Reflections to the ELCIC Task Force on Decisions at the End of Life

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ELCIC Task Force on Decisions at the End of Life
A Medical-Theological Response

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Dear Colleagues,

I would like to thank the members of the ELCIC Task Force on "Decisions at the End of Life" for the opportunity to respond to this theological survey. The very act of responding to this survey helps me to clarify my own thoughts and feelings about this challenging and changing subject.

I am writing as an ordained Lutheran minister, a graduate of Waterloo Lutheran Seminary (2005) with ten years experience in cross-cultural pastoral ministry with the people of Maranatha Lutheran Church (2005–15), a Caribbean-Canadian mission congregation of the Eastern Synod.

I am also writing as a Canadian-trained family physician (UofA 1990). For over 25 years, I have practised family medicine in Edmonton, Inuvik (NT), and Kitchener-Waterloo. I have valued providing palliative care to my patients in every environment where I worked. I have worked with Dene and Inuit Canadians. I have worked for nine years with new Canadians and with marginalized Canadians at a Kitchener community health centre. I have worked for the past five years as a hospitalist in a rehab hospital, working primarily with patients who have either severe and persistent mental illness or advanced dementia. I regularly work with patients who present with impaired thinking and executive functioning and try to elucidate which impairments are permanent (related to dementia) and which are reversibly, related perhaps to a treatable delirium or a reversible mood disorder. I clearly understand the social and geographic disparities of resources and trained staff available to dying Canadians and their families. In the past six months, I have started to work as a medical resource to the Delton Glebe Counselling Centre—a counselling ministry of the Waterloo Lutheran Seminary.

As a minister and physician, I have deep respect for the Christian understanding that human beings have been created in God's image. I have a deep love for the sanctity of human life—embodied in that declarative command of the Sinai Covenant—"Thou shalt not kill." This has found powerful expression for me in both the Hippocratic oath and in the physician prime ordinance—*primum no nocere*— first, do no harm. The role of suffering in our Lutheran tradition, with its emphasis on being justified by grace through faith in what Christ has accomplished for us on the cross—has also been powerfully influential. Can we imagine the Christian story if assisted suicide had been offered and accepted at Golgotha? How would the powerful historical witness of Christian martyrs be different if, again, assisted suicide had been an option?

As a Canadian-trained physician, trained to understand the importance of providing high quality palliative care, I took ethical comfort in the knowledge that, with informed consent, withholding and/or stopping care treatments at the end of life was both a moral and a merciful act, both towards the patient who was dying and towards the patient's family who was grieving. It is this understanding that continues to undergird my weekly conversations around patient code status and "do not resuscitate" orders. How surprised, and chagrined, I am to read in the Carter decision that from an ethicist's perspective, there is little difference between stopping or withholding treatments at the end of life and providing euthanasia or assisted suicide! I have to say, over the past 25 years, there certainly seemed to be an ethical distinction. I venture to say, many of my clinical colleagues (medical, nursing, and pharmacist) who practice palliative care would agree with me on this point.

Nevertheless, on a regular basis, in my current hospital practice, I meet patients who have what would be regarded as "grievous and irremediable illnesses" according to the Supreme Court of Canada language. It never ceases to astound me how some severely and permanently afflicted individuals and their families find faith, hope and meaning in situations in which many Canadians would feel completely hopeless and overwhelmed. It is true, also, that some Canadians despair both at their current experiences of suffering and at the terrifying thought of their own future irremediable suffering. Who has the right to impose on-going suffering on someone who clearly can no longer bear their current burden?

After five years of assessing treatment and financial capacity and incapacity on our specialized mental health unit, and having regularly to defend my findings before the Ontario Consent and Capacity Review Board, I have to affirm that assessing capacity is difficult. Does a patient truly understand the treatment options before them? Does the patient understand the consequences of making or not making a treatment decision? With many treatments, if capacity changes or consent changes—a treatment can be modified or abandoned. One might wryly observe that all consent is valid, so long as no complications occur. However, with medical assistance in dying, the treatment in question (death) is also the complication. Once a treatment is initiated to end a life—there is a clear point of no return.

I think it is important to say that the Supreme Court of Canada's Carter decision requires urgent yet thoughtful theological reflection and response. Even now, hospitals are working out how they will respond to this new ethical landscape. Physicians, nurses and pharmacists are being recruited to comprise "medical assistance in dying" internal resource groups. Oversight groups and mandates are being struck. Basic questions remain unanswered (what, exactly, do you write as the cause of death on a patient's death certificate, if they receive medical assistance in dying?) Thank you for this important work, that you are doing—for Lutherans, for Christians, and for all people of faith and good hope in Canada.

Questions for Theological Reflection:

1) The Supreme Court Carter decision signals a change in society's understanding of death and dying. How does such a transition in understanding influence theological understandings of death and dying?

As the parliamentary background paper, *Euthanasia and Assisted Suicide in Canada*, makes clear, changing Canada's laws around assisted dying has been a 30–40 year journey. This journey has been made possible by the tremendous medical and technological advances of the past 100 years which have preserved life at the cost, sometimes, of significantly reduced quality of life. We now have the possibility of "brain dead" existence. We accept the right of individuals to be fully informed about treatments they will receive and the right of individuals to refuse treatments they do not want—for a variety of personal, moral and religious reasons. We have had debates and legislation around the right to refuse or halt treatment. We accept the reality and benefit of advanced directives. Until the past two years, however, Canadian society has not legally allowed for medical assistance in dying.

My understanding of the summary of the Rodriguez case is that, at the time, there were no jurisdictions offering assisted dying anywhere in the world. So no one could say with certainty whether such a system would be moral and continue to protect vulnerable members of society from harm, or whether the system would quickly become abusive. In the last 13 years, we now have multiple western jurisdictions which legally support assisted dying. Jursidictions range from European countries (Holland, Belgium, Switzerland), to American states (Oregon), to the province of Quebec which recently passed a provincial law (Bill 52—2013) legalizing medical assistance in dying. Clearly, these jurisdictions have continued to function as law-abiding democracies where the rights of the vulnerable are still protected. These are jursidictions that developed their jurisprudence from a Christian theological background, just as we ourselves have.

So, now, with the Carter decision, the Supreme Court of Canada has signalled its belief that Canadians, in the face of severe and irremediable illness, have the ability and maturity to seek out medical assistance in ending their own lives. Parliament has agreed with this court decision by creating the first Canadian laws that decriminalize medical assistance in dying in these specific circumstances.

Theologically, North American Lutherans have created several social statements in the past 40 years. In 1978, the LCA adopted *A Social Statement on Ageing and the Older Adult*. In 1982, the LCA adopted *A Social Statement on Death and Dying*. Our own ELCIC, in 1997, approved an *ELCIC Resolution on Decisions-At-The-End-Of-Life*. There is much in these thoughtful social statements that remains true and helpful today. There is wording around "Active Euthanasia," declaring it to be "contrary to Christian conscience" (LCA, 1982, p. 5) that needs to be reviewed and revised. Likewise, our ELCIC resolution declares that we "do not support the legalization of 'physician assisted' death or 'mercy killing.'" The reason provided is that "such action would too easily allow persons to take advantage of those most vulnerable." Clearly, in light of the past 13 years of western experience with jurisdictions which allow medical assistance in dying, this rationale is no longer valid. A new social statement on Death and Dying, or at least a new resolution, ought to be articulated. Using the lens of Christian mercy to end unbearable suffering would be a reasonable perspective from which to re-edit this section. Such arguments are already present elsewhere in these documents.

I believe it behooves us to create a process of discussion, dialogue, reflection and new articulation of Christian insight into the meaning of faith throughout life, dying and death. A social statement only lives if it is discussed, debated, challenged, upheld and reaffirmed or revised by the people who created it. Not only do we need to discuss with our Lutheran community what this means, we need to help Canadians who come from ecumenical and interfaith traditions come to terms with what this legislation means in ways they can understand. As future court challenges to the current Canadian legislation are made, it would be appropriate and helpful for Lutherans and our ecumenical partners to articulate our theological, social and cultural insights into how prepared we believe Canadians are for further legislative changes. Clearly, these insights would be most helpful if based on 5–10 years of experience with the current changes, accompanied by thoughtful debate about their meaning and effect on Canadian lives, families and communities.

2) The Carter decision upheld an individual's freedom to choose. How does our faith tradition balance its communities' shared value of the sanctity of life against the individual's right to seek assistance with her/his death?

The sanctity of life is a founding principle in Christian theology. It is also a guiding principle in the deliberations of the Supreme Court in its Carter decision. Quoting from the Rodriguez decision (Rodriguez, p. 595), while sanctity of life remains "one of our most fundamental social values," "sanctity of life is no longer seen to require that all human life be preserved at all costs." Put another way, "right to life" is not a "duty to live" (p. 63). The Supreme Court justices were balancing the fundamental value of the sanctity of life with patient autonomy and patient dignity. The justices concluded that competent, informed patients who were grievously and irremediably ill could legally seek and receive medical assistance in dying if such assistance is "clearly consistent with the patient's wishes and best interests and [provided] in order to relieve suffering" (para. 24). This is clearly not a blanket endorsement of suicide by any person at any time for any reason. In directing parliament to create national legislation to legalize the medical assistance in dying for the "grievous and irremediably ill," I believe the Supreme Court was emphasizing that society needs to have clearly articulated rules and procedures for when an individual's life situation falls outside the norms of experience envisioned and upheld by society's overarching value of preserving human life. This is not just an individual decision. It is a decision that an individual needs to discuss with at least two qualified medical practitioners—who both need to agree that the conditions for medical assistance in dying have been met. Medical assistance in dying needs to be provided by qualified and trained personnel. Following "administration" of medical assistance in dying, a full report needs to be filed and all cases need to be reviewed on a regular basis.

It should be pointed out that while the legislation requires two medical practitioners to affirm that the necessary conditions to proceed with medical assistance in dying have been met, in practice, many more clinical staff will be involved. Direct involvement will include nursing staff and pharmacists. Indirect involvement will include hospital administrators, cleaning staff, and other ward staff. All these individuals will be impacted by medical assistance in dying that will occur in our public hospitals. These individuals will bring their questions, hopes, fears, guilt and shame to their pastors and local theologians for understanding and support.

Theologically, we affirm that "human beings, whatever their age [or infirmity], are to be viewed not as individuals in isolation from one another, but as persons in community." (LCA, 1978, p. 2). I believe we want to strongly encourage individuals contemplating medical assistance in dying to involve their families and their faith communities as well as their friends and neighbours in these conversations. So often, in my clinical experience, suffering is intensified by lack of social support and lack of resources. Suffering borne by a whole community is infinitely lighter than that borne by an individual on her own. That being said, if after wide conversation, prayerful consideration, reflection, assistance in finding resources and building community, and informed consent about all available treatment options including palliative and hospice care, an individual freely chooses to explore medical assistance in dying, then the community can affirm that it has supported the individual to the very best of its ability and the individual has the right to say "no" to community. Even so, just as the medical colleges encourage physicians to continue to provide medical care and support for patients who are choosing medical assistance in dying, we should encourage pastors and congregations not to abandon their members at this critical stage but to continue to accompany them and support them—reminding them that the love of God surrounds us in death and dying as well as in life and living.

3) Traditional faith perspectives often view suffering as an appropriate if not valued dimension of authentic witness. Has our experience and tolerance for suffering changed calling into question the validity of such traditional perspectives on suffering?

What are you prepared to suffer for? If suffering is defined as how we spend our time, our mental and emotional energy, and our physical strength, does this not help define what is most dear and cherished in our lives? We suffer to live. We suffer to educate ourselves. We suffer to care for our families and raise our children. We suffer to support and grow our faith communities.

Clearly, in Christian theology, patiently and faithfully enduring the vicissitudes of life, anticipating both God's presence in the midst of the struggle and God's ultimate deliverance from the struggle (either in this life or the life to come) is a central theme. I have previously alluded to the central role in Lutheran theology of our being justified by God's grace through faith in what Jesus Christ has done for us through his life, death via torture and crucifixion, and resurrection on the third day. I have alluded to the powerful witness of Christian martyr's in centuries past. The healing miracles of Jesus in the four Gospels imply patient endurance of suffering and social isolation by people of faith—in the sure though patient hope that God will act decisively to bring health, healing, and wholeness.

Of course, medical suffering is usually not of our own choosing. When suffering is "grievous and irremediable", who sets the standard for patient endurance of suffering? Who is able to say, with authority—"You, sir, have not yet suffered enough! Even though there is no cure for your illness, and no treatment provides any relief, you need to suffer more and there is no foreseeable end to the length of your suffering."

Clearly, an individual's ability to bear suffering depends on many considerations—the formation and education of the individual, their spirituality, their physical abilities and disabilities, the level of social support they receive, their ability to communicate, their ability to exert some control over their daily lives, the resources they have at their disposal, the availability of accessible medical and social service supports including high quality palliative care. I am certain this list is not exhaustive.

So, in direct answer to your question: no, I do not think that our traditional perspective of suffering are invalid. I do believe, from personal experience, that there are individuals who face situations outside the normal spectrum of experience who do experience lives marred by grievous and irremediable illness and suffering. Some of these individuals and families deal with these situations with surprising grace and faith. Others are clearly overwhelmed and at the end of their ability to cope. If we, the community, do not care to better engage these individuals, offer better services or resources, or offer to accompany them; if we cannot be bothered to insist that high quality palliative care is a right for Canadians regardless of where they live, then can we really be surprised if some individuals choose to consider medical assistance in dying? And if we, the community, say "no" to all other options of support and accompaniment, then who are we to insist that unbearable suffering continue to be enduring without foreseeable end or limit?

4) Can assisting another in her/his death be understood as a faithful witness of Christian healing?

Yes. Using the lens of Christian mercy to assist in the ending of unbearable suffering, I think offering medical assistance in dying could be understood as a faithful Christian witness. I would ground this in the understanding that God is present in every aspect of life, including in death and dying. I would also ground this in the understanding that this in not a routine or an everyday form of witness. It is a witness in exceptional circumstances. And it is a witness that needs to be public. It is a witness that needs to fearlessly explore all options and to seek out all other treatment options and support options. I think it would be dangerous to support the creation of "medical assistance in dying" silos, where an individual goes alone and the only option considered is medical assistance to end life. To do so would be to risk creating silos of death. Somehow, both for the well-being of individuals seeking these clinical services, as well as for the well-being of those who offer these services in faithful Christian witness and good conscience, these services must be grounded in a life-affirming ethos and environment. It goes without saying that no clinician ought to experience coercion to offer these services if they understand the provision of medical assistance in dying to be against their own faith and good conscience.

5) How can a Christian tradition such as ours justify/explain/support assisted dying in such a way as does not betray centuries of theological practice as belief?

I think we answered this question in the answers to the preceding questions. Historically, our Christian tradition never needed to worry about issues like nuclear waste, nuclear war, global warming, the implications of genetic modification, or the protection of personal information on social media. As times change, as knowledge expands and as technology proliferates, we are called, as people of faith, to return to our faith roots to examine what it means to be human at this particular time in human history. We are also called to examine again what God is calling us to do, at this particular time, given the particular challenges we are facing.

I do not understand assisted dying as a repudiation of centuries of theological practice or belief. I understand that there are always outlier clinical or human situations that don't easily fit into the rules of behaviour that we create as a society. In my view, exceptions do not negate the rule. Providing medical assistance in dying, in Canada in 2016, does not negate centuries of wisdom in upholding and

defending the sanctity of human life. Martin Luther helped Christianity hold two opposing ideas in tension (law/gospel; kingdom of God/secular kingdom; sinner/saint). I think this was a first step in helping us hold more complex ideas, with perhaps a spectrum or range of responses, in theological tension. If the church is always under reformation, we need to risk reviewing our thinking and the tenets of our faith to ensure that they still help us be the people God is calling us to be in this place and time.

6) Suggest a theological framework within which pastoral/spiritual care providers may ground their ministry with those who seek assisted dying.

I again raise up the theological themes of Christian accompaniment, incarnating the abiding presence of God in the midst of death and dying, Christian mercy, and the Christian goal of relieving unremitting suffering as Christian values for this framework.

7) Suggest a faith-based model for ethical decision making appropriate to this concern.

Anyone seeking to accompany an individual or family in a journey to explore medical assistance in dying would be wise to:

- Encourage an individual to talk about their faith and what suffering, death and hope mean to them.
- Encourage an individual to actively seek out the best medical care and advice possible and to explore all options of care.
- Encourage an individual to consider what resources might make life more bearable.
- Encourage the individual to actively discuss the possibility of medical assistance in dying with family, neighbours, friends and faith community. Encourage regular prayer about this plan.
- If there are families willing to speak about their experiences with medical assistance in dying in a local community, encourage individuals to contact these families to learn, as best as possible, from their experiences.
- Offer to accompany the individual and their family thru the process of medical assistance in dying.
- When appropriate, offer support for those clinicians who offer medical assistance in dying.
- Be willing to volunteer to support the regulatory framework that monitors and reviews all cases of medical assistance in dying.
- Be willing to participate in community conversations as the boundaries of this intervention are reconsidered by Canadian society.
- Ensure that spiritual-care providers are supported in their role for their own well-being as well as their own on-going professional development.

8) Suggest a theological framework which understands assisted dying within the context of achieving a faith-based quality of life.

God's love for us is abiding. It existed before creation, calling forth light and life from the waters of chaos. God's love called us forth into life. Through the waters of baptism, God calls us into eternal abiding relationship with both God and all the people of God, from every time and every place. We are called to serve one another, especially at our time of greatest need and distress. God's love finds us wherever we are in life, including all stages of death and dying. God's love does not insist that we bear suffering beyond our ability to endure for our whole remaining existence. We are always surrounded by the

great cloud of witnesses, so we will never be alone. God's love will be awaiting us beyond death when we will join that great cloud of witnesses in a new and different way from our earthly existence. We look forward to the new creation—when we will experience God in new and intimate ways, as part of the new heaven and the new earth. Soli Deo Gloria.

Other goals and objectives worth considering:

- How do we dialogue with our multi-faith neighbours to help them understand why Canada might morally chose to offer medical assistance in dying?
- How do we encourage a national standard for oversight, data collection and review?
- How will we be involved in the ongoing debate about the boundaries of medical assistance in dying? Are we willing to share our insights publicly?
- Will we advocate for a 10 year moratorium on further changes—so that Canadians can debate and consider and experience what medical assistance in dying means in their communities according to current legislation?

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