confident hope in the Gospel's promise of eternal life.

ENDNOTES TO ELCA MESSAGE

1. The social statement, “Death and Dying,” was adopted in 1982 by the Lutheran Church in America. In 1977 The American Lutheran Church developed an analysis paper, “Death and Dying,” which was not an actual social statement, but also provides background for this message. Both are available from the ELCA Distribution Service.
2. “Advance directives” commonly include designation of a durable power of attorney, living wills, and an advance directive form. The exact meaning, however, may vary from state to state.
3. LCA, “Death and Dying,” p. 3.
4. Physician-assisted death or “aid in dying” refers to situations in which a physician (or other health professional at the physician’s request), in response to a patient’s request, either administers a medication or performs a treatment, or enables the patient to do so, with the intent of bringing about that patient’s death.
5. The above convictions are quoted from LCA, “Death and Dying,” pp. 2-3. 6. LCA, “Death and Dying,” p. 6



A Health Care Covenant for Canada

This Health Care Covenant was proposed to the Royal Commission on the Future of Health Care by the Ecumenical Health Care Network of the Canadian Council of Churches in May 2003. It was the first recommendation of the Commission in its final report to the Canadian Government.

dian Government.

“We recommend... this covenant as the set of principles guiding the direction for health care reform in this country.” Ecumenical Health Care Network May 2003

Preamble

Ecumenical Health Care Network May 2003

People in Canada understand that how we care for others defines the nature of who we are as a national community. We also know that what we owe each other is essential for who we are as a people. Thus, we have empowered our governments to steward public resources and develop and administer social policy for the common good of all; to ensure that:

Everyone has the right to a standard of living adequate for the health and well-being of himself and his family, including food, clothing, housing, and medical care and necessary social services, and the right to security in the event of unemployment, sickness, disability, widowhood, old age or other lack of livelihood in circumstances beyond his control.

Universal Declaration on Human Rights Article 25

As signatory to the World Health Organization Charter, we in Canada have pledged ourselves to a holistic vision of well-being that understands 'health' as [...] a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity.

As members of a national community, we in Canada understand that a community actively promotes and nurtures health through compassion, mutuality, care, trust, respect, security and active attention to what justice requires of us.

Thus, in fulfillment of our mutual responsibilities, we and our governments solemnly promise to actively pursue and safeguard a holistic and integrated vision of health care for all people in Canada.

A Health Care Covenant for All People in Canada

Through government, we in Canada pledge to:

Universal Access, Comprehensiveness and Portability

- provide access to comprehensive health care services for individuals, families and communities that places the priority on the worth and dignity of the whole person and their biological, emotional, physical, environmental, social and spiritual needs wherever they may be in Canada;

Social Solidarity and Justice

- uphold a health care system through which all people in Canada share the benefits of health and the burdens of illness with particular compassion for the weak, caring for the vulnerable, solidarity with our neighbours and a commitment to social justice for all;

Open to All People in Canada

- preserve inviolate a health care system that applies to all people in Canada without discrimination toward race, colour, sex, sexual orientation, ability, disability, ethnic origin, language, place of residence, economic status, religion or any other distinction;

Social Health and Well-being

- utilize a systemic approach to creating public policies that, intentionally integrate the social, economic, cultural and environmental determinants of well-being with health;

Human Right and Public Good

- ensure that access to health care is maintained as a human right and a public good, recognizing that health care interactions have meaning to people as a way of caring; health care is not a commodity;

Honour the Vocation and Contribution of All Health Care Providers

- utilize fully the capabilities of all health care professionals, including indigenous practitioners covered under the Canada Health Act, and honour the vocation of all who provide care, whether paid or unpaid;

Public Stewardship and Accountability

- safeguard public administration and limit for-profit delivery of care through mutually enforceable federal and provincial regulations upholding standards of public accountability for a system that addresses the health care needs of individuals, families and communities;

Collaboration and Shared Responsibility

- develop and sustain a health care system founded upon the principles of collaboration and shared responsibility between governments and among providers, not competition or market imperatives; and

Participation and Decision-making

- recognize that health is unique to individuals, families and communities and as such, to honour the right of people to participate in the decisions that affect them and their health.