

A CATHOLIC PERSPECTIVE ON HEALTH DECISIONS AND CARE AT THE END OF LIFE



“I am the resurrection and the life..... Everyone who lives and believes in me will never die” (John 11.25-26)

A FAMILY’S JOURNEY

Four years ago today, my then seventy year old father, Paul, was diagnosed with lung cancer. He died fourteen months later.

Even as I write this, the words “lung cancer” hang in the air much in the same way they did that day when I sat next to my dad as his doctor delivered this news. It was a strange and unsettling experience. At one level nothing changed in that exact moment; at another level everything changed. Holding his hand, to steady both of us, I remember thinking “We are turning a corner here... How will we find our way through this?” For her part, Dr. Everett moved on in the conversation to outline options and possible next steps to consider.

Driving over to my brother Jim’s house after the appointment, my dad’s first words tumbled out – thoughts, reactions and memories pinging off one another in no particular order. Even in this early time just after “the news”, I remember dad’s mix of emotions. He reminisced about my mom’s relatively quick, but unexpected, death following a massive heart attack twelve years earlier. He spoke of his anguish about agreeing to discontinue efforts to resuscitate her.

These memories seemed to blend seamlessly with the present realities and his first, but not last, acknowledgment “Patty, this may be it for me... but you can never really imagine your own death, can you?”

And so began what was to be a long and sometimes difficult journey for Paul and his loved ones. Day in and day out, decisions regarding health care are made in living rooms, offices, clinics, hospitals and personal care homes throughout Canada. While these discussions are everyday events for health care providers, they are pivotal, life-changing moments for people like Paul and his loved ones.

The Catholic Health Alliance of Canada believes it is important to provide some information and reflection from a Catholic perspective on these life-changing moments that patients and families so often face. The Alliance is a forum of twelve Catholic sponsorship organizations of more than one hundred hospitals, community health centres, nursing homes and long term care facilities dedicated to continuing the healing ministry of Jesus Christ in today's world. This ministry is committed to both the provision of excellent medical and technical care and to understanding and supporting the deeper issues of meaning that arise for patients and their loved ones when illness temporarily interrupts life or causes death.

It is only human to fear death and, even more, to fear dying. Dealing with these fears, Catholics and others, may benefit from understanding and re-claiming a rich tradition regarding health care decision making in the face of life-limiting illness and reflecting on the meaning of a *good death* now, in our time.



WHY IS CLARIFICATION NEEDED TODAY?

Medical advances have brought enormous improvements in the treatment of many conditions – devastating injuries after an accident, dreaded cancers, chronic illnesses, like diabetes, and the array of complications that come with them. With such success, many have come to believe in the power of technology to cure every disease or to rescue people whenever illness appears to be a life-ending event. For them, this means a relentless pursuit of cure in the belief that it is always possible and that we can always somehow control death and disease.

While death is our common human fate, how, when, and where we die has changed profoundly in the past fifty years. Unlike our grandparents' deaths, our own deaths will more likely than not follow an explicit decision to set aside or to stop on-going use of life-sustaining therapies. Indeed, over the past few years, Canadians have been regularly exposed to media stories of high profile court cases demonstrating uncertainties and conflicts that arise when patients, families and healthcare providers have different ideas about what “counts” as the appropriate or right response to a life-threatening condition.

In addition, there has been and will continue to be much discussion and debate in Canadian society about whether or not to legalize assisted suicide and euthanasia. Quebec has passed Bill 52 (*An Act Respecting End-of-Life Care*) and included physician administered (assisted) death in its understanding of “medical aid in dying”. At the time of writing, the Supreme Court of Canada prepares to hear the British Columbia Carter case, challenging the law that prohibits assisted suicide.



Under the banner of “death with dignity”, assisted suicide and euthanasia are often pictured in the media as the main options for a dignified or “good” death. The message that death with dignity is a death we control by our own actions (i.e. assisted suicide) or through the actions of others (i.e. euthanasia) feeds the illusion that death itself is optional rather than a human reality.

Within the Catholic community the debates have also revealed enormous confusion:

1. about the moral obligations of patients in making health-care decisions;
2. about the morality of withholding or with-drawing life-sustaining treatment;
3. about the goals and effectiveness of palliative care; and
4. about the Catholic tradition of a good death.

Understanding that the goals of palliative care fully fit with the Catholic tradition of a “good” death may, in particular, address the confusion and fears Catholics themselves experience. With so much at stake for us individually and as a country, there is a crucial need for clarification.

WHAT CAN WE LEARN FROM THE STORY OF PAUL AND HIS FAMILY?

A reflection on the experience of Paul and his family, from the diagnosis of a life-threatening condition to end-of-life palliative care and a peaceful death, is offered as a guide to the Catholic tradition’s approach to health care and end-of-life decision making. It is meant to correct misconceptions and to offer practical suggestions about navigating both the anticipated and unanticipated features of death and dying. It is rooted in an empathic understanding of the emotional and spiritual journey, as well as the physical realities of dying.

A week after receiving his diagnosis, Paul begins his journey with the first of many consultations and investigations to obtain more detailed medical information about his cancer. Like so many others he heard very little his family doctor said after hearing the dreaded word, “cancer”. But he now needs to think about his future and to make decisions.

WHAT IS NEEDED TO MAKE GOOD HEALTH CARE DECISIONS?

In both the Catholic tradition and modern health care ethics, persons like Paul who have the capacity to make their own decisions are the primary decision makers regarding proposed treatment and care options. This promotes and protects interests people typically value, namely, the patient’s dignity and autonomy or ability to be self-directing. For this reason, information regarding a patient’s values, beliefs, commitments, wishes, preferences, life-defining historical events, and hoped-for life goals is as crucial to making health care decisions as information about the patient’s physical condition.



Paul is overwhelmed and feels out of control in a whirlwind of medical activity. He is not dealing with all of this alone. He has a caring family doctor who knows him well, a daughter, Pat, who has been very close to him and a son, Jim, who has been estranged.

WHAT IS MEANT BY INFORMED DECISION MAKING?

To make informed decisions that are meaningful to them, people require information that is presented in a manner they can understand and appreciate, and the freedom to ask questions about that information. Some want as much information as possible; others want much less. Some want to receive this information in the company of family or friends; others prefer one-on-one meetings with health care providers.

This information should include:

1. the diagnosis (i.e. what is going on in the person's body);
2. the prognosis (i.e. what is likely to happen as the illness progresses); and
3. the anticipated benefits, possible risks and any potential harms of possible options including the option of treating the symptoms associated with illness (e.g. pain, shortness of breath, anxiety) while not attempting aggressive curative treatment of the underlying disease.

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After an exhausting set of investigations, Paul's diagnosis is confirmed as a stage three lung cancer. This means the likelihood of cure is small and the probability the tumor will return is high. There is hope for significant improvement, especially with a combination of treatments including chemotherapy drugs to shrink the tumor before surgery or a combination of chemotherapy and radiation. Paul needs to decide if going through all this is worth it for him.

The issue of figuring out (assessing) “benefits”, “risks” and “harms” is a particularly delicate matter. For instance, when a doctor speaks of a benefit, she may be talking about how effective a treatment is; does it work or accomplish what it is supposed to do. While a treatment might be effective, a patient may or may not value the treatment or consider it worth doing. For example, a person with advanced heart disease whose kidneys fail to function may or may not want to accept dialysis as a means of dealing with kidney failure if pursuing dialysis means leaving home in a remote community to relocate near a centre that provides dialysis.

Finally, when a doctor speaks of “risks”, he may be talking about the kinds of negative side effects that could happen when someone is receiving a treatment and the likelihood that the negative side effect will happen. The acceptance or avoidance of “risks” from a patient's perspective may have less to do with percentages and possibilities and more to do with personality. Some patients can live with much uncertainty; others cannot tolerate any uncertainty.



Similarly, doctors and their patients may have very different ideas about what counts as “harm”. Some treatments, while life-sustaining, are physically and emotionally demanding. Some people might look at such treatments and assess them as “harmful” or “too much to take”; others might look at the same treatments and see them as burdens worth bearing.

Paul is a Catholic, and it is important to him to know if his Church has anything to say about the difficult decisions he is faced with. He is unsure of what the Church teaches.

DO WE HAVE A DUTY TO PROLONG LIFE AT ALL COSTS?

The question of whether or not there is a duty or an obligation to prolong one’s life is a concern for many Catholics. Regarding the acceptance and/or refusal of life-sustaining interventions, some mistakenly believe that Catholics are required to do everything possible to stay alive as long as possible. This idea does not reflect Church teaching on this matter. The moral tradition of the Church provides important guidance:

“Life and physical health are precious gifts entrusted to us by God. We must take

reasonable care of them, taking into account the needs of others and the common good” (*Catechism of the Catholic Church*, no. 2288).

“If morality requires respect for the life of the body, it doesn’t make it an absolute value.” (*Catechism of the Catholic Church*, no. 2289).

Over centuries, the Catholic faith has developed principles or ways of thinking about what “reasonable care” means. Generally speaking, “reasonable care” would include interventions that are readily available, effective and not excessively burdensome. Most importantly, the interventions are those valued by the person; they allow the person to pursue spiritual goods and life goals (e.g. relationship with others and union with God). From a moral perspective, the Church’s understanding of “reasonable care” has never required individuals to accept interventions that they experience as overwhelming or too burdensome even if such therapies work. When the demands of life-sustaining interventions interfere with a person’s spiritual concerns, including relationships and emotional and psychological burdens, they may be rightfully set aside or declined.

Broadly understood, the balancing of benefits and burdens of available interventions, which is a part of any major health care decision, rests with the person. The idea that the patient’s judgment is to be respected is consistent with the Church’s understanding of “reasonable care”.

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Paul hopes to live long enough to see grandchildren and, encouraged by his children, opts to get aggressive treatment with the hope of cure. He understands cure is unlikely but hopes for more time with family and friends.

Pat faithfully brings her father to chemotherapy sessions and multiple visits for blood work that come to dominate their lives. Jim has great difficulty in seeing his father fatigued, nauseated and dependent. Paul has a slow recovery but is encouraged by the hope that he now has more time.

A year after the original diagnosis, Paul develops memory loss and periods of confusion. He is told that the cancer has spread to his brain.

Despite some episodes of confusion, Paul reconsiders his options. Over the last year he has been unwell most of the time. He is tired of having his life dominated by medical tests and interventions. He begins to think he has “given it his best shot.” He says he is “ready to go to God” and wants to shift his goals of care to comfort care and support for his last days. Pat, who has been nightly in conversation with her father and providing care at home for him, is supportive of his wishes. But she is concerned this is a kind of suicide or passive euthanasia.

Jim is extremely upset about his father’s “giving up”; wants him to consider experimental treatment.

IS DECIDING TO STOP TREATMENTS ACCEPTABLE?

Patients have a right to refuse and/or to withdraw consent to any type of care or treatment. This includes potentially life-saving or life-sustaining treatments. The person receiving care determines the benefit and/or burden of these interventions. In the words of Pope John Paul II,

“To forego extraordinary or disproportionate means is not the equivalent of suicide or euthanasia; it rather expresses acceptance of the human condition in the face of death”
(*Evangelium Vitae*, no.65).

It is essential to remember that euthanasia is deliberate killing in order to end suffering by ending the person’s life. In the case of assisted suicide, persons take their own lives with the direct assistance of others in the provision of lethal drugs. To allow death to occur, recognizing the limits of medicine to cure and/or improve function, is not euthanasia or assisted suicide.

WHAT IS PALLIATIVE CARE?

Modern palliative care emerged to improve the care for the dying in today’s frequently death-denying, death-defying world. As a balance to the excessive and disproportionate use of life-sustaining interventions, palliative care’s stated goals are the relief of pain and other distressing physical symptoms, together with assistance responding to the spiritual, emotional and familial needs at end of life. Palliative care has made major advances in achieving these important goals. Pain and other physical symptoms are distinct from suffering but can be related. Pain is a physical reality; it can be relieved well by modern medicine. However, suffering is a total, human, spiritual experience; it requires attention to the deeper issues of meaning at end of life.

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Persons of faith experience the same difficulties as others in acknowledging the limits of medicine. Ideally, during his nine months of treatment Paul and his family would have been offered a palliative care approach to this life-threatening and ultimately terminal disease. This approach prevents the sharp distinction between treatment and palliative care. It makes palliative care available to patients and families on the continuum from diagnosis to death. After diagnosis and in the early stages of illness the focus is on communication, advance care planning, psychological and spiritual support, and pain and symptom management. At later stages the focus is review of the goals of care, ongoing support for patients and families, pain and symptom management and preparation for death.

Acceptance of dying can initiate a precious time of grace, reconciliation and healing. The goals of palliative care at end of life are compatible with the Christian notion of the *good death*.

Before a final decision is made to shift to the goals of palliative care, Paul loses consciousness. Despite the long course of this inevitably fatal disease, many long talks with his daughter, and the experience of the sudden death of his wife, Paul never formally engaged in advance care planning nor named who he would wish to speak for him if he could no longer speak for himself.

The differences between Jim and Pat's responses to their father's now inevitable death become apparent and create friction between them. Jim believes they have to continue aggressive treatment. But Pat knows her father best and wants to allow their father "to go to God" as her father had talked about with her.

WHAT IS THE ROLE OF ADVANCE CARE PLANNING AND SUBSTITUTE DECISION MAKERS?

Anticipating the loss of the ability (i.e. capacity) to make or voice health care decisions, advance care planning can be understood as a spiritual activity. Respect for a person's beliefs and values can be extended into the circumstances when they can no longer make their own decisions. Authorized proxies should be able to speak to the wishes, values and beliefs of the person receiving care. Wishes, values and beliefs of the person receiving care expressed previously, either orally or through advance care planning documents, should normally be followed by proxies when making substitute decisions for those who can no longer express their wishes. So, the substitute decision maker's knowledge and understanding of these beliefs and values is crucial. The proxy must also be able to assess when unanticipated circumstances require a departure from the person's requests.



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The parish priest helped Pat and Jim talk about their father and what he was like and what they believed he would want. They were reassured that stopping aggressive treatment was nothing like assisted suicide or euthanasia. Jim was helped to understand how his own guilt over his relationship with his father was impeding his ability to act in accordance with his father's wishes. Brother and sister agreed to stop treatment aimed at cure and to choose the palliative care approach to provide end-of-life comfort care. Several days later, Paul dies peacefully with his son and daughter and close friends with him. His funeral is a celebration of life!

ARE THERE OTHER ISSUES WHICH COULD HAVE ARISEN IN PAUL'S JOURNEY?

There are many other complex issues which arise for patients and their loved ones. These include the treatment of pain, other physical symptoms, suffering and issues with providing nutrition and hydration for dying persons.

Effective management of pain is critical in the appropriate care of the sick and dying, whatever their age or circumstances. The dying process is often accompanied by pain and other physical symptoms such as breathlessness. Catholic teaching emphasizes that we have a duty to provide relief. Some are concerned that the use of morphine and other opioid medications in control of pain and shortness of breath are equivalent to euthanasia. Church teaching is clear,

“The use of painkillers to alleviate the sufferings of the dying, even at the risk of shortening their days, can be morally in conformity with human dignity if death is not willed as either an end or a means, but only foreseen and tolerated as inevitable.”
(*Catechism of the Catholic Church*, no. 2279)

We need to be clear that the proper titrated use of medication in the alleviation of pain does not hasten death. Such treatment does not constitute euthanasia but rather good pain management.

Optimal palliative care can provide considerable relief for almost all symptoms. When there is intractable pain, palliative sedation may be considered. Since persons have the right and obligation to prepare for their death while fully conscious, they should not be deprived of consciousness without a compelling reason. However, palliative sedation, that is sedation for palliative purposes, can be morally permissible within the Catholic tradition.

Because of the profound emotional, social and spiritual significance of feeding, issues of medically assisted nutrition and hydration (often referred to as tube feeding) are particularly difficult. It is important to distinguish between persons with chronic conditions who might benefit from medically assisted nutrition and hydration and persons who are dying. For those who are approaching death, the loss of appetite and the loss of a need for food are normal and expected.

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In principle, there is an obligation to provide patients with food and water, including medically assisted nutrition and hydration, when they cannot take food orally. However, feeding becomes morally optional when it cannot reasonably be expected to prolong life or when it would be “excessively burdensome for the patient”. As a patient draws close to inevitable death from an underlying progressive and fatal condition, certain measures to provide nutrition and hydration may become excessively burdensome and therefore not obligatory in light of their very limited ability to prolong life or provide comfort. Comfort and personal care for the dying person continue to be provided in many other ways.

UNDERSTANDING REQUESTS FOR ASSISTED DEATH

While sad and at times difficult, Paul’s death is an example of a good death in the Catholic tradition. It is the completion of life as a journey of faith and family with possibilities for reconciliation and healing with loved ones at the end. It is quite different from modern conceptions of “assisted death” – ending one’s own life and/or having one’s life intentionally ended by another.

It is important to understand requests for death by assisted suicide or euthanasia. Sometimes, when coming from the dying person, it is a signal to review their pain and symptom control and their spiritual and emotional support. Sometimes it is a cry from the heart prompted by fear of the unknown; of being abandoned; of being a burden; or of pain and suffering. Sometimes it comes from a belief that the only way to die with dignity or have a “good death” is by means of assisted death or euthanasia.

For many, assisted death is about individual rights and autonomy. Christians, however understand that life is a gift which has both personal and communal dimensions.

“The life and death of each of us has its influence on others...” (Romans 14.7).

In the media and in public opinion polls, assisted suicide and euthanasia are often presented as acts of compassion for persons who suffer intractable pain. However, pain and other physical symptoms play a small part in the actual requests for assisted death. The most common reasons for wanting assisted death are fear of future pain or suffering; the sense of loss of dignity; feelings of being a burden to others, especially loved ones, and a desire for some control in the out-of-control experience of dying. These feelings are experiences of human suffering, not pain.



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Assisted suicide and euthanasia are a medicalization of death and of human suffering – the false belief that somehow all human pain and suffering can be cured by a medical intervention. This is a notion that pervades contemporary society – the illusion that somewhere there is a “quick fix” for every ill and every kind of human distress. As part of this trend, assisted death would certainly not be confined to end of life care or terminal illness. The potential implications for all society are staggering.

IS A “GOOD DEATH” POSSIBLE IN MODERN TIMES?

Like Paul, many of us may wonder if it is possible to imagine our own deaths. While we witness death every day in remote ways (e.g. accidental or violent deaths reported on television news; obituary accounts of the premature deaths of the very young and anticipated deaths of the very old), most of us have yet to experience imminent life threatening illness even if we have kept vigil with friends and family members in their passages from life to death.

Ironically, the possibility of a “good death” in modern times may well be undermined by the availability of life-sustaining interventions not imagined or available to those who lived before us. The traditional Christian notion of a “good death” offers insights that are essentially timeless. In the face of life-changing and life-ending illness, the thoughtful consideration of important life goals – material, relational and spiritual goods – may best be served through the thoughtful use of means to promote well-being, to protect and preserve life and, finally, to provide for a peaceful death.

Paul’s death is an example of a *good death* in the Catholic tradition. All life is a journey, like Paul’s, and most of that journey is spent learning about what life means. We learn that all life is a gift from God. We learn about the world, about relationships, about love, about dependence, about independence and about balance. We learn that there is so much about life that we do not control, and so must trust. Dying is part of

that journey, part of life, and Christians believe that dying well means acknowledging our dependence, being thankful for life and for those that are part of that life, giving up control and trusting in God. *A good death* is the completion of life as this journey of faith and family. It is quite different from modern conceptions of assisted death.



A good death is the completion of life as this journey of faith and family.

Such a perspective does not minimize the need for good decisions as death approaches. Life is to be treasured and protected with “reasonable care.” But the spiritual goals of life require that decisions about treatments not be out of proportion to the benefits and burdens of the treatments.

And finally, family and those who provide care should advocate for optimal pain and symptom relief and personal and spiritual comfort and support. Sometimes, what is most needed is that caring people be present with the dying person. Accompanying

a dying person on that final part of their journey is a privilege. It provides comfort and shows respect for that person and for their journey. Such is death with real dignity, a *good death*.



Questions for your prayerful reflection

1. What do you think of as a “good death”? Have you had personal experience of a “good death”? What did it look like? Feel like?
2. Have you thought about the care you would hope to receive from medical staff if you were terminally ill or dying? What kind of care would you want for your family members who are seriously ill or dying?
3. Have you done advance care planning: clarified your own beliefs, values and wishes; spoken to your loved ones and care givers and named a substitute decision maker? If not, do you have reasons for not doing so?
4. What are your thoughts on euthanasia and assisted suicide?
5. How do you think the possibilities for a “good death” and care for the dying would be affected by the legalization of euthanasia and assisted suicide?
6. How do you think Canadian society would be affected by the legalization of euthanasia and assisted suicide?

Some helpful resources...

Catholic Health Alliance of Canada, *Health Ethics Guide*

Catholic Organization for Life and Family

Canadian Catholic Bioethics Institute

Canadian Virtual Hospice

Canadian Hospice Palliative Care Association

Pallium Canada

Speak Up

The Way Forward: An Integrated Palliative Approach to Care

Catechism of the Catholic Church



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