



IN SURE AND CERTAIN HOPE

RESOURCES TO ASSIST
PASTORAL AND THEOLOGICAL APPROACHES
TO PHYSICIAN ASSISTED DYING



THE GENERAL SYNOD *of*
THE ANGLICAN CHURCH OF CANADA

Faith, Worship and Ministry
Task Force on Physician Assisted Dying

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TABLE OF CONTENTS

1. Introduction	4
2. Theological Concerns and Questions	5
3. Palliative Care	14
4. Pastoral Care	19
5. References and Definitions	25
6. Prayer Resources	29
7. Bibliography	33
8. References	36

Appendices

1. <i>Submission of the Anglican Church of Canada</i> to the Special Joint Committee on Physician Assisted Dying, February 3, 2016	37
2. Summary of questions from submissions to the Task Force	48



ONE

INTRODUCTION

*But seek the welfare of the city where I have sent you into exile,
and pray to the Lord on its behalf,
for in its welfare you will find your welfare*

Jer. 29:7

In 1998 The General Synod of the Anglican Church of Canada commended the Statement on Euthanasia and Assisted Suicide, *Care in Dying*,¹ to the wider church for study and reflection. This resource was intended to be a contribution to a debate that was, at that time, very much alive in Canadian society.

With this in mind *Care in Dying* addressed itself to the debate in two important ways. First, it brought clarity to some concepts that

frequently were misunderstood and confused. It distinguished helpfully, for example, amongst the terms “termination of life support”, “termination of treatment”, and “euthanasia” (voluntary, involuntary, and non-voluntary). Careful definitions were—and still are— necessary. Confusion amongst these terms was at the time common, and a cause of burden for patients and caregivers.

Second, *Care in Dying* cast the societal debate

1. <http://www.anglican.ca/faith/focus/ethics/care-in-dying/>

within the framework of the call to care. The responsibility to care—understood broadly and not only in terms of medical therapy—is an overwhelming obligation for all of those who surround a patient in serious and irreversible illness. *Care in Dying* sought to address the question of what care might look like in a variety of circumstances.

In the process of their work, members of the task force of the time examined specific case studies, paying special attention to the experiences and roles of different people in the health care context and to the interactions amongst them. It soon became apparent that members held different interpretations of the stories. We each bring our own experience and understanding into dialogue with the story presented. Consequently *Care in Dying* acknowledged a diversity of perspectives amongst the task force members, in the life of the church, and in that of the wider community. However, the members of the task force together agreed that they could not at that time support physician assisted suicide².

Roughly twenty years later, we find ourselves in a changed situation, legally speaking. There have also been significant changes in medical technologies and therapies over these years. Changes in public opinion have followed. The Faith, Worship, and Ministry Committee of General Synod (FWM) agreed in 2013 that it was time to review *Care in Dying* in light of these changes, knowing that legal challenges around physician assisted dying were on the increase

and changes were likely to happen. They also expressed concern about the health care system as a whole, and the effects that underfunding have on the most vulnerable in society. FWM appointed the Task Force on Physician Assisted Dying in 2014. Its mandate was to provide resources to inform helpful discussion of these issues within the life of the Church.

With the Supreme Court of Canada's decision in February of 2015 finding that physician assisted dying is constitutionally permissible for a small class of persons, the public debate concerning the legal ban on physician assisted dying is in some ways over. Physician assisted dying will now be an option for competent persons with grievous and irremediable illness who are experiencing intolerable suffering. The societal and legal context within which the pastoral and prophetic ministry of the church takes place has shifted.

While many may regret this change, the task force believes that 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 their circumstances. Theologically we continue to assert that human persons, being in the image of God, are the bearers of an inalienable dignity that calls us to treat each person not merely with respect, but with love, care, and compassion. This calling, being a reflection of God's free grace, is in no way qualified by the circumstances that an individual may face, no matter how tragic. Neither is that

2. The terminology used over the years, and in different contexts, has changed. The language of *physician assisted suicide*, as used in *Care in Dying*, emphasizes the choice to kill one's self by proxy through the assistance of a physician. For some, the use of that terminology immediately places a negative prejudgment of the choice in unhelpful ways. To others, it is a simple statement of the act and its intention. The language generally used in the courts and government has been *physician-assisted death*, or *physician-assisted dying*, or *medically assisted dying*. When referring to points made in *Care in Dying*, the *physician assisted suicide* is used, as it was the terminology of that document. For all other references, we have endeavoured to be consistent in the use of the term *physician assisted dying*.

inherent dignity diminished nor heightened by the decisions they make in those circumstances, even if they differ from the decisions that pastors might in good conscience make or recommend. The judgment of the Supreme Court opens up a new layer of difficult decisions, ones that will be difficult no matter what the initial preferences of the patient or their final decision.

We also need to recognize the challenges faced by family, loved ones, and care providers in these difficult processes. We need to pay attention to how we are to sustain communities of care around patients, respecting the decisions of, and exercising the best possible care first for the patient and then also with care for the immediate supportive community. In this context the church needs neither to surrender its basic principles and insights nor propound them in a way that simply isolates the church from the theologically essential task of empowering individuals caught up in these situations to make sense of their own lives, their hopes and fears, their pain and distress.

The new task force expressed its gratitude for the work of the Anglican Church of Canada Committee that produced *Care in Dying*, and they did not wish to revisit the basic insights of that document. They did, however, recognize that those insights had been articulated in a manner that has not been the most helpful to every part of

our Church over these intervening years.

Public opinion has moved clearly and decisively in favour of physician assisted dying, though with notable debate within professional medical associations. Many who favour this shift would draw on some of the same or similar principled insights and commitments as articulated in *Care in Dying*, particularly in considering the framework that ought to be built around the practice.

Those insights and commitments need to be restated in ways that shed clarifying and question-raising light specifically on our current circumstances. What is offered in the pages that follow is a framework for effective pastoral support for all concerned (patients, family, loved ones, care providers, and wider communities of support), whatever decisions particular patients ultimately believe themselves called to make. We also recommend study of *Care in Dying* along with this present text.

We will first outline some basic theological and biblical insights and seek to imagine how they might serve us in our current situation. This will then lead us to some unanswered questions. We believe that those questions need to be addressed in the regulations that will surround and support the social practices associated with physician assisted dying.



TWO

THEOLOGICAL CONCERNS AND QUESTIONS

INSIGHTS FROM SCRIPTURE AND TRADITION

The approach taken by *Care in Dying* was to dive directly into some of the most controverted issues with respect to biblical witness. The most difficult questions still remain with us: the issue of suicide, the notion of life as gift, and the meaning of suffering. In each of these areas, the concern of the task force at the time was to elucidate and differentiate between acceptable and non-acceptable theological approaches, setting up contrasting views. The key points, with further elucidation, follow.

SUICIDE

Care in Dying pointed out clearly that none of the biblical passages that seem to refer to suicide³ can be applied to the question of assisted dying in the context of a life maintained by intensive and often dehumanizing technological intervention, or in the face of unbearable pain and suffering.

In addition, the document acknowledged how the church's approach to the question of suicide has changed from one of a blanket condemnation of the act of suicide to one of compassion and pastoral care for the one driven to suicide and to their family and loved ones. This shift has been driven both by a fresh articulation of the implications of the call to live in ways that reflect the unbounded love and compassion of God,

3. Examples cited in *Care in Dying* include: 2 Samuel 17:23; 1 Kings 16:18-19; Matthew 27:3-5

and also by a more nuanced understanding of the situation, health, and motivating factors that might lead an individual to believe that the only viable option in front of them is to take their own lives.

The church *no longer sees as acceptable* interpretations of the motives for suicide cast in terms of lack of courage, unfaithfulness, or in terms of the rejection of God's will. We have also become increasingly skeptical of our capacity to understand and interpret the work of God in the life of another person. And though we have a long way to go, Christians have benefitted from advances in public awareness and professional education regarding mental illness. Pastoral care of those with suicidal ideation begins in the seeking of immediate qualified critical psychiatric care and appropriate medical intervention. Questions of situation and cause need to be assessed within the context of medical treatment wherein mental health diagnosis and treatment are involved.

SUFFERING

A distinction needs to be made between suffering for the sake of the Gospel, and suffering within the human condition. When St. Paul speaks of suffering, for example, it is a suffering for the Gospel that comes as a result of his living out of his faithful response to the call of God. This is one sort of suffering which has its own theological meaning.

That form and meaning of suffering must be differentiated from the pain and suffering that is experienced as part of the human condition with its vulnerability to mental illness and physical sickness, aging processes, injury, suffering, and death.

Care in Dying rejected the claim that such suffering might be simply viewed as "devoid of purpose, and thus without redemptive value"⁴

4. P.21 discussing the report of the Episcopal Diocese of Newark from which this quote is taken.

5. Zizak, *The Puppet and the Dwarf*, p.125

and strove to be more nuanced. The report acknowledged that suffering might be meaningful. However, it also noted that suffering might be devoid of redemptive value in and of itself. It still remains to be asked for whom this suffering might be meaningful. How is this sense of meaning to be established, and by whom?

The *Book of Job* has been upheld as profound wisdom tradition about the nature of human suffering, and has itself suffered from its vulnerability to misinterpretation. Looking closely at the biblical story of Job, we see that Job and his comforters seek to ascribe meaning and purpose to the mounting catastrophes that Job experiences. The interventions of the comforters are particularly problematic, but even Job's own search for meaning in the end comes face to face with the utter and impenetrable mystery of the being of God. In the face of this, all attempted explanations of human experience function ideologically.

Job's properly ethical dignity resides in the way he persistently rejects the notion that his suffering can have any meaning, either punishment for his past sins or the trial of his faith, against the three theologians who bombard him with possible meanings—and, surprisingly, God takes his side at the end, claiming that every word that Job spoke was true, while every word of the three theologians was false.⁵

Compare this with biblical scholar Walter Brueggemann's observation that, "The friends are dismissed because they had settled for an ideological conclusion, without taking into account the problematic of lived experience. The response to the encounter with the mystery of human suffering is not mere silence." As Brueggemann further clarifies, "Yahweh does not want ideology to crush experience. And that

leaves only two parties to draw the most authentic of conclusions: Yahweh and Job, face to face.”⁶

If this encounter of the individual sufferer with God in faith is indeed the place where the mystery of their seemingly incomprehensible suffering is addressed (we cannot simply say resolved) and meaning evoked, then we as the church need to be reticent about proposing generalizable solutions. Of course, we believe that there is meaning, but it is a meaning for which we listen in the encounter between God and the patient, not one which we interpose to frame that encounter and define it.

LIFE AS GIFT

The scriptures affirm that life is a gift. However, the notion that the choice for death represents a disrespectful abandoning of that gift is one that comes from later periods in the Christian tradition. *Care in Dying* draws particular attention to the views of Augustine of Hippo and Thomas Aquinas. Augustine argued in his highly influential *City of God* that suicide amounts to cowardice in the face of pain and suffering. Aquinas argued from natural law that suicide violates our love of self and our instincts to self-protection. He builds on this, theologically, to say that suicide offends God who has given us life, and hurts the human community of which one is a part.

Augustine and Aquinas, arguably, set the stage for the development of Western Christian theology, and so it is not strange to find their approaches to this matter sounding somewhat familiar.

However, in each case, these two heavyweights of theology were doing what theologians do: bringing the lens of the culture,

6. Brueggemann, *Theology of the Old Testament*, p.391.

7. For example, a close reading of John Donne’s *Biathanatos*, rather easily dismissed in *Care and Dying* might prove provocative and rewarding.

scientific knowledge, and philosophy of their day to bear on the Christian story. And those philosophic presuppositions were precisely of those times, the 5th and the 13th centuries respectively.

Given the shift in Anglican thinking about suicide, we may need to rethink the easy assumption that receiving life as gift means that we cannot faithfully decide that the gift is one that we must now let go. Already in the case of the withdrawal of treatment we recognize that life is not an end in itself, and that the approach of death need not be resisted by all available means.

If the chief purpose of life is to know God and to enjoy God for ever, is it possible to conceive of circumstances where a person might faithfully conclude that this purpose could no longer be furthered by the extension of their life and might choose, not merely to cease to resist the approach of death, but to actively embrace it?

To approach this question helpfully would require a more nuanced read of the tradition⁷, including its minority voices, than we are able to offer here. It would require as well a more intentional listening to the experience of those who see no way in which their continued living can contribute to the ends of the life for which the gift was received.

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There remain a number of theological commitments to be addressed:

CARE AND COMMUNITY

Understandings of care, and how those understandings shape and express community, lay at the heart of the reflections in *Care in Dying*. Indeed, the trajectory of that document

was in many ways set by the way it answered the question of what constitutes care. In seeking to answer the question of whether a decision to participate in the ending of life could be construed as an act of care, the study was in some ways quite tentative. In the end however, that question was answered in the negative. The decision that there were problems so construing the ending of life as care were linked to questions of intentionality.

Perhaps a more telling question at this point might be to do with how our actions may be construed as examples of care. While it is fairly obvious that palliation and pain relief are acts that show our continued care for a patient for whom we can offer no cure, killing is a much more ambiguous act. (p.28)

Killing is more ambiguous because it can more easily be construed as an act of abandonment, a decision that the patient's life is not worth living and therefore not worth our continued investment in care. If, as *Care in Dying* insists, intentionality is important, then surely the points to be looked at are not simply whether we intend death or pain relief but also why we intend death and whether that intention is rooted in the life and dignity and choices of the one whose death we intend.

In other words, the question is more complex than *Care in Dying* allowed. It is not simply that we need to only intend death as an unfortunate, but unwilling consequence of our attempt to provide care, but also, and crucially, that in both dying and living, our care is articulated in terms of our covenant of presence to the other. This covenant is binding in health and in suffering, in life and in death. This is so because it reflects and communicates the presence of God to the other in their suffering and in their dying, and in the difficult and demanding decisions that might surround these experiences.

More careful reflection on the nature and demands of care is now particularly necessary in light of the decision of the Supreme Court of Canada. That decision 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.

A broadened view of matters of care, community, and conscience give rise to a complex of questions. *Care in Dying* asked whether a decision for physician assisted dying might be a response to the suffering not only of the dying but also of those who accompany them on that process. What constitute healthy relationships amongst caregivers, patient and supportive community in the patient's process of discernment? How does a refusal to provide assistance in dying represent a commitment to continue with care? What does care look like in this context? What happens when my conscience is in conflict, in either direction, with the decision of the patient? What needs to be done within this conflict? How do I tend to my conscience as well as to the patient in a situation of pastoral care in which I am uncomfortable with the patient's decision? These are the sorts of questions that will be dealt with later in this document.

INTENTIONALITY AND RATIONALITY

There have been many debates over recent years concerning the role of intentionality. What does it mean to intend to do something? In debates about physician assisted dying intentionality is primarily used to distinguish between acts all of which result in the death of the patient but in some of which that death was not the willed or desired outcome.

Yet, as *Care in Dying* noted, intentionality can, in this sense, be only one part of the picture. While it is true that a foreseen consequence of our actions may not be what we intend, that it is foreseen means that we have at least some level of responsibility for it as an outcome. Perhaps more helpful in our context is the recognition that intentionality is about rationality and about narrative.

One of the things that makes a human action an action and not merely a reflex is that it is intended. If I am struck on the knee, I do not intend to kick the person in front of me. It is simply a reflex action over which I have no control. For something to be an action, at least in the moral sense, it must be something that I intend, something that I choose either explicitly or at least implicitly. This has a number of consequences.

First, it means that actions, properly so called, are expressions of who I am as a person, they reflect my intentions and in order to do so those intentions must be related to the wider narrative of who I am. I cannot simply intend anything, but only those things that make sense of my character, wider purposes, values, and commitments.

This means that what I might be able to intend changes over time as my character is shaped and reshaped by my intended actions. It means that the rationality of moral actions is in the end a form of narrative rationality because it is about rooting those actions within the story of a life in the broadest sense.

Finally, this also means that the task of moral understanding is in the end an interpretive one. I do not simply analyse actions on the basis of preformed rules and commitments, I consider actions in terms of the shape of a life. From a Christian perspective this means that I am attempting to understand how an individual life participates in and reflects the life of Christ into which my life has been incorporated at baptism.

VULNERABILITY AND JUSTICE

This life into which we are incorporated is never merely about our individual lives. It is not a life that is lived for myself but rather one that shares in self-offering for the other. Christians have, from our beginnings, been concerned therefore for the well-being of the marginalized, the outsider to society.

In the area of physician assisted dying there are still reasons to be concerned about the impact of this change on those in our society who are most vulnerable. This is the reason why most groups advocating on behalf of those who live with disabilities have not welcomed this change. While advocating against the change in the law would not at this time be a practical or useful activity for the churches it is important that we continue to express concern for those who might be adversely affected. This is not simply a slippery slope argument. It is rather based in the complexity of how constitutional protections work and the experience of other jurisdictions where the initially narrow grounds for physician assisted dying became widened out of legitimate concern that some who might benefit were excluded under the initial definitions.

In the Canadian context this is particularly telling, as the conditions under which physician assisted dying will be made available remain in so many ways vague at this time. The regulations to be adopted will be crucial in ensuring that individuals are not either actively or implicitly coerced and that those who are vulnerable and at risk receive particular protection.

DIGNITY AND ITS MEANING

Central to the debates concerning physician assisted dying, on all sides, is the question of the dignity of the human person. Yet, while all agree on affirming the dignity of the human person, there is little agreement on what that

means and little public reflection on the dangers or difficulties involved in various approaches to uphold such dignity. In our society dignity is most commonly linked to the capacity to be the author of one's own destiny. However, this is linked with understandings of human individuality and freedom that are difficult to maintain.

All of us wish to affirm the freedom of the individual, but as our discussion of intentionality made clear, this does not mean that individuals can simply do anything.

While we all understand that freedom as involving authorship of our own acts, the idea that this is done *ex nihilo* (*out of nothing*) is simply unsustainable. In truth, who we are, and therefore what we are free to choose and to do, is already to some degree shaped by our personal histories, our background, our education, our cultural and religious assumptions and many other factors. Any adequate and morally informative description of human freedom and its exercise needs to take into account the very real limitations involved in living out that freedom in real historical lives.

Further, the simple link of dignity with the capacity to be the author of our own lives rather prejudices the issue for those persons whose capacities in this regard are significantly, and perhaps permanently diminished.

Others would argue that 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 recognise 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 relationships is compromised.

In both of these approaches the difficulty is that dignity is only construed on the basis of the possession of certain qualities and capacities

and this once again may lead to a devaluing of those persons lacking those qualities. Perhaps the key point, however, is that the language of dignity is supposed to remind us that in decisions about the life of a person it is that person's life, inherent worth (however that is ascribed), values, hopes, aspirations, story, etc. that drive the decision-making process and not the imposition of interpretive frameworks from without, the imposition of what Zizak and Brueggemann would call ideology.

"*You matter because you are you.*" These are the words of Dame Cicely Saunders, expressing the foundational values of the modern palliative care movement. To uphold the intrinsic worth of the human person is to protect the very vulnerable members of society—those who have (or appear to have) little if any extrinsic value, because they do not have the capacity for full authorship or autonomy, and are not able to have the same sorts of relationships that more "productive" members of society have. This value challenges the linkage of dignity and worth with autonomy and ability to be in control of all aspects of one's life.

CONSCIENCE

One of the matters that was touched upon in *Care in Dying* and which is increasingly important in our new context is that of the role of conscience. It will surprise some people that the principle that the conscience must always be followed (*conscientia semper sequenda*) is a key element of Catholic moral theology that has continued if not with greater importance in the churches of the reformation. The role of conscience grants to the individual believer the responsibility to be the author of his or her own decisions.

This responsibility cannot be ceded to another, even to the church. Having said that, individual Christians have a responsibility to educate their conscience and this means a responsibility to

engage seriously with the teaching and traditions of the church. A decision to place oneself at odds with a longstanding and widely held teaching is not to be taken lightly. However, changing social context can lead to situations in which that tradition can seem misleading, unduly burdensome, or even simply destructive.

Christians are not of one mind as to whether changes in the context of our dying are sufficient to change or qualify traditional views regarding assisted dying. In this context, especially given the changed legal situation, effective pastoral care will need to be quite clear in its respect for the conscience of the person making decisions around their own dying. At the same time, this is not to be construed as pastoral indifference, or even abandonment. We can minister with respect and care even in situations that will unfold in ways that make us uncomfortable. Indeed, it is arguable that this is where our pastoral presence is most eloquent and important.

HOPE

As Christians we are called to lives shaped by hope. Hope involves the commitment that, whatever our circumstances, God is at work for our good (Ro 8:28 c.f. Mat7:11). It stands opposed to despair. At the same time hope is not to be confused with a passivity that is unresponsive to our circumstances. Hope requires that we cooperate with God in the purposes that God is working out in our lives. Under all circumstances this will involve seeking what God is doing in our lives. This is true even in adverse circumstances, and it is not contrary to the notion that hope might include the embrace of our death.

Paul, writing to the Philippian Church chooses life for the sake of the Philippian Christians, although he clearly indicates that his

personal hope is to “depart and be with Christ” (Philippians 1:23). Further, the willing embrace of death as an expression of hope in God’s faithfulness lies at the heart of our faith in the work of Christ.

Neither of these examples can be seen as either the act of, or the willing of, suicide, because neither of them are acts of despair. They raise for us the challenging pastoral question of how we might assist those faced with decisions around the end of life to make whatever decision they chose in faith and hope and in the embrace of God’s presence to them.

PROVIDING ALTERNATIVES

Having said this, if indeed decisions are to be made out of the commitments of those about whom decisions are made, then there need to be genuine alternatives and this currently does not seem to be the case.

In *Care in Dying* the argument was made that to move towards physician assisted death at a time when there were health care cuts and utterly inadequate provision of palliative care might be seen as cynical rather than caring. While it is now clear that the provision of such alternatives cannot function as a bar to patients making decisions to seek assistance to end their lives we remain of the view that this change will not reflect the intended affirmation of the dignity of patients unless there are genuine alternatives amongst which they can discern real and significant choices.

Urgent attention therefore needs to be given to the provision of appropriate (we would say excellent) levels of palliative care, social support and pain management so that any decision to avail oneself of physician assisted dying will indeed be a reflection of what expresses the patient’s dignity and not an act of desperation or fear.



THREE

PALLIATIVE CARE

Palliative care (from the Latin *palliare*, to cloak) aims specifically to relieve suffering—literally, to cloak, or wrap, the individual for protection from hurt. The derivation implies an approach to care that is more than simply the administration of pharmacological and other therapies.

Suffering may be physical, psychological, spiritual, or any combination thereof, it may be of intrinsic or extrinsic causation (or both) and it may occur for persons of all ages and at any stage in a disease or illness.

The words *miser cordia* and *caritas* can perhaps be applied in this sphere of health care more aptly than in any other. Palliative care truly requires the gift of heart—the deepest and fullest understanding of and compassion for the human condition and the willingness of providers to give of and from their very hearts to ameliorate that

condition. Together with the relief of suffering, palliative care aims to improve the quality of life for those living with and ultimately dying with or from serious illnesses.

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. For example: palliative oxygen therapy is often provided for people with advanced lung or heart disease, long before those people are explicitly near death. Notwithstanding its role in relieving suffering induced by or coincident with ongoing treatment, palliative care as referenced by the

Supreme Court in *Carter* is understood to mean the care of persons suffering with irremediable illness.

“You matter because you are you, and you matter to the end of your life. We will do all we can not only to help you die peacefully, but also to live until you die.”

–Dame Cicely Saunders, 1918–2005, founder of the Hospice Palliative Care movement.

Palliative care recognizes and addresses individual suffering. Palliative care also recognizes and addresses suffering that extends beyond the individual. Care is both patient-centric and family-centric, and may include not only the relief of specific symptoms but also palliation of distress arising out of conflicting individual understandings or experiences of disease, or out of varying expectations for treatment. Palliative care embraces the importance of relationship in human lives.

Good palliative care meets the patient within that person’s family and community contexts, facilitates important interpersonal contacts and assists patients and families to resolve issues relating to or arising from these contexts. Excellent palliative care is facilitative and permissive rather than prescriptive.

Although palliative care may be provided within any care setting including acute care hospital beds, it is often (and some would argue better) provided in the patient’s home (domiciliary care) or in more home-like institutions such as hospices.

Absent the availability of free-standing hospices, many health regions in Canada co-locate hospice or palliative care units (wards) within existing hospital structures or complexes. Regardless of location, the goal is to minimize intrusive institutional processes and optimize the normal rhythms and routines of the person’s life. Palliative care recognizes the therapeutic

importance of the external environment (gardens, green spaces) and incorporates music and other art forms in the care and support of patients. Palliative care facilitates spiritual care and support, whether faith-based or otherwise. The concept of “care close to home” is specifically and especially important in palliative care.

Modern palliative care is a multidisciplinary and specialized approach to the care of persons with serious illnesses. Multidisciplinary teams include physicians, nurses, therapists of all types, pharmacists, social workers, spiritual care providers, and many others. These teams are collaborative and non-hierarchical. Many of the team members will have taken extra training and/or have acquired specific expertise in the field and may include the patient’s usual Family Physician and other community caregivers who have ongoing therapeutic relationships with the patient. In addition, effective palliative care includes the invaluable contributions from volunteers both in practical and less tangible ways.

Palliative home care is about offering the same high level of care to the dying person in his or her home and is designed to provide care and comfort, as well as pain and symptom control to relieve suffering. Good palliative care at home does not leave the family and supporting community alone to make do in caring for the patient. The primary caregivers are supported by the same sorts of trained professionals described above, in addition to home care workers to assist in providing relief and assistance with household duties.

For Canadian physicians, Palliative Care crosses all traditional medical disciplines but is also a recognized special competence requiring the physician to take a one year post-certification program (that is, an additional year of training and evaluation subsequent to completion of specialty training and certification in the physician’s chosen discipline.) Training

is conjointly accredited by the Royal College of Physicians and Surgeons of Canada and the College of Family Physicians of Canada. Accredited programs offering this extra training to physicians exist in 13 of the country's 17 medical schools.

The Canadian Society of Palliative Care Physicians (CSPCP) is a voluntary organization of palliative care physicians. The CSPCP has published a brief position paper subsequent to the SCC *Carter* decision, and in its submission to the parliamentary Special Joint Committee on Physician Assisted Dying, in January 2016, included in its recommendations the following:

The Canadian Society of Palliative Care Physicians strongly advocates for a National Secretariat in Palliative Care. This recognizes that the most important priority is adequate investment in, and enhancement of, palliative and end of life care services. This investment in palliative and end of life programs must continue prior to and after introducing an option for physician- hastened death, to ensure patients do not choose hastened death due to lack of access to high quality palliative care services. If patients have a right to access hastened death, they should also have a right to quality palliative care. A National Palliative Care Secretariat could be charged with making this commitment to improved palliative care a reality.

Our Canada Health Act states that all Canadians should have universal, comprehensive access to care. This should include access to high quality palliative care. This is currently not the case [1][2] While we are discussing ways to provide assistance in hastening death, we need to ensure that access to high quality palliative care is prioritized as well.

The concrete suggestions in The Way Forward [3], the Canadian Medical Association "National Call to Action on Palliative Care" [4] and the Canadian Cancer Society report "Right to Care: Palliative Care for all Canadians"[2] could serve as a blueprint for the National Secretariat to implement a national strategy on palliative care.⁸

The care of persons with serious illnesses takes place across a number of distinct acts of care over time and in a particular context. Each episode of care, each decision taken (or not taken) and acted (or not acted) upon builds upon previous, and in turn sets the stage for subsequent, episodes and decisions. Such care is highly relational. The relationships between the recipient and the providers of care is fundamental to the experience of care and to the real and perceived outcomes of care. This type of care is person intensive and may place exceptional burdens on members of the care team; nevertheless, the care needs of the patient and family are always paramount. However, members of the team individually and collectively must attend to their own support and nurture.

Occasionally, caregivers may find themselves conflicted by the decisions or requests of patients. These situations will require caregivers to undertake a process of discernment and reconciliation of their roles. Rarely, caregivers may need to withdraw, in whole or in part, from some portion of the care plan for that individual. In such circumstances, the provider has a duty not to abandon the patient and not to frustrate the plan of care. Particularly in the context of palliative care, such decisions are potentially traumatic for all involved. Again, this care takes place in discreet acts and interventions over a period of time. Because of this, it may be extremely difficult for caregivers to recognize their need to withdraw

8. Canadian Society of Palliative Care Physicians, *Submission to the Special Joint Committee on Physician-Assisted Dying*, January 27, 2016.

and to determine the appropriate timing thereof. While supporting and enacting the patient's plan of care, members of the team may be called upon to support the provider(s) experiencing personal distress or conflict.

Unfortunately, and notwithstanding examples of excellence in many jurisdictions, the current state of palliative care in Canada does not meet the ideal described. Palliative care is insufficiently resourced, both in human and fiscal terms. Geography and population density are major factors preventing or limiting "care close to home" for many Canadians. These regions are particularly but not uniquely challenged by the resourcing of health care. Health care providers in these areas are often spread too thinly to have the capacity to provide high quality palliative care while simultaneously meeting the acute care needs in their communities. Even in regions with higher population density and/or more resources and capacity, acute care often trumps both home and hospice care of the elderly and those with chronic and/or terminal illnesses.

Within the narrow context of physician assisted suicide as described in the *Carter* decision, the Supreme Court has acknowledged the potential for physicians to be conflicted in the face of requests from patients for their explicit assistance in bringing about their deaths. The Court has expressly affirmed the right for a physician to exercise conscientious objection. The Court has not defined the term; nevertheless conscientious objection is ordinarily understood to be a fundamental inability for an individual to perform an act due to deeply held moral or religious convictions that are in direct and irreconcilable conflict with the requested act. The Court has assigned responsibility for managing conscientious objection to the legislative bodies and to professional regulatory authorities. Physicians will need assistance and support to discern their individual responses to this additional expectation and to deal with the

possible personal and professional consequences.

When the Supreme Court of Canada ruled in favour of assisted dying it accelerated not only the conversation of what assisted dying might mean and how might it be legally facilitated, but conversations as to what might constitute palliative care and what might the scope of such care include.

Comprehensive understandings of what palliative means and what constitutes palliative care are fundamental to facilitating pastoral conversations regarding assisted dying because either the conversation will happen within the context of a palliative care setting, whether that be within a clinical palliative care facility or a community palliative care program, or palliative care may be a viable option to assisted dying if such a service of care is not already part of the care plan of the individual who is seeking counsel regarding assisted dying.

The World Health Organization defines palliative care as follows;

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.

The Canadian Hospice Palliative Care Association builds upon this understanding of palliative care;

Hospice palliative care aims to relieve suffering and improve the quality of living and dying.

Hospice palliative care strives to help individuals and families:

- address physical, psychological, social, spiritual and practical issues, and their associated expectations, needs, hopes and fears
- prepare for and manage self-determined life closure and the dying process
- cope with loss and grief during the illness and bereavement experience.

Hospice palliative care aims to:

- **treat** all active issues
- **prevent** new issues from occurring
- **promote** opportunities for meaningful and valuable experiences, personal and spiritual growth, and self-actualization.

Hospice palliative care is appropriate for any person and/or family living with or at risk of developing a life threatening illness due to any diagnosis, with any prognosis, regardless of age, and at any time they have unmet expectations and/or needs, and are prepared to accept care.

Hospice palliative care may complement and enhance disease-modifying therapy or it may become the total focus of what constitutes palliative care.

Hospice palliative care is most effectively delivered by an inter-professional team of health care providers who are both knowledgeable and skilled in all aspects of care within their discipline of practice. Providers are typically trained by schools or organizations governed by educational standards and are accountable to standards of professional conduct set by licensing bodies and/or professional associations.



FOUR

PASTORAL CARE*

Pastoral care, in its many forms, involves no more precious mandate than the support and compassion required in the journey with a parishioner at the end-of-life. Care givers hear questions like:

“I have looked for God everywhere and can’t find him, where is he?”

“why wouldn’t God call me home?”

“why am I left to linger so?”

“why must I suffer so ... this is so unbearable”

These and similar words are often voiced by those who are facing the end of their lives. It matters little whether the source of their pain is physical, psychological, emotional or spiritual suffering.

What matters is that for many, the premium challenge of end-of-life is to continue to experience meaning, purpose and control over one’s life.

The legality of assisted dying will dramatically reshape the scope and tenure of pastoral care provided to those who face end-of-life concerns. Before the Supreme Court of Canada’s 2015 decision, end-of-life concerns were limited largely to questions of treatment, pain control and comfort. Now the 2015 Supreme Court decision places end-of-life care within a new legal and ethical framework that allows for the choice of assisted dying.

Faith communities, through their ministries of spiritual and religious care, will now be

* For purposes of clarity in this section dealing with pastoral care, those living with a mortal illness facing end-of-life challenges are referred to as parishioner. Pastoral care-provider refers to the priest, chaplain, deacon or lay visitor who provides spiritual and religious care to the parishioner and her/his circle of family, friends and care providers.

challenged to clarify their role in the provision of guidance and assistance at this final stage of an individual's life journey.

This presents our church, and those who care for the ill, with two fundamental challenges.

First: pastoral care-providers must discern honestly through prayer and consultation their personal views and values and how they affect their capacity to support patients in decision-making in relation to end-of-life and assisted dying. Can the pastoral caregiver, whatever their personal views, support an authentic request for assisted dying? If not, then the pastoral caregiver must seek out and make available to the parishioner appropriate alternate pastoral resources. The duty of care requires that the church be present in that care. If I determine that I am not the one to be able to provide the best pastoral care in that context, it cannot ensue that the patient is abandoned by the church.

Second: pastoral caregivers must assess the strengths and limitations of available resources that can, or cannot, support the parishioner who seeks assistance with dying. To promise support for a parishioner who seeks assisted death and then to discover there are either limited or non-existent medical resources to make such a request possible, is to create the opportunity for additional emotional distress for the parishioner. Likewise to deny existing resources to a parishioner seeking assisted dying because of the personal beliefs of the pastoral care-provider, (I do not believe in assisted dying and so I will not refer to those who do), is equally harmful to the parishioner.

Our faith tradition holds that all life is sacred. This belief is the foundation of all healing ministries. Support for assisted dying seems antithetical to this belief. And yet, for those who seek assisted dying, exploring fully the questions and implications regarding assisted dying often requires a fundamental and deep examination of the meaning and purpose of life for both the one

who is seeking assisted dying and the pastoral care provider. Seeking assisted dying is a reflection of the struggle for a quality of life upheld by a deep and abiding belief in the sacredness of life. It is certainly possible that life has become too painful, bleak or lonely. Abandonment by community, including church can only contribute to that loneliness. Or maybe life is too limited by illness. Or maybe life is understood as sacred, fully lived, complete and ready to end.

To "listen" another's soul into a condition of disclosure and discovery may be almost the greatest service that any human being ever performs for another.

—Douglas Steere, *Gleanings: A Random Harvest*
author, theologian, philosopher

Narrative methodologies, exploring a person's life story, may provide a framework helpful to both the pastoral care provider and the parishioner as they explore together the deeper meanings of assisted dying. For within one's narrative or life story lies the meaning which may inform the life and death decisions of assisted dying.

Ultimately, it is not the pastoral care givers belief, nor the traditions or dogma of any faith tradition, nor the hopes and desires of family and friends which will determine the choice of assisted-dying. The final choice remains with the parishioner, informed by their own conscientious appropriation of their faith tradition. Family and friends provide the primary community within which the conversations that shape decisions happen. The pastoral care giver's role becomes that of spiritual guide or facilitator. It is the pastoral care-giver who reminds and draws everyone's attention back to the reality that God is present and amongst them sustaining this difficult journey of discernment and choice within God's embrace of love and grace.

The pastoral care giver will be challenged to address the spiritual and religious needs not only of the parishioner who seeks assisted dying, but

of the parishioner's circle of family and friends who will struggle with their loved one as she/he discerns a desire for assisted dying and the care providers themselves, the professional health care providers who will facilitate decisions made. Here the role of the pastoral caregiver is to be present with and give expression to the needs and concerns of all who are involved in the process of assisting another to die.

Resources available to the pastoral care provider or pastor can be found within the rich Christian traditions of sacrament, ritual and the ministry of presence.

O God of peace,
who taught us that in returning and rest we
shall be saved,
in quietness and confidence shall be our
strength;
by the might of your Spirit lift us, we pray, to
your presence,
where we may be still and know that you are
God;
through Jesus Christ our Lord. Amen.

—*Book of Alternative Services, Collect,
Ministry to the Sick*

PASTORAL CARE AND SACRAMENTAL LITURGY

Our Anglican faith and witness rests within our sacramental traditions that mark the passages of life from birth to death. Our sacramental liturgies for those who are ill or approaching death provide for the lifting up of petitions and questions of faith, the searching for God in our present moments and the reassurance that God is ever present amongst us. As such, our sacramental liturgies can assist those who are dying to find the answers they seek and to experience, even in such difficult times as end of life, God's abiding love.

PASTORAL CARE AND THE USE OF RITUAL

Christian ministry, by its very nature, involves ministries of healing which strive for the well-being of the mind, body and spirit. In May 1968, the *Bishop of Toronto's Commission on the Church's Ministry of Healing* noted;

Health and healing are difficult to define, but health may be described as a condition of satisfactory functioning of the whole organism. The words; health, wholeness and holiness are closely linked in origin. Healing may, therefore, be described as the process by which a living organism, whose functions are disordered, is restored to health or "made whole"; that is to say, returns to complete functioning. In a sense, all healing maybe considered to be Divine. Many aspects of healing are still outside our present knowledge, and this we should honestly and humbly admit.

Rituals have always been an important part of our lives. Rituals give form and symbolic meaning to feelings and events. Rituals provide a container or catalyst that allows for the exploration and expression of whom one understands oneself to be. Rituals assist in the articulation of meaning. Rituals can capture and give expression to the emotions and experiences of separation, transition, healing and celebration, to name but a few of those elements which constitute and give structure to our lives. Rituals can capture the experiences of life and frame them into moments of meaning within which decisions can be made.

It is a commonly held truth of the Christian experience that the healing of a person can be achieved without the blessing of a cure. The Christian ministries of laying on of hands and holy anointing bear testimony to the lived experience that wholeness of person, despite the reality of terminal disease, is possible. These two rituals, which rest upon the healing presence

of God made manifest through the Holy Spirit can become a powerful resource available to the pastoral care giver.

The laying on of hands, holy anointing, guided meditation and structured prayer are but a few of the rituals available to the pastoral care giver which may provide a valuable container or frame within which the parishioner and her/his family, friends and care providers can find resolutions to the difficult questions surrounding assisted dying.

Rituals, designed by the pastoral care giver, using symbols unique to the circumstances of the parishioner can also significantly frame the experience of the parishioner and facilitate resolution of end-of-life questions.

A young man, dying of AIDS, was surrounded by his family who were conflicted and distraught over his illness, which had revealed his homosexuality, bringing moral judgement upon him which was difficult for the young man to bear. The family's distress over their dying brother and son seemed to crowd out his ability and need to be heard. The chaplain suggested a ritual that might facilitate much needed conversation amongst family members. Using the tradition of the talking stick, the chaplain designed a ritual involving prayer and a candle. The chaplain met with the family in the young man's room, and, after a short prayer and a moment of silence, the chaplain lit the candle. All had agreed that whilst the candle was lit, only the young man could speak. Which he did, addressing each family member separately, mother, father, siblings, sharing his feelings of loss, love and hopes for forgiveness. Once the young man was finished, the chaplain read another prayer appropriate to the setting and extinguished the candle. The family, centered by the candle and prayer and ritual of structured conversation, broke through all of their fears and judgementalism and embraced

anew their son and brother. Significant healing took place, health care decisions were made in a collaborative way and planning for the future was made together. Because of this simple ritual, the young man was able to share his feelings, express his love and say his farewells.

—Reverend Canon Douglas Graydon

PASTORAL CARE AND THE MINISTRY OF PRESENCE

Our Christian tradition is in many ways built upon the practice of being present to God. The ministry of presence builds upon this tradition whereby the pastoral care-giver gives oneself over to the other, in this case, the parishioner and their community. It involves active listening skills combined with unconditional regard for the parishioner, family, friends and other care providers. The ministry of presence waits upon the *disclosure of one's soul* (as articulated by Douglas Steere).

It is within such a ministry of presence that the narrative of the person seeking resolution of questions regarding assisted dying arises. With God's good grace, resolution is found within the life story of the parishioner.

Being present to another requires the sacred ability to listen, to speak and to touch. It is within the sacred conversation of being present that one can sometimes discern most clearly the needs, questions and desires of the other. Within the ministry of presence, sacred conversations remind us of our mortality and vulnerability, our sense of self-worth and the beliefs that give shape to the meaning of our lives. To enter into that conversation, to be truly present, the pastoral care-giver must be deeply aware of her/his own values, faith and spirituality. The pastoral care-giver must be willing to share non-judgementally their own stories, experiences and life lessons and must strive to build bridges between the stories told by the

parishioner and the stories / teachings of Christ.

The ministry of presence builds bridges and linkages between the parishioner and their community of care. A ministry of presence empowers truth telling and the making of meaning. A ministry of presence connects life with faith and in as such can facilitate resolution of the challenges of end-of-life care and questions regarding assisted dying.

SELF-CARE

This ministry can be a taxing and stressful one. End of life care requires that the pastoral care giver set aside one's concerns and worries, so as best as possible to enter into the deep listening which will be required within a ministry of presence. The practice of self-care by the care-giver is essential. Self-care resources are readily available and pastoral care givers are encouraged to seek out prayerful support groups and/or spiritual guides to assist them in their ministry. Collegial support—even simply connecting with others who undertake the same or similar ministry—is also critically important.

REFLECTIONS

The reflections included here arise from the chaplaincy community of the Diocese of Toronto. The Task Force would recommend that each Diocese access the wisdom and experience of end-of-life stories within their own communities of faith.

I HAD A PATIENT in her mid 40's who had a rare disease that affected all of her digestive organs. Her lungs were filled with liquid and she could not eat without vomiting. She was profoundly unhappy with her quality of life. Doctors generally answered all her questions with "we don't know" and then sent her for

more tests and to see more specialists who also did not seem to know. She once asked one doctor if she was dying—the answer she received was "not today." Another doctor told her they did not want to do some possible procedures because of the harm they would cause. The patient was worried that she wasn't able to give all her fears to God—that she kept taking them back again, not wanting to be honest with God. She worried that she wasn't battling hard enough for health, and that made her not a good mother or wife or friend, because she felt that she was only thinking about herself. At least that's how she was owning up to it. When I asked the question, "Can you tell me about your fears?" she said, "I am not ready to die. My children are being forced to grow up. It's my fault. And I won't see it either." In fact, she wasn't thinking about just herself at all, but her thinking was confused and tied up with worry.

Human life is profoundly relational. There are no isolated, self-made individuals. We are made for relationship and find fulfillment in healthy and life-supporting relationships and communities.

My patient was struggling with her place and her life and death in relationship. In the next breath after expressing her worry for her children, she told me, "but for me I want this to end well, if I could choose just for me." I asked her if she was thinking about how that end might look as a choice. She was, in fact, viewing it in terms of choice, and she felt guilty for that. As it was then, it is my work as a pastoral caregiver to have the patient honour her own desires, to help her hear her own judgments. I invited her to talk about her sense of God and God's presence with her in these judgments, and of her values, however she might choose to act upon them. I asked her to ponder the thought that relationships can also be part of dying. It was important

that she allow herself the possibility of choices that give her peace, and in those she could also serve her relationships after her death. My role was to work with her to untie the knots in her thinking, knowing that the moment of death is a time of ending and beginning for those left living. At heart, it was for me to accompany her in making the choice that she saw as possible and best for herself and for those whom she loved. These relationships and sense of self were in the knots she needed untied. And they were all untied by her within her own narrative, never with me telling her what must be done or what was “right.”

– The Reverend Joanne Davies, Anglican priest and Ecumenical Chaplain, Mount Sinai Hospital, Toronto

FOR OVER 20 YEARS I was a chaplain who specialized in end-of-life care. Fifteen of those years were spent within the HIV/AIDS community, mostly at Casey House Hospice in Toronto. During the early days of the AIDS pandemic, young gay men were facing catastrophic illnesses. Many railed against the injustice of facing an early death while also battling the fear, social stigma and judgementalism that HIV/AIDS engendered around the world. Many wanted to die while still in control of their life. Everyone had a very clear understanding of the pain and suffering which awaited them as AIDS destroyed their immune systems and then destroyed their bodies.

Seeking assistance with dying was at times a daily conversation. Most of the men I met had been part of the gay pride movement advocating for the right to live openly and authentically as gay men who wished nothing more than what society offered - that being the right to love and be loved without fear of being judged.

Assisted suicide, (as it was referred to then) was illegal. All that I could promise was a willingness to stay with these men and to seek with them the presence of God who was there amongst and with us.

What arose from that catastrophic world of illness was the creativity of many who embraced their dying as best as they were able. Extraordinary healing took place within that painful place. Young men healed family wounds, expressed deep and abiding love for one another and celebrated their lives with extraordinarily creative funerals.

Within that experience I learned that, for some, assisted dying, if it had been possible, would have been a choice that would uphold the dignity, autonomy and humanity of their lives. Assisted dying would have been the natural extension of ensuring control within their life and therefore would have maintained a sense of quality of life and a recognition of the sacredness of life. I learned that my role as chaplain was primarily to assist them in searching out an answer to the reason for unrelenting suffering and loss of quality of life. For others, assisted dying, if it had been available, would have been an authentic reflection of our God given freedom of will and self-determination which is, I have learned, a fundamental dimension of who we are as created by God.

Our society is now at that place where assisted dying is a reality. For me, as a person of faith, the challenges and questions involved in this reality are deep and nuanced. My ministry as a chaplain has taught me that even within this new reality I know God is with us and amongst us. This for me, is good news indeed.

–The Reverend Canon Douglas Graydon, Coordinator of Chaplaincy Services, Diocese of Toronto



FIVE

REFERENCES AND DEFINITIONS

ABANDONMENT: In health care, the act of leaving a patient in need of care without care, i.e. walking away from that person which could be due to several factors, but is considered an unprofessional and inhumane act.

ADVANCE CARE PLANNING: An ongoing process of reflection, communication and documentation of a person's values and wishes for future health and personal care in the event that they become incapable of consenting to or refusing treatment or other care. Conversations to inform health care providers, family and friends—and especially a substitute decision-maker—should be regularly reviewed and updated. Such conversations often clarify the wishes for future care and options at the end of life. Attention must also be paid to provincial/ territorial legal and health guidance. (Canadian Nurses Association (CNA, 2015).

ASSISTED SUICIDE: The “intentionally killing oneself with the assistance of another who deliberately provides the knowledge, means or both” (Dickens et al. 2008, p.72).

AUTONOMY: Our capacity to be the authors of our own actions, to make free choices, and thus take up our role as co-creators with God

BEST INTERESTS: A term used to describe the basis for a decision made on behalf of an incapable person in the absence of knowing what that person would have wanted.

BRAIN DEATH: The term relates to the clinical criteria developed to determine that death had occurred in patients on life support systems that masked the occurrence of death, diagnosed according to the more traditional heart-lung

criteria. According to this definition, death has occurred when the entire brain, including the brain stem, have irreversibly ceased to function

COMPASSION/COMPASSIONATE: The ability to convey in speech and body language the hope and intent to relieve the suffering of another. Compassion must co-exist with competence. (CNA Code of Ethics 2008, p. 23).

DEHUMANIZATION/DEPERSONALIZATION: These are terms used in *Care in Dying* but not defined. One definition is “the perception of people as objects; the instrumental use and exploitation of patients and providers; coldness and indifference in social interaction; the repression and limitation of human freedom (loss of options) and social ostracism and alienation” (Howard et al. p. 12).

DESIRE FOR HASTENED DEATH (DHD): A term inevitably intertwined with physician assisted death (PAD) and physician assisted suicide (PAS) and euthanasia. (Branigan, 2015, p.1)

DESIRE TO DIE STATEMENT (DTDS): A patient’s expression of a desire to die, described as ‘death talk’ or ‘suicide talk’. Not all ‘desire to die’ statements represent suicidal ideation. They may have other foundations “not necessarily associated with a specific desire to expedite the dying process”. (Hudson, Schofield, Kelly, Hudson, Street, et al. 2006).

DOUBLE-EFFECT: A principle that means that “some human actions have both a beneficial and harmful result, e.g. some pain treatment for the terminally ill person might carry a possibility of shortening life, even though it is given to relieve pain and is not intended to kill the person. (Catholic Health Alliance, p.115)

EUTHANASIA: occurs when a physician intervenes directly to bring about the death of the patient, e.g. to inject a patient with a lethal dose of morphine at the patient’s request would constitute euthanasia.

Types of Euthanasia:

Voluntary: and act carried out according to the wishes of an informed and competent patient who without coercion requests that his or her life be ended involuntarily—occurs when a person who is competent to consent but, has not requested euthanasia, is killed

Non-voluntary euthanasia: refers to a situation in which the patient does not have the capacity to consent either through age or immaturity, unconsciousness, mental illness, or incompetence is killed.

EXTRAORDINARY TREATMENT: A treatment that is both ineffective and unduly burdensome; may prolong the process of dying rather than save life. (The use of these two terms above is discouraged by current experts in palliative care and by some theologians)

PALLIATIVE CARE: Care given to improve quality of life for people facing challenges associated with chronic, life-threatening illnesses. Through the prevention and relief of suffering, palliative care promotes early identification and comprehensive assessment and treatment of pain and other challenges, including physical, psychosocial and spiritual issues (CHCPA, 2014, p.2). Palliative care is provided in all care settings including homes, communities, institutions (e.g. hospitals, hospices, long term care facilities). It is care that starts at a diagnosis of a chronic, life-threatening condition, carries through until death and continues into bereavement and care of the body (Carstairs, 2010).

PALLIATIVE CARE APPROACH: Takes the principle of palliative care (dignity, hope, comfort, quality of life, and relief of suffering) and applies them to the care of people with chronic, life-limiting disease conditions by meeting their full range of physical, psychosocial and spiritual needs at all stages of life, not just the end. It does not link the provision of care too closely with prognosis but more broadly focuses on conversation with people about their needs and wishes. (Stajduhar, 2011).

PALLIATIVE CARE IN HOSPICE: Specialized end of life care that “aims to relieve suffering and improve the quality of life and death. It is “provided by health professionals and volunteers who give medical, psychosocial and spiritual support. The goal of care is to help people who are dying and their families to have as much peace, comfort, and dignity as possible. The caregivers try to minimize suffering as well as control pain and other symptoms so a patient can remain alert and comfortable as the person wishes. Hospice palliative programs also provide services to support a patient’s family. (WPCA & WHO, 2014, p.6). As of 2015, only 30% of the population of Canada has access to Hospice Palliative Care.

PALLIATIVE SEDATION: The use of sedative medications to sedate, either lightly or deeply, a person who is experiencing intractable symptoms such as shortness of breath, confusion or pain when all regular methods have failed or are not possible (Catholic Health Alliance of Canada, 2012, p. 127)

PASSIVE EUTHANASIA: Occurs where the intention is to allow the patient to die from a treatable condition. The example given is a decision not to treat a Down’s patient for duodenal atresia which is easily correctable.

PHYSICIAN ASSISTED SUICIDE (PAS): The provision by a physician of the means by which a patient ends his or her life, or the provision of information which a patient may use to obtain effective means to end his or her own life.

PHYSICIAN ASSISTED DYING (PAD): Where a physician intentionally participates in the death of a patient by directly administering the substance or by providing the means whereby a patient can self-administer a substance leading to his or her death (Canadian Medical Association, 2014).

SANCTITY OF LIFE: That human life is valuable and precious since human persons are made in the image and likeness of God.

SUBSTITUTE DECISION-MAKER: A capable person with the legal authority to make health-care treatment decisions on behalf of an incapable person. Since provincial and territorial legislation is not uniform across Canada, each jurisdiction has its own guidelines related to substitute decision-making and instructional directives for treatment and care. (CNA 2015, p.9)

SUFFERING: A state of real or perceived distress (i.e. physical or emotional pain) that occurs when a person’s quality of life is threatened. It may be accompanied by a real or perceived lack of options for coping, which create anxiety. (CNA, 2015)

TERMINAL SEDATION: Sedation provided to those patients where suffering is deemed uncontrollable. It is a means of keeping a patient asleep and pain free until they pass peacefully (Wilke, 2013). This would be equivalent to palliative sedation to unconsciousness.

TERMINATION OF TREATMENT: Refers to medical situations where medical treatment is no longer indicated and all treatment except **palliation** (food, hydration, pain relief, etc.) is withdrawn. *Care in Dying* included a lengthy summary distinguishing the law of refusal of treatment, intention, and passive euthanasia which is considered not helpful in this definition.

VOLUNTARY REFUSAL OF FOOD AND FLUID (VRFF): Choice made by an individual to refuse food or fluid voluntarily with our without the aid of physicians (Branigan, 2015).

WISH TO DIE (WTD): A patient's expression of a wish to die which must be understood because a superficial understanding could lead to someone taking the statement at face value or medicalizing it. (Ohnsorge, Gudat & Sutter, 2014).

WITHDRAWAL OF TREATMENT: Allows for the removal of therapies that are useless or unduly burdensome.

WITHHOLDING, WITHDRAWING, AND REFUSAL OF TREATMENT: Actions such as withholding or withdrawal of life-sustaining treatment (**WWLST**), such as ventilation, cardiopulmonary resuscitation, chemotherapy, dialysis, antibiotics, and artificially provided nutrition and hydration, is ethically acceptable. WWLST is allowing the patient to die from their underlying medical condition and does not involve an action to end the patient's life (American Association of Nurses, Position Statement on Euthanasia, Assisted Suicide and Aid in Dying, 2013, p. 5).



SIX

PRAYER RESOURCES

In this collection are resources for prayer in addition to those provided already within the Anglican Church of Canada's *Book of Common Prayer*, *Book of Alternative Services*, and *Occasional Celebrations*.

O GOD our Creator and Sustainer, receive our prayers for N. We thank you for the love and companionship we have shared with him/her. Give us grace now to accept the limits of human healing as we commend N. to your merciful care. Strengthen us, we pray, in this time of trial and help us to continue to serve and care for one another; through Jesus Christ our Saviour. Amen. (*Evangelical Lutheran Worship* – [ELW])

O LORD our God, send your Holy Spirit to guide us, that we may make our decisions with love, mercy, and reverence for your gift of life; through your Son, Jesus Christ our Lord. (ELW)

LORD Jesus, in the night before your suffering and death, you struggled with all you were about to encounter. Be with N [and her/his family] in this anxious moment as they face difficult choices about medical treatment, especially those that may involve suffering and pain. Through it all, Lord Jesus, be a strong companion and guide along the way, for your love's sake. (*Ministry With the Sick [MWS]*)

LORD of all wisdom and source of all life, we come before you as we struggle with decisions about life and death that rightly belong to you alone. We confess that we act with uncertainty now. Give us your help, and guide us, merciful God, in your loving concern for N. who lies in grave illness; through Jesus Christ our Redeemer. Amen. (ELW)

GOD our Wisdom: Bless the decisions we have made in hope, in sorrow, and in love; that as we place our whole trust in you, our choices and our actions may be encompassed by your perfecting will; through Jesus Christ who died and rose for us. Amen. (ELW)

JESUS, at Gethsemane you toiled with terrifying choices. Be with me now as I struggle with a fearful choice of treatments which promise much discomfort and offer no guarantee of long-term good. Help me know that you will bless my choice to me, and, good Saviour, be my companion on the way. Amen. (*Enriching Our Worship [EOW]*)

O GOD, who in Jesus stills the storm and soothes the troubled heart, bring hope and courage to N as she/he waits in uncertainty. Bring the assurance that you will be with her/him in whatever lies ahead. Give her/him courage to endure all that she/he now faces, for you are our refuge and strength. You are God, and we need you. We pray in the name of Jesus Christ, our Saviour and Lord. (ELW)

LOVING God, in every age you listen to the cries of lament and the questions about your wisdom from your servants who face suffering and death. In this time of distress and despair, hear the cries and questions of N [and her/his family and friends]. Stand with them in their suffering, that they may face the future with the confidence that nothing can separate them from your love in Christ Jesus, in whose name we pray. (EOW)

GOD, our Healer and Redeemer, we give thanks for the compassionate care N. has received. Bless these and all health care providers. Give them knowledge, virtue, and patience; and strengthen them in their ministry of healing and comforting; through Jesus Christ our Saviour. Amen. (ELW)

LITANIES

Let us pray to God, the helper and lover of souls, saying “**Holy One, help us!**”

That we may know your near presence with us, blessed God:

Holy One, help us!

That N. may be released from the bondage of suffering, blessed God:

Holy One, help us!

That our actions may proceed from love, blessed God:

Holy One, help us!

That our best judgments may accord with your will, blessed God:

Holy One, help us!

That you will hold N. and us in the palm of your hand this day, blessed God:

Holy One, help us!

That all our fears may be relieved as we place our trust in you, blessed God:

Holy One, help us!

That as N. labours into new resurrection birth, we may surround him/her with courage,
blessed God:

Holy One, help us!

That although we now grieve, joy may return in the morning, blessed God:

Holy One, help us!

(ELW)

Hear, encourage, and strengthen us as we pray to you, Holy One, saying,
“**We put our trust in you.**”

As the centurion placed his sick servant under Jesus’ authority, Holy One:

We put our trust in you.

As Jonah cried out from the belly of the fish, Holy One:

We put our trust in you.

As did the three young men in Nebuchadnezzar’s fiery furnace, Holy One:

We put our trust in you.

As Gideon laid siege to his enemy with a tiny force, Holy One:

We put our trust in you.

As the sons of Zebedee left their father and their boat to follow Jesus, Holy One:

We put our trust in you.

As the magi followed the star, Holy One:

We put our trust in you.

As did Martha and Mary at the opening of Lazarus’ tomb, Holy One:

We put our trust in you.

As Mary Magdalene released her risen Teacher, Holy One:

We put our trust in you.

(ELW)

Let us pray with confidence, anticipating heaven, and let the people respond,
“**Lead your child home.**”

To the gates of Paradise: **Lead your child home.**
To your mercy-seat: **Lead your child home.**
To the kingdom of heaven: **Lead your child home.**
To the crown of glory: **Lead your child home.**
To the land of rest: **Lead your child home.**
To Jordan’s other shore: **Lead your child home.**
To the Holy City, the Bride: **Lead your child home.**
To the safe harbor: **Lead your child home.**
To the font of life: **Lead your child home.**
To the gates of pearl: **Lead your child home.**
To the ladder of angels: **Lead your child home.**
To the land of milk and honey: **Lead your child home.**
To the clouds of glory: **Lead your child home.**
To the refreshing stream: **Lead your child home.**
To the reward of the righteous: **Lead your child home.**
To the dwelling-place of God: **Lead your child home.**
(ELW)



SEVEN

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EIGHT

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SUBMISSION TO THE SPECIAL JOINT COMMITTEE ON PHYSICIAN ASSISTED DYING

THE ANGLICAN CHURCH OF CANADA
3 FEBRUARY 2016

BACKGROUND

The Anglican Church of Canada includes approximately 700,000 people across Canada, including a strong indigenous membership, along with people who come from every continent. While we were once a church of dominantly anglo-celtic ethnicity, we are now a multi-ethnic church with a face that looks a lot like the face of Canada. We are also a church of diverse perspectives on almost any issue you can say. We are rooted, though, in a shared compassion and a shared conviction of the worth and dignity of human persons, a compassion and conviction we share with many Canadians.

We have chosen here to frame our submission based on questions that arise from extensive Anglican pastoral practice and reflected upon experience, along with insights from our moral and theological tradition. Regardless of their position with respect to the Supreme Court's Decision in the Carter Case, Anglicans across the country are deeply involved in thinking about and discussing the complexity of its implications. Our church leaders have been providing leadership in public forum discussions and in consultations with regulatory bodies.

We trust that the questions raised here will contribute to your deliberations as you work out a legislative framework following upon the decision of the Supreme Court in the Carter case.⁹ We recognize that Anglicans across the country hold, in differently nuanced ways, views on the rightness or wrongness of the Supreme Court decision. We also, though, share fundamental values, points of doctrine, and ways of moral discernment. At root, these values are not incompatible with those shared more widely in Canadian society.

Ours is a contribution that comes from the concrete experience of accompaniment with the sick and dying, their families and communities. It is shaped by our commitments to social, economic and racial justice, the dignity of the human person, and the practices of love, compassion, and care. We are learning continually what it is to walk in committed partnership with those who are different from our majority population, and know what it is to listen well. When we listen, on this matter, we hear very good questions.

The Anglican Church of Canada is not new to the consideration of tough ethical issues regarding death and dying. In the mid-1970s, a report was commissioned to offer guidance on end of life care. When

9. What follows is not a formal *statement* of The Anglican Church of Canada either for or against physician assisted dying. Such a statement would require a resolution of our highest decision making body, the General Synod, and would presume a will to action by that body on a matter that may well fall within the category shared by other issues held by us to reside within the sphere of conscience.

issues relating to euthanasia rose to prominence in public discussion in the 1990s, our Church carefully conducted research and engaged public discussions. The result was *Care in Dying* (1998), a resource still much in use today. It has helped to educate our constituency, for example, on the distinctions between pain relief that has a secondary effect of hastening death, and passive and active euthanasia. Though not a statement of policy, it has served us well in raising issues of concern and questions for further deliberation.¹⁰

At present we have a dedicated task force working specifically to address the matter of physician assisted dying. Its members include health care and legal professionals, (with specialists in medical ethics, palliative care, health care law, family medicine, and nursing) pastors, ethicists and spiritual care providers. It is as such deeply inter-disciplinary, and involves highly-placed professionals.

Within our church, lay leaders and lay pastoral visitors, parish nurses, deacons, parish priests, and chaplains have long and deep experience in accompanying the sick and dying, along with their families and primary communities. We know what it is to walk with people who are in pain and suffering, and through difficult end of life decisions.

Spiritual care providers are often intimately involved within the wider framework of the health care team and the family of the patient. Though spiritual care involves prayer and sacrament, it is even more about sharing a journey, both with the patient and with the family, in which deep listening fosters reflective openness—emotionally, morally, spiritually and intellectually. Spiritual care is always about inviting and attending to the patient's own narrative and reflections, and always carries with it an element of conversational moral and ethical discernment. In all of this, we are called to walk together, listening and talking, without being prescriptive, but enabling patients and families to make the best decisions they can within the context in which they are living, and within the best possible support systems.

The Anglican Church of Canada Task Force on Physician Assisted Death has just completed a resource to support those who provide care and accompany the dying.¹¹ The introductory chapter is headed with a verse from the Hebrew Scriptures (The Old Testament) that reads:

*But seek the welfare of the city where I have sent you into exile,
and pray to the Lord on its behalf, for in its welfare you will find your welfare*

—Jeremiah 29:7

10. "The General Synod in 1975... established a task force on human life whose work resulted in the report, *Dying: Considerations Concerning the Passage from Life to Death*. This report did not give extended attention to issues of euthanasia and assisted suicide. In 1990, the Doctrine and Worship Committee was asked to formulate a theological statement on euthanasia. A draft statement was produced by a working group in 1995... (but was put on hold) ...In the fall of 1996, the Faith, Worship and Ministry Committee were approached by the Canadian Council of Churches... (who) asked whether a draft statement prepared by their Faith and Order Committee... was consonant with the policy of the Anglican Church of Canada. (We)... were unable to confirm that the statement was consonant with the church's policy because, at this time, we have no policy. ...Further, (our)... conversation suggested that, although there were clear differences of perspective, there were some common concerns. While they recognized the need to think carefully about the status of any statement, the committee came to believe a statement whose primary intention was pastoral would be valuable. They believed that the aim of the statement should not be primarily to seek to dictate policy to lawmakers, but to raise issues which might be of concern to many Anglicans and other people of good will on both sides of the debate." From *Care in Dying*, 1998. The present stage of work in 2016 takes the same approach: raising issues and questions.

11. Expected to be released by the end of February 2016.

This part of our Jewish and Christian story reminds us of several things, with respect not only to this particular issue in health care. We are part of ‘the city’, a wider community, nation or country in which not everyone is like us, nor should they be, nor do we expect that the wider community outside (in our case) the Anglican Church of Canada to have the same faith perspective, or any faith perspective, to bring in to moral discernment, debate or the creation of legislation.

And, in that context of ‘the city,’ we have a duty to care about, to pray for, to live in harmony with, and to act with respect to all others on the basis of their inherent human dignity and worth. This extends to the ways in which Anglicans have consistently offered spiritual care to any who call upon us, and those whom we encounter in daily life (of any faith tradition or no faith tradition). Our understanding of the duty to care for all extends, truly, to all: persons of different or no faith tradition, and those who choose physician assisted death, and those who do not choose this way.

These experiences have nurtured in Anglican pastoral sensitivities a lived wisdom that has become quite good at asking questions, particularly when faced with what seem to be binary positions or options. One of the things that we therefore offer, in seeking “the welfare of the city” is a stance that looks squarely at these options, pays attention to wider contexts of persons-in-community, cultures, power and privilege issues and considerations of compassion and justice all around, and says “it’s not that easy.” From there, we begin to raise important questions.

In light of the Supreme Court decision, the following are questions and concerns that we offer with the request that the Joint Committee receive with a commitment to engage.

1. DIGNITY, PERSONHOOD, AND COMMUNITY

At the foundation of Christian faith is the assertion that all human beings are created by God, in the image and likeness of God. It is on the basis of our very creation that we are motivated to uphold the dignity and worth of every human life. At the roots of our faith is the assertion that human persons, being in the image and likeness of God, are the bearers of an inalienable dignity that calls us to treat each person not merely with respect for their personhood, but with love, care, and compassion.

From these assertions follow the high value placed on personal conscience. It is not in juxtaposition but in harmony that we also say that persons do not exist apart from relationships. The questions are not about individual versus community based decision making (either-or), but rather about the person within his or her relationships (both-and). Personal conscience must be honoured, conscience shaped in the context of non-coercive, healthy, and just relationships towards sound decision making. The right to individual self determination and personal freedom and choice, and the right not to be coerced, are themselves rights shaped in concrete relationships.

Noting that the Supreme Court decision in Carter presumes the person to be a fully autonomous being, we raise here several questions.

Many cultures and faith traditions within the Canadian context are of the view, shaped by lived experience, that every person is part of a community, wherein they participate in receiving and in shaping values and responsibilities. Individual values and decisions are shaped by relationships, and individual choices and concomitant actions have an effect on the community. Personal conscience must be followed; and all personal conscience shaped within the complexity of real relationships.

Q How might the legislative framework pay attention to key relationships around the patient, when looking at the causative elements in the patient's decision making in order to determine the freedom of a decision?

It is said by some that from North Atlantic/Western culture has emerged a sense of selfhood and individual rights that is simply a matter of inevitable positive development. However, assertions of this sort are continually tested and found wanting, both in everyday interdependence of persons in communities and families, and at times of crisis. The Anglican Church of Canada knows deeply, and in ways that challenge our own structures and priorities and values, how colonialism has devastated the Indigenous peoples and the cultures of this land, enforcing more individualistic systems and destroying communal cultural ways.

Q What do the Indigenous peoples of this Land, and others whose lives and decision making processes are more shaped by the high value placed on community, have to teach us? What will a legislative framework look like after having listened and learned to these experiences?

To assert that each human being has inherent dignity is to talk about worth and value in the essence of the person. We wonder how it has become that the notion of dignity has come to be equated with the power to have authorship over one's own life. In this shift, dignity is construed on the basis of certain qualities and capacities—an ideological equation that implies that those without full power of self-determination and autonomy over their own lives (bodies and minds) have lesser dignity than others. Is this not a dangerous path, and contradictory to advances that have been made with respect to care for vulnerable populations and those who have had their self-determination stripped from them?

Q When referring to dignity of the person or of the choice, what are the factors that determine dignity? Does someone without the capacity to opt for a choice not to ask for physician assisted death not have sufficient dignity? How will you treat the notion of dignity within the legislative framework without narrowing to a definition that excludes large segments of the population from being considered to possess dignity?

Anglican tradition and practice uphold some core principles, namely that moral discernment be:

- Compassionate: rooted in love and empathy;
- Concrete: more concerned with faithfulness to the gospel and character of Jesus, than with abstract and generalized rules or principles;
- Communal: taking place within community;
- Conscientious: respecting and calling forth the conscience of a person within the reality that they face (conscience must be followed)
- Critical: not content with the simplistic totalizing responses of other sides.

Q Will a framework for legislation foster a context in which the conversations called for by these principles will be encouraged, or be truncated?

Our Canadian society reflects the conflict between our commitment to care for the vulnerable, and the pressures of a more competitive individualism. The health care system is perhaps the place wherein these conflicts are enacted the most, and where—in situations of extreme financial pressure—duty to care is vulnerable to an interpretation that defaults to a less expensive set of options.

Q *How can a legislative framework ensure that appropriate care does not suffer from economic restriction, either real or ideological?*

2. NATION TO NATION RELATIONSHIP

We rejoice in the commitments, made by our Federal Government under Prime Minister Justin Trudeau, to new and just relationship between the Federal Government and First Nations, Inuit, and Métis communities. These are being framed as “Nation to Nation” relationships. We have learned so much, and we have so much more to learn from conversation with First Peoples. The conversation starts from the stance of newcomer peoples and dominant cultures and powers first *listening*.

On the basis of longstanding commitments and actions towards healing, reconciliation, and justice in right relationships with the First Peoples, the Anglican Church of Canada is conscious of when and where Indigenous voices and perspectives are present and when and where they are not.

Q *What assurance can the Joint Committee provide that First Nations, Inuit, and Métis leaders, and those who provide health care in those communities, are being consulted fully, Nation to Nation?*

Q *How would a legislative framework include values and perspectives from Indigenous peoples not as a special case, but integrated in a fully Canadian piece of legislation?*

Our Task Force invited submissions from Anglicans across the country about the matter of Physician Assisted Dying. Amongst others, we heard from health care workers in northern and Indigenous communities wherein, as is commonly known, the rates of suicide especially amongst young people is highly disproportionate to those in the rest of the population. This extends beyond the north to Indigenous peoples living in urban centres. Those who wrote to us expressed bafflement that there could be decisive and swift action on provision of physician assisted suicide when a) the crisis in suicides has not been addressed in ways that have made a difference in their communities, and b) there is inadequate health care and social service provision in so many poorer parts of our nation—for primary, specialist, psychiatric and palliative care.

Our church has undertaken a major initiative in suicide prevention. For many years our leaders have been on public record urging change in the conditions of poverty, intergenerational healing from Residential Schools, and other major social and economic illnesses at the root of the crisis of suicide.

Amongst the *Calls to Action in the Final Report of the Truth and Reconciliation Commission* is to be found a large section on health care (Numbers 19-24 especially) and justice (Numbers 36-41). It is clear that these priority areas demand immediate action. Issues of the suicide of teenagers and the requests for physician assisted suicide are not unrelated when we look at them from the perspective of these vulnerable populations.

Q *What related initiatives will be recommended by the Special Joint Committee for equally immediate and decisive action?*

Q *How might the legislative framework under construction at present contribute towards a wider, coherent expression of values in health care for Canadian society?*

We acknowledge the difficulty of speaking into the context of legislation framing around physician assisted death—on such a very tight timeline—when so many of our Indigenous Anglican members, and all Indigenous Peoples with whom we are walking in solidarity and partnership, have yet to see significant action on the health care aspects of the TRC.

3. CONTEXTS OF CARE AND ACCESS: GROUNDS FOR QUESTIONS ABOUT COERCION AND DECISION

We note that the Supreme Court Decision in the Carter case uses the word “care” as synonymous with “treatment.” Care is about more than active treatment, provision of medication or therapies. It is about the wider context of care for the whole person, whose whole being is involved in any decision making process. This extends to spiritual care, psychological care, economic care, physical care that is much wider than medical treatment, support, and social welfare. Views have been expressed that provision of spiritual care is an automatic form of coercion against a free and clear decision to request physician assisted death. This bias does not reflect the realities of many professional spiritual care providers. Furthermore, the provision of this form of care to someone who has made the choice to be assisted into death can be one of the most critically important ways of supporting the patient and family in the process of waiting, in dying, and in the immediate time of grieving in which complex emotions and thoughts will need careful tending.

Q Will the framework for legislation make provision for and encourage access to spiritual care?

Some ask: how to ensure universal access to physician assisted death? The very deep and wide gaps in provision of universal access to medical care broadly speaking, both primary and specialist, pain relief and particular treatments, let alone palliation and hospice care (about which we will speak more fully below) raise critical questions about the free nature of a decision. If there are no other options available—whether high quality active treatment of disease or good palliative care, can a choice be considered ‘free?’ Are there not contexts wherein the lack of options itself creates a context of coercion? There is a difference between having a right, and giving access to structures respecting full dignity in which to exercise that right.

Q How can the legislative context itself provide a structure that supports healthy decision making, including assurance of quality palliative and hospice care within the issue of universality of access?

This Canadian Supreme Court decision, unlike those of other countries, does not require the patient to be terminally ill, only a “competent adult” who is “grievously and irremediably ill.” Several questions come into sharp focus around this particular clause:

- The definition of an ‘adult’ is not provided. *What if a child is ‘grievously and irremediably ill’? How can legislation aid in measuring maturity and competence, and deal with the complex matter of coercion of a young person?*
- Those in perpetual, excruciating pain are in a different world from those who are not. *How might the legislative framework provide guides to evaluating a patient whose pain, or pain relieving medication, may decrease mental clarity?*
- If suicidal ideation in someone who is mentally ill is treated as a symptom of the disease, how

do you determine the difference between the causality of decisions, especially when in many cases the symptom of suicidal ideation is a first presenting public symptom of mental illness? *How is mental health—as a ground of competence and freedom from coercion—to be assessed? What are the implications for mental health care?*

- Coercion can take many forms: finances, a sense of family responsibility, putting the elderly into institutions, lack of knowledge, societal pressures, lack of access to medical treatment and pain management or the options of palliation. *Will the legislative framework identify possible forms and signs of coercion and how such will be assessed?*

4. PALLIATIVE CARE AND HOSPICE

You matter because you are you, and you matter to the end of your life. We will do all we can not only to help you die, peacefully, but also to live until you die

—Dame Cicely Saunder (1918-2005), founder of the Palliative Care and Hospice movement.

Palliative care and physician assisted suicide are not complete opposites. They have a complicated relationship. Palliation is a form of assisting a person in their dying. The Canadian Association of Palliative Care Physicians (CAPCP) has reported to this Special Joint Committee, palliative care is only accessible by approximately 30% of Canadian citizens.

Anglican spiritual care providers—often serving as multifaith chaplains—have a great deal of experience in palliative and hospice care. One of our Task Force members served to found spiritual care at Casey House in Toronto and accompanied patients with AIDS for close to two decades.

Where the provision is of high-quality care, the journey of dying is accompanied by care that extends well beyond that of medical therapy. Many of our leadership, it is safe to say, would support the initiatives of the CAPCP in their call for a National Secretariat in Palliative Care, as reported in their brief of January 27, 2016.

While it may not be something within the direct and narrow remit of those drafting legislation for physician assisted dying, *how might this Special Joint Committee raise into prominence the critical need for more, and better, palliative care as central to the priorities and values of our health care system?*

IN CONCLUSION

Our reflections here, and the questions raised, are not an objection to the decision of the Supreme Court—that decision has been made by the court, and we welcome the opportunity to contribute to a carefully crafted legislative framework that serves the inherent dignity of each human being within their primary community of support.

We care for the most vulnerable in our society, and walk with them. We are committed upholding the importance of personal conscience, and wish to find ways to ensure that such is formed without coercion. We are concerned about limited access to high quality medical care, including palliative and mental health care, especially in northern and Indigenous communities, with whom we walk in partnership. And we will continue to equip and support our pastors in their compassionate and wise care of the dying.

SUMMARY OF QUESTIONS:

1. How might the legislative framework pay attention to key relationships around the patient, when looking at the causative elements in the patient's decision making in order to determine the freedom of a decision?
2. What do the Indigenous peoples of this Land, and others whose lives and decision making processes are more shaped by the high value placed on community, have to teach us? What will a legislative framework look like after having listened and learned to these experiences?
3. When referring to dignity of the person or of the choice, what are the factors that determine dignity? Does someone without the capacity to opt for a choice not to ask for physician assisted suicide not have sufficient dignity? How will you treat the notion of dignity within the legislative framework without narrowing to a definition that excludes large segments of the population from being considered to possess dignity?
4. Will a framework for legislation foster a context in which the conversations called for by these principles will be encouraged, or be truncated?
5. How can a legislative framework ensure that appropriate care does not suffer from economic restriction, either real or ideological?
6. What assurance can the Joint Committee provide that First Nations, Inuit, and Metis leaders, and those who provide health care in those communities, are being consulted fully, Nation to Nation?
7. How would a legislative framework include values and perspectives from Indigenous peoples not as a special case, but integrated in a fully Canadian piece of legislation?
8. What related initiatives will be recommended by the Special Joint Committee for equally immediate and decisive action?
9. How might the legislative framework under construction at present contribute towards a wider, coherent expression of values in health care for Canadian society?
10. Will the framework for legislation make provision for and encourage access to spiritual care?
11. How can the legislative context itself provide a structure that supports healthy decision making, including assurance of quality palliative and hospice care within the issue of universality of access?
12. The definition of an 'adult' is not provided. What if a child is 'grievously and irremediably ill'? How can legislation aid in measuring maturity and competence, and deal with the complex matter of coercion of a young person?
13. Those in perpetual, excruciating pain are in a different world from those who are not. How might the legislative framework provide guides to evaluating a patient whose pain, or pain relieving medication, may decrease mental clarity?
14. If suicidal ideation in someone who is mentally ill is treated as a symptom of the disease, how do you determine the difference between the causality of decisions, especially when in many cases the symptom of suicidal ideation is a first presenting public symptom of mental illness? How is mental health—as a ground of competence and freedom from coercion—to be assessed? What are the implications for mental health care?

15. Coercion can take many forms: finances, a sense of family responsibility, putting the elderly into institutions, lack of knowledge, societal pressures, lack of access to medical treatment and pain management or the options of palliation. Will the legislative framework identify possible forms and signs of coercion and how such will be assessed?
16. How might this Special Joint Committee raise into prominence the critical need for more, and better, palliative care as central to the priorities and values of our health care system?

For further information, please contact:

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APPENDIX 2:

WHAT PEOPLE TOLD US

SUMMARY OF QUESTIONS FROM SUBMISSIONS TO THE TASK FORCE

In the winter and spring of 2015, the work of the Task Force was highlighted by articles in *The Anglican Journal* and on the website of the General Synod, inviting Anglicans across the country to submit their reflections on the implications of the Carter Case Supreme Court decision for the church, for themselves, for care-givers and for the dying. We received over thirty submissions representing a wide range of positions, views, and contexts. Most were rooted in a personal story and experience. There is nothing scientific about this report—it simply records the main points being made by those who chose to write their submissions to the task force. Here is what we heard.

COMMENTS:

- the right to choice should exist for persons at the end of life situation.
- there is a need to die peacefully—what are the limits on medical intervention—a fine line
- who knows best? Is there a lack of compassion in the church? Personal choice is important—as long it is informed
- most criticism of the “right to choose” comes from emotional and a misconstrued misunderstanding of the “sacredness of life”
- the Churches should be addressing the theology and ethics of the dying process as more and more people are living longer and face often alone the uncertainty of the future
- it appears the church prefers to sweep “people-issues” under the rug, rather than speaking frankly and clearly on the theological, ethical, and moral imperatives facing today’s society
- our bodies belong to God and the sacredness of life. What is the churches teaching on this and should there be new work done?
- are we robbing one of dignity and being paternalistic and lacking compassion when we who are active, independent say that to ask to die is wrong?
- suffering?? Needless or ...?
- doctrine before compassion, dogma before human dignity?
- in its teaching of Sanctity of life, the church could be sanctioning anguish and pain.
- it’s an individual choice, a process and discernment that each person has the right to journey with
- was distressed to find some of the scripture used (in *Care in Dying*) to be extreme in judgment on suicide especially the exegesis of Judas death by suicide and his utter exile and banishment from grace.
- these references (to biblical examples of suicide) perpetuate a view that many would question. I am not convinced that physician assisted death is un-Christian yet do confess to moral reservation when thinking through such actions for myself if I had a terminal illness

- in the same way that the churches are rethinking sexual orientation and same sex-relationships, death and dying needs to be revisited in light of terminal illness, suffering and physician assisted death.
- medical technology is keeping more people alive than ever before.
- when is suffering beyond the pale, seemingly beyond a human being's ability to endure it?

QUESTIONS:

- Is life sacred?
- What does it mean that life was given by God and at his bidding?
- Dignity and rights are very value laden words. What does dignity actually mean and which rights can we honestly articulate and protect with concomitant obligations?
- What does it mean to be human?
- How do we live so that our lives have meaning? Suffering vs lack of meaning?
- What is the role of community?
- Are we just looking for control, cleanliness or are we crying out for connection?
- What are we most afraid of?
- Is euthanasia/assisted death really to be defined as a right, and what would that imply in terms of obligations?

WHAT THE CHURCH NEEDS TO DO:

- Regardless of what actions the federal and provincial governments take, the Church must lobby for extended efforts to fund and put in place excellent palliative and hospice facilities throughout the country. There is absolutely no reason for anyone to suffer in pain. If a person is dying, then there should be no concern about addiction. There must be adequate training of physicians, nurses and therapists in palliative and hospice care.
- The church must ensure that every effort is made to train the clergy and lay visitors in dealing with the persons who are dying or suffering. In fact I would urge our bishops to mandate pastoral care training or CPE as essential to ordination as New Testament studies. Efforts should be made to provide training to existing clergy. The laity also needs to be trained.
- I anticipate that whatever position the Anglican Church takes, there will be some clergy who cannot walk with a parishioner who is determined to avail themselves of physician assisted suicide in Canada (assuming it will be legal by February of 2016). Such clergy must be allowed to exercise their conscience. However what will the Bishops do when such a person contacts them and asks for a priest to walk with them when their rector cannot? Our Bishops must be ready for such a situation. I can also anticipate that some Bishops will not even be able to contemplate assisting someone who will ask. Who will they refer a person to obtain spiritual comfort?
- Revisit the use of Scripture and how it is being used to support the con side. Is the way it has been used in "care for dying" damaging? Good theology?
- People are struggling with how to balance life as being sacred and the quality of life. How do we respond to those in unbearable suffering?

- Compassion and suffering. The age old questions how do we view suffering and place that beside a compassionate God?
- Are we in a place that we need to take the side of judge? People are calling for more of a pastoral response to the issue not a moral one.

These reflections and questions have been drawn verbatim from submissions to the Task Force, and have not been altered. Here we see—though not a reliable sociological study or poll, but nevertheless a glimpse—into some of the complexities of where Anglicans find themselves in grappling with the challenges posed by—and to some, promises opened by—the Carter Case. We recommend further study of all of the issues involved, especially those raised in this document. Some study resources can be found within the Bibliography in this resource. Others will be forthcoming and promoted along with this document.

Please send any comments, questions, or suggestions
of additional helpful resources to:

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