



ELCIC Study Guide for
**Conversations on
Medical Assistance in Dying**



ELCIC Study Guide for Conversations on Medical Assistance in Dying

~ TABLE OF CONTENTS ~

Introduction to this study	2
Session One – <i>Where Are We Now? And How Did We Get Here?</i>	5
Session Two – <i>A “Good Death”</i>	15
Session Three – <i>Rights and Responsibilities, Autonomy and Community</i>	24
Session Four – <i>What Values Guide Our Work as People of Faith?</i>	32
~ ~ ~	
Appendix 1 – Medical Assistance in Dying (MAID)	41
Appendix 2 – <i>An ELCIC Resolution on Decisions-at-the-End-of-Life</i>	43
Appendix 3 – Reflective Questions for Input to the Task Force	46
Appendix 4 – Glossary	47

Additional Resources available at www.elcic.ca, including Suggestions for use of this Study Guide.

ELCIC Study Guide for Conversations on Medical Assistance in Dying

INTRODUCTION

Background

This study has been prepared by the ELCIC Task Force on Decisions at the End of Life in order to encourage conversations across our church regarding the needs of people in times of death and dying.

On February 6, 2015 the Supreme Court of Canada ruled that sections of the *Criminal Code* that had prohibited physician assisted death were no longer in force and that a medically assisted death could be allowed, but under strict criteria of protection.¹ This decision has generated a new set of conversations about medical assistance in dying in the public square and in the church.

In July, 2015, the ELCIC National Convention met and adopted the following motion (NC-2015-08):
That in light of advances in medical science and the recent Supreme Court of Canada's ruling decriminalizing doctor assisted death the National Church Council be directed to review our current Resolutions on Decisions-At-The-End-Of-Life approved at the Sixth Biennial Convention of the Evangelical Lutheran Church in Canada (1997). CARRIED

In November, 2015, the ELCIC National Church Council (NCC) began to follow up on the convention motion by reviewing the ELCIC current public policy statements and considering how to faithfully and effectively review our current resolution. The conversations meaningful, personal and thoughtful.

After due consideration, NCC passed the following motion (CC-2015-51).

That NCC establish a Task Force to encourage conversations across our church regarding the needs of people in times of death and dying, and to review our current Resolution on Decisions-At-The-End-Of-Life (1997).

The Task Force will prepare a study guide, and submit it to NCC by March 2017, that lifts up emerging realities with consideration being given to:

- *Vocabulary and definitions*
- *Legislation*
- *Core theological values*
- *Faith questions.*

A final report will be submitted to NCC by September 2018 including recommended updates to the current resolution.

1. See Session 1 of this study.

NCC asks the officers to appoint 3 to 5 persons, who collectively have the following:

- Palliative care expertise
- Medical ethics
- Theological expertise
- Member of NCC
- Member of the Anglican Church of Canada.

As per this mandate, the Task Force prepared this Study Guide in order to encourage conversations across our church regarding the needs of people in times of death and dying. The study has been prepared with deep respect for the fact that, with regard to times of death and dying, each of us has experiences, stories, grief and wisdom. Our willingness to listen to others with compassion, grace and faith is a profound gift.

The new legislation has a complex title that reflects the fact that for the Courts and Parliament to make this change, they had to amend the *Criminal Code of Canada*. Thus the whole title of the Act is called: *An Act to amend the Criminal Code and to make related amendments to other Acts (medical assistance in dying)*. These final words are those now used to refer to and discuss "Medical Assistance in Dying," often shortened to MAID. The importance of this change is that it provides protection for all involved, including nurse practitioners, pharmacists and others named in the Act.

Conversations on end of life decisions have been going on for on many years. Along the way, different terms have been used to refer to this important issue, for example: *active euthanasia, mercy killing, assisted suicide, assisted death, physician assisted death* and now MAID. Some words can be quite emotive, and the acronym MAID is not necessarily easily understood. In this study, the term *medical assistance in dying* is generally used. This choice is intended to offer space for fresh consideration of an important and complicated issue.

As part of this process, the Task Force on End-of-Life Decisions asked the doctors of our church (clerics with doctoral degrees) to reflect theologically upon a number of significant issues and questions currently facing society and the church. We are grateful for all the input received, and the Study Guide includes quotes and ideas from some of these unpublished papers.

Documents to compliment this study are online at www.elcic.ca, including:

- Suggestions on How to Use the ELCIC Study Guide.
- Additional resources for exploring the medical assistance in dying and decisions at the end of life.

It is our hope that through your conversations in local contexts, you will bless each other with compassion, enrich your community and discover the Holy Spirit's guidance for ways to demonstrate care as a church *In Mission for Others*.

Thank you for being part of the conversation.

Yours in Christ
ELCIC Task Force on Decisions at the End of Life

Rev. Dr. Dwight Biggs

Reverend Canon Douglas Graydon

Dr. Janet Storch

Rev. Lynn Granke

Ms. Jeanie Stann

ELCIC Staff: Rev. Paul Gehrs

ELCIC Study Guide for Conversations on Medical Assistance in Dying

SESSION ONE

Where Are We Now? And How Did We Get Here?

Introduction

In recent years, there has been significant public debate on *medical assistance in dying (MAID)* and on decisions at the end of life. The focus of this session is to consider where we are now, and how we got here.

In this session, we will consider:

- The context of our times, including changes observed in society, health care and the church.
- Previous to present considerations about death, dying and suicide, including biblical passages influencing our thinking as well as the experience of our own upbringing.
- The changes in law to permit *medical assistance in dying (MAID)* in Canada.
- A gradual shift from an emphasis from upholding rules to an ethic of compassion has affected our thinking and beliefs.
- A case study.
- Actions for the church today.
- Theological considerations.

Reading from Scripture

For I am convinced that neither death, nor life, nor angels, nor rulers, nor things present, nor things to come, nor powers, nor height, nor depth will be able to separate us from the love of God in Christ Jesus our Lord. (Romans 8:38.)

Opening Prayer

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 Lord².

Changes in Society, Health Care and the Church

As the body of Christ, the church participates in God's mission in particular contexts. Members of the church are influenced by changes in society and seek to offer faithful witness to the gospel in changing contexts. In the area of health care, significant changes in medical treatment, legislation and personal care are affecting our context and calling us to reflect theologically on our ethical perspective. In such a changing context, faithful discipleship involves asking *what is God calling us to do as people of faith?*

The quotes below may help us frame the picture of how things are changing in our society.

A quote from a nurse author:

The generations alive today are the first to live in an era of advanced medical technology, like ventilators, cardiopulmonary resuscitation (CPR), and tube feedings that can prolong life and delay death. Patients and families face difficult choices and nurses are often in the centre of these difficult situations³.

A quote from the College of Family Physicians of Canada Paper:

Recent legal changes raise profound questions for the medical profession. For example, what are the goals and limits of medicine?" What is the nature of the physician-patient relationship?⁴

2 *Evangelical Lutheran Worship (EvLW) Pastoral Care*, page 175.

3 Norlander, L. (2014). *To comfort always: A nurse's guide to end-of-life care* (2nd ed.) Indianapolis, IN: Sigma Theta Tau International, page 156.

4 College of Family Physicians of Canada. (2015). *A Guide for reflection on ethical issues concerning assisted suicide and voluntary euthanasia*. Ottawa: CFPC Task Force on End of Life Care.

A quote from an ethicist:

*This issue is not one of life or death. The issue is what kind of death, an agonized or a peaceful one. Shall we meet death in personal integrity or in personal disintegration? Should there be a moral or demoralized end of moral life?*⁵

A Quote from a Theologian:

*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 again what God is calling us to do, at this particular time given the particular changes we are facing.*⁶

Early theologians have influenced our thinking about end of life decisions. One of those was Aquinas whose views were that (1) killing one's self is contrary to natural law –suicide is a sin against one's self, (2) killing one's self injures the community because removing any part of the community to which we belong damages the whole, (3) killing one's self is a sin against God to whom we belong. The choice of life or death does not belong to us.⁷

Principles such as sanctity of life and being created in God's image have been passed down to us as reasons why suicide or an assisted death is contrary to God's law. Included in some guidance for the Christian community in the late 1990's have been statements that "life is not to be discarded"⁸ because life is a gift from God. Part of our history is that "there is general ecumenical and multi-faith consensus opposed to euthanasia and assisted death."⁹

Earlier guidance documents referred to biblical passages about individuals committing suicide and which in most cases this was considered evidence of punishment and the wrongness of the individual's actions. Such passages include Abimelech (in Judges 9), Samson (in Judges 16), Saul (in Samuel 31), Ahithophel (in Samuel 17), Zimri (in 1st Kings 16) and Judas (in Matthew 27). These deaths were by sword, by a falling house, by hanging, and by self immolation¹⁰. Given that none of these texts involve "a grievous and irremediable medical condition," it may be argued that they are not pertinent to deliberations on medically assisted death.

5 Fletcher, J. (1954) *Morals and medicine*. Princeton, N.J.: Princeton University Press, page 754.

6 Rev. Dr. Peter Kuhnert, unpublished paper submitted to the Task Force on Decisions at the End of Life, page 6.

7 Driedger Hesslein, unpublished paper submitted to the Task Force on Decisions at the End of Life.

8 Euthanasia: General Synod 1998, page 27.

9 Rev. Dr. David Pfrimmer, unpublished paper submitted to the Task Force on Decisions at the End of Life.

10 Source: www.cmf.org.uk

Changing Perspectives: Suicide

One example of how attitudes and theology change over time is the difficult matter of suicide. Many of us grew up with a very clear set of do's and don'ts including that taking one's own life was a mortal sin. This perspective resulted in institutional restrictions following a suicide, such as not allowing that person to be buried in the church cemetery, denying access to funeral rites, and not publishing an obituary.

There has been a gradual change of emphasis from judgement to compassion. Some of this has come about because we have a better understanding of mental health and distress. Some of this has come from reclaiming the values of compassion, love and forgiveness in the midst of tragic circumstances. In many places, this change in perspective led to changes in institutional practices so the obituaries, funerals and burials could be used to try to offer some comfort to families.

A Lutheran theologian reminds us that Christian teaching, theology and practice all need to be taken seriously, **but those elements must never become gods in themselves**...thus allowing or not allowing for change and newness beyond those long held Christian convictions out of the past.¹¹ For example, in its teaching of sanctity of life, the church could be sanctioning anguish and pain. How do we respond to unbearable suffering?¹²

Discussion

- *What experiences have you had with people dying by suicide? What attitudes have you encountered? What were you taught growing up?*
- *In what ways have your perspectives on suicide changed over time? What has influenced the change?*

The Changed Law on Medical Assistance in Dying (MAID)

In October 2014, the Supreme Court of Canada heard legal arguments involving a request that laws be changed to permit physician assisted dying in cases of extreme suffering and loss. The Court registered their judgment in February 2015 removing prohibitions on physician assisted dying and gave the Parliament of Canada one year to bring such legislation into effect. Due to a change in the governing party, this deadline was extended and the new law was passed on June 17, 2016.

In order to consider *what God is calling us to do as people of faith*, we need to know and understand this legislation—what it says and does not say.

It is important to keep in mind that a competent person has a right to refuse treatment. This has been a valid legal right for quite some time. Which is to say, deciding not to start treatment, or if started, to withdraw from treatment, is **not** a medically assisted death because a person has a right in Canada to decide what shall be done with their own body.

11 Bishop Allan Grundahl, unpublished paper submitted to the Task Force on Decisions at the End of Life.

12 Amy Hamilton, Anglican respondent

There have been several legal cases in Canada where a person's right to refuse treatment has been tested and found to be valid. (Examples of such refusals could be a decision to not be resuscitated, to not continue kidney dialysis, to not take recommended cancer treatment, etc.). One example of such a legal precedent in Canada is the case of Nancy B.

The Case of Nancy B.

Nancy B. was a young woman who sought a court injunction to compel the hospital and her physician to respect her request to discontinue the use of a respirator. Nancy B. suffered from irreversible paralysis from the neck down caused by Guillain-Barre Syndrome. With respirator support, she might live for quite some time. Without it, she would die very quickly. Justice Dufour deliberated on the clauses of the *Criminal Code* that prohibited assistance in dying and determined that in a case of someone wishing to withdraw from treatment the *Criminal Code* should not apply to anyone who discontinued the respirator. Thus, Common Law developed further to the point of determining that to continue to treat the patient when the patient has withdrawn consent to their treatment constitutes battery.¹³

Changes in the Law in Canada

For several decades there have been attempts to change our *Criminal Code* in Canada that has prohibited mercy killing or assistance in dying. Many notable individuals have struggled to have the law changed so they could "die with dignity." Among these most notable would be Sue Rodriguez who suffered from Amyotrophic Lateral Sclerosis (ALS). ALS is a progressive neuro-degenerative disease which attacks cells in the brain and the spinal cord needed to keep muscles active, causes weakness, paralysis, and inability to speak or swallow, and ultimately respiratory failure.

Sue was only 41 when she began to experience the painful muscle cramps and twitching that are early signs of ALS. Sue asked the Courts to allow her an exemption from the *Criminal Code* section that prohibited a person from having a physician assisted death. Sue wanted control of her own life and death. Sue's request was denied by the Supreme Court of Canada by a vote of 5 against and 4 in favour.

Two other women whose cases were heard by the Courts in B.C. and then the Supreme Court of Canada were Gloria Taylor who also suffered from ALS and Kay Carter who suffered from advanced compression of her spinal cord. Both died before a change in the law was made, but Carter's daughter Lee took her mother's case to the Supreme Court of Canada. The common request amongst these women was that they wished to have assistance to die when their medical condition would no longer permit them physically to bring about their own deaths.

13 Downie, J. (2004). *Dying Justice: A Case for Decriminalizing Euthanasia & Assisted Suicide in Canada*. Toronto: University of Toronto Press Downie 2004, pages 17-20.

On February 6, 2015 the Supreme Court of Canada ruled that sections of the *Criminal Code* that had prohibited physician assisted death were no longer in force and that a medically assisted death could be allowed, but under strict criteria of protection. On June 17, 2016 the House of Commons of the Government of Canada passed Bill C-14 making *Medical Assistance in Dying* (MAID) legal in Canada. Parliament adopted the key criteria for MAID as recommended by the Supreme Court of Canada.

Discussion

- *Who comes to mind when you hear the phrase medical assistance in dying? (Persons you know and/or stories from the media.)*
- *What is your first reaction to the legalization of medical assistance in dying?*

Ethical Concerns

Review the handout *Medical Assistance in Dying* (MAID) in Appendix 1, which includes *The Criteria for MAID*.

From an ethical standpoint, each criterion raises questions.

Some questions are about **equal access** to this kind of care and procedure geographically and politically. For example, how will people in rural and remote communities who wish to have a medically assisted death be able to meet the process criteria of two independent physicians or two nurse practitioners, or one independent physician and one independent nurse practitioner (np)?

Also, how will individuals access this type of care and procedure when they are in health institutions opposed to the new legislation that do not allow them access to medical assistance in dying on their site? Will these individuals be forced to move to another setting in their final days of life? This may be particularly challenging for long-term care settings since we often assure the resident that “this place is their home.”

Will the criteria for determining competency or capacity be well understood and applied fairly? Will better and common guidelines be provided to assess capacity/competency in order to make this type of decision fairly?

How will the diagnostic criteria of a grievous and irremediable medical condition be applied fairly? Are the criteria too subjective? Could these criteria be so subjective that there may not be commonality in medical doctors (MD)s or NPs decision-making about whether the criteria are met or not? Will the subjective nature of some of these criteria allow appropriate variation in how they are applied?

Is it fair to have excluded those suffering from severe mental depression who may have pain far worse than physical pain?

Also, are there chronic diseases or chronic conditions that may be more difficult to live with than i.e. cancer treatments, etc.?

Given these criteria, whether or not Sue Rodriguez, Gloria Taylor or Kay Carter would be eligible for MAID depends on how “reasonably foreseeable” is interpreted. (See the points of *Process and Safeguards* in the Appendix 1 of this Session).

A point of interest

In Quebec in 2014, the Quebec Legislature passed Bill 52 called *An Act Respecting End of Life Care* giving attention first to palliative care, then aiding a person to die. In their law the only way to provide assistance is by administering a substance and they call this practice *euthanasia*. Quebec did not have to amend another act to bring theirs into effect, so their Act is tidier and a more understandable Act to read. *Euthanasia* actually means a “good death.”

Discussion

- *When you read the Medical Assistance in Dying Handout, which phrase or sentence makes you pause and wonder? What new insight or discovery do you have regarding our Canadian context?*
- *What feelings do you have when you read over the ethical concerns listed above?*
- *What ethical issues and questions does MAID raise for you?*

Case Study

Your neighbor has invited you over for coffee one morning and you accept that invitation. She suffers from Multiple Sclerosis (MS) and you know she has had many years of struggling to cope with her condition. Lately her MS has worsened and you are surprised that she is feeling up to having you over since she has seemed to be so ill. When you arrive, she seems happier than you have seen her for some time. After you have finished the visit, she asks you to stay just a little longer because she has something to tell you. She then announces that she is scheduled to die on Friday at 10 a.m.

Discussion

- *How would you feel? What would you think? What would you want to know?*
- *What actions might you take?*
- *Might you respond differently if she was a member of your own congregation? Why or why not?*
- *Could you consider this a good death for your neighbour? Why or why not?*

Actions for the Church Today

Within the new law, there is also a provision for **conscientious objection** by those opposed to MAID for physicians, nurses, pharmacists, and others **to not be involved** in providing assistance to a person who is having an assisted death. There are several other situations in which health professionals may opt out of or withdraw from those practices which conflict with their moral or religious beliefs. There is a process to be followed in such situations so as to avoid a health professional simply abandoning people in need of their care. Some health care staff have expressed concern about how they exercise their right of conscientious objection without appearing to abandon clients who are in need. Similarly, any of us may find this new law may go against our conscience or beliefs. How do we respond when we disagree with a particular practice? One approach is accompaniment: respecting people's choices by walking with them and supporting them in Christian love, even when we disagree. Those who seek assistance to die, and those who choose to provide this assistance to them, are dealing with the difficult circumstances of suffering and death. Compassion, rather than judgement, seems an appropriate Christian response.

Theological Considerations

As part of this process, the Task Force asked the doctors of our church (clerics with doctoral degrees) to reflect theologically upon a number of significant issues and questions currently facing society and the church. The Task Force invited theologians to offer input on decisions at the end of life. Here are some theological perspectives to consider.

We live in a country that has legislated that we have freedom and a right to access physician assisted death. As a church, our place is not to contest that right (although we may do so as individual citizens). Our place is to guide one another always to move towards God in faith, love and trust, and to humbly walk alongside one another in that journey.¹⁴

14 Driednger Hesslein, unpublished paper submitted to the Task Force on Decisions at the End of Life. page 7.

Since Almighty God works through the world and in the church, we need to be alert to the possibility of God sometimes using the world to prod Christians to take a fresh look at possibilities which traditionally we have felt to be clear-cut...while at the same time to be alert to what expressions we Christians should make out of our religious convictions to influence society and the government.¹⁵

...my job as a pastor and our job as a church is to do everything possible to enable people who have to make difficult decisions not to be incapacitated by guilt or be afflicted by guilt after making a difficult decision. This requires continued love, support and affirmation by both the pastor and the community of faith, the church.¹⁶

A decision to end one's life may be a decision to limit one's own life to make room for others. Conversely, a palliative care patient might decide to extend life in order to support others.¹⁷

The church is called to be present as a Christian decides whether to end his or her life to declare the good news of Jesus, that neither death nor life will separate us from the love of God in Christ Jesus.¹⁸

[We need] a new articulation into the meaning of faith throughout life, dying and death.¹⁹

Ideally I picture a community offering people to walk with an individual (the calling of elders in a sense) where the community supports the person—through listening, theological reflection, Eucharist, prayer, treatment—to journey with a person so that the person has time to wrestle, grow and come to their freedom to choose, amidst those who love and support them.²⁰

Discussion

- *What role do you see for your faith community during times of death and dying?*
- *What values do you want to live out when encountering times of death and dying?*
- *Do you think that you could be involved in supporting someone when you disagree with their decisions?*
- *What values guide our work as we address issues of death and dying?*
- *What is God calling us to do as people of faith?*

Review

Consider what happened for you during this session.

- *What did you hear during this session?*
- *What questions arise?*

15 Grundahl, unpublished paper submitted to the Task Force on Decisions at the End of Life, page 1.

16 Foglemann, unpublished paper submitted to the Task Force on Decisions at the End of Life, page 1.

17 Harder, unpublished paper submitted to the Task Force on Decisions at the End of Life, page 4.

18 Gram, unpublished paper submitted to the Task Force on Decisions at the End of Life, Gram, page 2.

19 Kuhnert, unpublished paper submitted to the Task Force on Decisions at the End of Life, page 3.

20 McNabb, unpublished paper submitted to the Task Force on Decisions at the End of Life, page 1.

Take home: for reflection this week

In the next session, we will be considering the question: *What is a good death?*

As you prepare for the next session, consider:

- *Spend some time pondering your own mortality.*
- *What would a good death look like for you?*
- *What is God calling us to do as people of faith?*

Concluding Prayer

O GOD the Word that leads all to freedom and the peace that the world cannot give, help us to know that you will call our names, embracing our pain, and that through you we can stand up and walk and live. Help us to believe that you will bring us home because you love us, and we are yours. Amen.²¹

21 Paraphrased from EvLW Hymn #581. "You Are Mine"

ELCIC Study Guide for Conversations on Medical Assistance in Dying

SESSION 2 A “Good Death”

Introduction

One of the realities of being born is that we will all die. And yet, death is something that many deny. Some avoid discussing death at all costs, while others actively seek to extend their stay in this world through projects such as cryogenics. As baptized Christians, we are welcomed into this world and incorporated into the life and witness of Christ. That incorporation is finally complete in death. Baptism ushers us into the world.... Death in the Lord is final inclusion into the body of Christ.²²

In this session, we will explore some thoughts that constitute what is referred to as a “good death.”

A good or a satisfactory death, whether it is protracted or sudden, involves living in ways that set us on the path to a good death. Who we are as a person, in all our many roles, is how we will deal with life threatening illness and impending death. It is important to do that work—including having open and forgiving relationships with those we love throughout our lives.

In this session, we will consider:

- Theological reflections and considerations on suffering, the faith community, scripture and reformation.
- Elements of a good death.
- Decisions when death nears.
- A case study.
- Giving permission to die.

²² Driedger Hesslein, unpublished paper submitted to the Task Force on Decisions at the End of Life, page 6.

A Reading from Scripture

We do not live to ourselves, and we do not die to ourselves. If we live, we live to the Lord, and if we die, we die to the Lord; so then, whether we live or whether we die, we are the Lord's. For to this end Christ died and lived again, so that he might be the Lord of both the dead and the living. (Romans 14:7–9.)

For those who live with this confidence, neither life nor death are absolute. We treasure God's gift of life; we also prepare ourselves for a time when we may let go of our lives, entrusting our future to the crucified and risen Christ who is Lord of the living and the dead.²³

Opening Prayer

Compassionate God, we ask for your presence in our midst for our discussion today. Give us open and fearless hearts and minds, knowing you are with us as we live and as we die. Amen.

Theological Considerations

As we continue our conversations about decisions at the end of life and what a good death might look like, it is also important for us to reflect theologically on the discussion. As part of this process the ELCIC Task Force on End-of-Life Decisions asked the doctors of our church (clerics with doctoral degrees) to reflect theologically upon a number of significant issues and questions currently facing society and the church. Drawing on some of the material from these responses, we briefly reflect on some important concepts related to a good death and current end-of-life issues: suffering, the faith community, scripture, and the Reformation.

Suffering

Can a person experience a good death in the face of suffering? Most of us have known someone who upon nearing the end of his or her life simply wanted to die so that the suffering would end. Times like these make us wonder what we would do if we were in the same situation.

Christian thought varies widely today on how we might view people's suffering, in particular physical suffering toward the end of life. For some Christians, the view toward suffering holds a more traditional thought that suffering is a sign of God's will. From this perspective a person's suffering is viewed as bringing us closer to Christ who suffered on the cross which eventually led to resurrection and new life. Other people may consider that suffering is not a part of God's way in the world and instead is something that simply happens in the world. Over the last century there has been a shift in how we view God, from a patriarchal, knowing-what's-best figure who corrects us to a more loving and relational figure who grants us the freedom to choose our path in life. In this relationship God does not impose suffering upon us, but instead grants space for us to find meaning in our suffering only when we choose to endure it voluntarily.²⁴

23 A Message on End of Life Decisions, ELCA, 1992.

http://download.elca.org/ELCA%20Resource%20Repository/End_Life_DecisionsSM.pdf?_ga=1.205442128.1744276550.1481735980

24 Driedger Hesslein unpublished paper submitted to the Task Force on Decisions at the End of Life, pages 1-2.

Discussion

- *What experiences have you had with people who are suffering while dying? What insights do you have for how we might find meaning in our suffering when we are dying?*
- *How do you think God fits into our suffering? How does your faith help you deal with suffering?*

The Faith Community

How do we as a faith community respond when someone is dying and nearing the end of his or her life? How do we as individual members of that faith community fit into this ministry? Perhaps this is familiar territory for us from past experiences and we readily take on the mantle to offer care and compassion to the dying person and his or her family. Maybe we've never before experienced the death of someone close to us and the thought of walking alongside someone in his or her dying hours causes us fear and anxiety. Perhaps we even consider that we need not worry about such things in the first place because it is the pastor who does that sort of stuff.

Death—the final experience of life—is something we all must do someday. However, the dying journey leading up to that point is something we need not do alone. In fact, the presence and support of a faith community may be something that adds to a person having a good death. Indeed, it is important to involve as many supportive individuals as possible in the dying process, because otherwise, a dying person's suffering can sometimes be intensified by a lack of social support.²⁵ As dying persons face this unknown journey for the first time, we may McNabb (p.1) envisions "a community offering people to walk with an individual (the calling of elders in a sense), where the community supports a person—through listening, theological reflection, Eucharist, prayer, treatment—to journey with a person, so that, the person has time to wrestle, grow, and come to their freedom to choose, amidst those who love and support them."²⁶

25 Kuhnert, unpublished paper submitted to the Task Force on Decisions at the End of Life, page 4.

26 McNabb, unpublished paper submitted to the Task Force on Decisions at the End of Life, page 1.

Discussion

- How might we as a faith community assist a dying person to experience a good death?
- How would you like your faith community to support you and your family if you were dying?

Scripture

What does the Bible have to say about death and dying? A lot! Certainly our whole faith as Christians is based on the belief of Jesus Christ's suffering and death on a cross for our sake so that we might know eternal life with God. But what stories can you recall from the Bible about the dying process itself and what might make for a good death? Perhaps that is a little tougher to answer.

Our western thinking has been deeply influenced by historical church figures like Augustine and Aquinas who believe the choice of life and death is not ours to make. In various texts, the Bible presents various characters wrestling with questions of dying and demonstrating a full range of human emotions and reactions.

There are several biblical accounts of people desiring to end their lives.²⁷ For example, Moses, Elijah and Jonah all prayed at one time that God would take their lives and end their misery. Jeremiah lamented and Job cursed the day he was born. Paul expresses a longing for death and desire to leave this human body behind to be united with Christ. (2 Cor. 5:1–8, Phil. 1:21–26.)²⁸ Those who find living too much to bear are not alone when you remember these faithful people.

Samson spends his life using his strength to defend the faith and to protect God's people; most often by killing his enemies. Having surrendered the secret of his strength—never cut your hair—to his beloved Delilah, he is betrayed into the hands of his enemies. His hair is shaved off and he loses his strength. After some time as a prisoner, Samson prays to God, asking for his strength to be restored. God grants Samson's request so that Samson can kill himself and a large number of his enemies at the same time.

It is disturbing that, in life and in death, Samson's way of upholding the faith is to use his strength to kill so many enemies. However, if we can briefly ignore the violence, the question *Did Samson have a good death?* is interesting and provocative. Samson's decision at the end of his life is to keep trying to fulfill his life's purpose; to find a way to uphold the faith and to protect God's people. He does this by prayerfully seeking a restored relationship with God, and by trusting in God for the strength to complete his journey.

Jesus embraces his own dying and death, including when he prays in the garden of Gethsemane. Did he have a good death? In one way, Jesus' death is unique as God's universal and ultimate saving act. In another way, Jesus' suffering and death are God's act of solidarity with all suffering and with every experience of dying and death. His crucifixion was a miscarriage of justice and dying by torture. It is also God's act of solidarity with every human rights violation.

²⁷ We are indebted to Driedger Hesslein and Knudson Munholland for pointing out these stories.

²⁸ Numbers 11:10–15, 1 Kings 19:4, Jonah 4:8, Job 3:1, 2 Corinthians 5:1–8, Philippians 1:21–26.

Discussion

- *What stories and passages from the Scriptures contribute to your understanding of dying and/or to the meaning of “a good death.”*
- *How might a Christian’s trusting in faith of an afterlife affect his or her decision to discontinue a treatment or perhaps even seek medical assistance in dying?*
- *What might the end-of-life decisions we make say about our trust in God?*

A Reformation People

As Lutherans, we have a rich history and tradition stemming out of the Protestant Reformation. The quotes below highlight the value Lutherans place on engaging our current context as a reformation people.

*For the past number of decades much work has been done at ELCIC National Assemblies, and in Synods, **to emphasize that the Reformation was not the end.** Continual reformation has happened in the church and is an important part of our mission and faith today. Through honest theological reflection, Lutherans, have faithfully wrestled with many issues over the past century (post-war WWII theology driven by Bonhoeffer, the ordination of women, the age of first communion/confirmation, same sex marriage, public statements on abortion), and reformed in a faithful way to live in the times and conditions present to us.²⁹*

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 to be the people God is calling us to be in this place and time.³⁰

Jesus himself said in the gospel of John that here was much more Christ could say but his followers were not ready yet...but the Spirit would lead in all truth...which indicates there will be newness of perspectives that may never have occurred to any generation before, all down through history.³¹

As medical technology advances, our decisions at the end of life become more complicated. We find ourselves able to keep a person’s physical body alive through the use of machines long after their brain has stopped working. This introduces an element of choice, to remove the machines or not, into circumstances where previously death would already have occurred. What does this mean when we make the decision to remove those machines and the person dies? Similarly, legalizing medical assistance in dying means our choices are more complicated. Can medical assistance in dying ever be part of a good death? Even when you are clear about the choice you would make for yourself as an individual, you may find yourself called to support someone who is making a different decision.

29 McNabb, unpublished paper submitted to the Task Force on Decisions at the End of Life, page 2.

30 Kuhnert, unpublished paper submitted to the Task Force on Decisions at the End of Life, page 6.

31 Grundahl, unpublished paper submitted to the Task Force on Decisions at the End of Life, page 4.

Discussion

- *What does it mean to be a reformation people as we consider end-of-life issues and the dying process today?*
- *As the church and our understanding of faith has changed over the years, is it possible the idea of a good death has also changed over time?*
- *As we consider death and dying in our society today, what kind of people do you think God is calling us to be?*

Elements of a Good Death

Some of the things that others have listed as elements necessary to have a good death are:

- Agency or the ability to make decisions for yourself
- Loved ones near
- Spiritual care
- Forgiveness
- Control of pain and other symptoms
- Clarity of mind
- Have input into the funeral
- Financial matters in order
- Everyone on the same page
- Acceptance of death as a reality
- Loving life to the end
- Full awareness to the end
- Physical contact (e.g. holding of a hand)
- Without uncertainties so as not to cause pain to loved ones
- A sense that one's life mattered—often affirmed by friends/family being present.

Giving Permission to Die

One of the greatest gifts we can offer our family and friends is helping them to die well. Sometimes they are ready to go to God but we have a hard time letting them go. But there is a moment when we need to give those we love permission to return to God, from whom they came. We have to sit quietly with them and say, "Do not be afraid...I love you, God loves you...it's time for you to go in peace...I won't cling to you any longer...I set you free to go home...Go gently with my love." Saying this from the heart is a true gift. It is the greatest gift love can give. When Jesus died he said, Father into your hands I commit my Spirit. (Luke 23:46). It is good to repeat these words often with our dying friends. With these words on their lips or in their hearts, they can make the passage as Jesus did.³²

32 Nouwen, Henri, Bread for the journey, 1997.

Discussion

- *What would you add to the list of elements of a good death?*
- *What elements are most important to you?*

Decisions when Death Nears

When death nears, there are options to consider:

1. Advanced Care Planning

Planning for one's death ideally begins early, when death is not imminent. In some families, death is part of life with the deaths of pets, friends, grandparents and extended family members. Children are included in funerals and questions are answered as they arise. But to plan for one's own death feels very close to the bone and different than in the abstract.

The concept of beginning an advanced care plan is all about conversation with those closest to you. (A comment has been made that as we age, we may be willing to talk to our children about these matters but the children are not at a stage to discuss what we want at our death.) It is a time to talk about different scenarios and what would be wanted in each different situation should be explored together. *Talking about our own dying and the death of those we love is an important moment of meaning.*³³ Nevertheless, talking about death and dying continues to be an uncomfortable exercise in many families and amongst neighbours. Often, the fear of death itself is overtaken by the fear of dying. This would include the fear of loss of control, increased suffering, loss of dignity, and fear of dependency. However, all this makes it more important and critical that families speak to each other about these fears.

It is also important to begin these conversations with your physicians. In many health-care regions and provinces across Canada, there are now documents that can be downloaded or obtained that will assist you in beginning those conversations. You may also find documents that can serve as a "living will" or "representation agreement." These too may be useful, depending on your circumstance. Once you are able to make your wishes for care concrete, these should be written down with copies to family members and to physicians. It is important to point out that any document can be updated as situations change over time.

2. Withdrawal of treatment

Remember that it is your right to withdraw from any treatment at any time. Withdrawing from treatment is not medical assistance in dying. Ideally, such decisions are made in discussion with loved ones and with medical personnel.

33 Pfrimmer, unpublished paper submitted to the Task Force on Decisions at the End of Life., page 10.

3. Palliative care

Palliative care has often become synonymous with a “place”; it is rather a concept of care provided in any setting (hospital, home, long-term care, etc.) where a person is, or chooses, to die. “Palliate” comes from a Latin word, *palliare*, meaning “to cloak” or protect from suffering. Suffering may not be limited to the physical but also spiritual, psychosocial, financial or bureaucratic concerns. This care often includes a whole team of professionals working with the patient and family, including physicians, nurses, home care support workers, pharmacists, social workers, physical and occupational therapists, volunteers, to name a few. It is a high level of care designed to alleviate any suffering and can include specific treatments that at one time were considered only for those receiving acute care.

The reality is these services are not available everywhere across the country and in many cases. The demands for this care can exceed the resources available.

4. Medical Assistance in Dying (MAID)

When Bill C-14 was made legal in Canada, *medical assistance in dying* also became another option people could consider as they approach death. Processes and societal understandings regarding MAID are still in their infancy in many ways, yet are inspiration in part for the conversations that are being encouraged through study guides such as this.

Discussion

- *What makes it difficult for you and your family/community to talk about death and dying? What wisdom do you have for addressing this?*
- *From your perspective, can medical assistance in dying ever be part of a good death?*
- *If a person’s desires for end-of-life care (eg. Considering medical assistance in dying) do not fit with our own beliefs, how might we minister to them still in their time of need so they experience a good death?*
- *What faith questions come to mind when you think about helping people to have a good death?*

Case Study

A Christian woman in her 50s has just learned that her cancer has returned after treatment for breast cancer 7 years ago. The increasing pain in her back was the first sign that it had returned. She has a husband and 2 grown children in their 20s. Pain medication is ordered and after a bit of adjusting, the best level of analgesic is reached. One day, after arriving in emergency with severe shortness of breath, the woman quits breathing. She is placed on a respirator and transferred to the critical care unit. Scans indicate that the cancer has moved rapidly through her body. She and her family are told the situation. The palliative care team is sent a referral for consultation. The woman tells the team that it is her wish to be free of the respirator, knowing full well that this means an end to her life. The husband contacts the children and arrangements are made for them to come home.

After they spend time together with their pastor, the family better understand the woman's wishes and agree that the woman's wishes will be honoured. The palliative care team discuss with her the steps that will be taken around the removal of the respirator and the medication that will be given to alleviate her distress. She is assured that her family and the palliative care doctor, who will administer the medication, will be with her. Prayers are said and the process begins. The woman dies about four hours later.

Discussion

- *How does this story impact you?*
- *Are there things that you think should have been done differently?*
- *What questions does the story raise for you?*

Review

Consider what happened for you during this session.

- *What did you hear during this session?*
- *What questions arise?*

Take home: reflecting and digging deeper

In the next session, we will be considering making decisions in times of difficulty and when the answers are not obvious.

As you prepare for the next session, consider:

- *What decisions do you find most difficult to make?*
- *What support and guidance from your faith community might help you when making decisions?*
- *How might you support a friend or neighbour in making a decision?*

Concluding Prayer

Eternal God, the Alpha and Omega in whom we find our beginning and end. We give you thanks for guiding our conversations as we continue our end-of-life study and in this session what a good death might mean for our lives and our loved ones. These are not easy conversations for us to have, but they are important ones for us to consider and explore. May you continue to bless us as we go from this place and reflect more deeply on what these conversations have held for us. We continue our journey in Jesus' name. Amen.

ELCIC Study Guide for Conversations on Medical Assistance in Dying

SESSION 3

Rights and Responsibilities, Autonomy and Community

Introduction

In this session we begin with a consideration of what makes talking about our mortality challenging. We will reflect on the continua of end of life options for others, and ourselves considering how suffering shapes the choices we make and how we communicate our choices to others. In considering the range of options at end of life we also reflect on our responsibilities to each other and the wider community as well as the role of advocacy for the church.

In this session, we will consider:

- What we don't want to talk about
- Two narratives and a case study
- The concept of autonomy
- Theological considerations

Readings from Scripture:

For grief has darkened my eyes; my body is like a shadow. My days fade like an echo; the strings of my heart have snapped. (The Book of Job)³⁴

If one member suffers, all suffer together with it; if one member is honoured, all rejoice together with it. Now you are the body of Christ and individually members of it. (1 Corinthians 12: 26–27)

Opening Prayer

Good Shepherd of us all, as we consider what it might be for us and those we love to walk through the valley of the shadow of death, fill us with courage and confidence that you walk with us. Amen.

What We Don't Want to Talk About

A nurse in the ICU begins a conversation with the adult children of an 84-year-old woman who is dying of heart failure. She is very fatigued and has trouble speaking. The RN wants to understand the woman's wishes for her care in this chapter of her life. Her children do not want to discuss anything other than life saving measures.

Daily, this is a typical conversation in health care. People who have lived with declining health or a chronic illness for many years, the aged with a long list of health challenges have not spoken with their family members about their wishes for care when they are not able to speak for themselves. As if not talking about it would keep illness and death at bay. Health-care providers often hear from families:

- *She can't die yet; I still need her.*
- *He was playing golf just last week!*
- *She wanted to live to be 100, can't you do something?*
- *I don't want to "pull the plug" ... I can't decide what to do!*
- *If we talk about dying she will lose hope and die!*
- *We never discussed our wishes for treatment if it ever got to this point.*

Talking about our mortality, our human frailty, our dying and death is rarely dinner table conversation. Largely we avoid considering the final goodbyes of life and death whether we are 10, 20, 50, 70 or 90 years old. The intensity of the emotions that arise in this context frightens us. Grief, fear, anxiety, anger, despair are emotions we regularly push aside. Then, suddenly, we find ourselves in a hospital having a conversation with medical personnel about a personal cancer diagnosis or a massive life altering injury of a loved one. In these moments we find ourselves talking about what we have tried so hard not to think about or consider. Now, in a pressure cooker when decisions need to be made for care, the conversation and inherent decisions are thrust upon us.

34 As quoted in *Healing through the dark emotions: The wisdom of grief, fear and despair*, Miriam Greenspan.

www.beyondmeds.com/2010/08/07/from-the-book-healing-through-the-dark-emotions/

Talking about illness and dying does not bring it on. There is a benefit to talking about it when we are outside of the pressure cooker as it offers us more time to consider what matters to us most when illness and dying come....As it will whether we talk about it or not.

Discussion

- *When you think about death what do you worry about?*
- *What makes it easier or more difficult to talk about dying and death?*

Narrative: Walter

Walter, a 74-year-old man, husband to Martha and father of 3 adult sons has pulmonary fibrosis and is nearing the end of his life. His philosophy of life is learnt from his father: work hard, be honest and stand on your own two feet. Walter's occupation was working in the construction business building houses. He's proud of how he has provided for his family including having all his sons in hockey in their teen years. Walter identifies as the "protector" in his relationship with Martha, "its my job to look out for her." In the last 2 years Walter has experienced some significant changes in his health. He began losing weight and has increasing shortness of breath. He finds himself exhausted, "I feel like I worked a ten hour day building a house when in fact I didn't leave the house, I sat and read the paper and watched TV and watched the world go by." He now requires home oxygen to make his breathing easier and sleeps in the living room because the stairs to the second floor of their home are too difficult for him. Walter is very discouraged by his declining health and often speaks of his fear that he is becoming a burden to Martha and their children. "I think I've outlived my usefulness. I hope I die before I need them to do much more for me," he says shaking his head. "I hope I go to sleep one night soon and never wake up...lets just get this over with." Lying awake at night Walter finds himself considering medical assistance in dying. As he voices this idea to Martha Walter declares, "I don't want to linger and rot away. I don't like who I've become. It's my time and you'll be better off."

Martha doesn't experience Walter as a burden. "I love him and we made a vow "for better or worse, in sickness and in health...till death we part. I want to honour him and my commitment to him and care for him as he has provided for us all these years." As his need for assistance increases and independence decreases, Walter struggles to hear or believe Martha. A private person, Walther has tried valiantly to keep up the pretense with his pastor that this is just a phase and he will soon be back on his feet. Walter fears judgment from his pastor if he were to speak of his desire to have a doctor help him die.

Narrative: Joanne

Joanne has given a great deal of thought and consideration into what it is that she wants her dying days to include. It is very important to her to have her two sisters and her three children present with her. Joanne has been very clear that she doesn't want them sitting with her around-the-clock for the last month of her life. She has stated that when her dying becomes so much more imminent, then she would like her family to be as available as they can be to sit with her, even when she is no longer able to communicate or be aware that they are there. In conversation with her pastor Joanne has identified prayer and listening to Taize music as a source of strength to her spirit. Joanne has asked her pastor to visit weekly in the last few months of her life and to bring sacrament to her. When her dying is

imminent she would like for her pastor to be available to offer prayer and anointing and support to her family. It is also important to her that her cat Luna is near her.

Joanne's hope is to die at home surrounded by her friends and family in a setting that is familiar and reassuring to her. In speaking with the palliative care nurse Joanne identified her goals of care: the comfort of having loved ones nearby, assistance for feeding and toileting, the importance of having her symptoms well managed so that she is as free of pain as possible. While Joanne is aware that some of her medications may make her sleepy she would rather be out of pain than experience physical distress; to not have her dying be prolonged.

Discussion

- *What feelings or thoughts arise as you hear the stories of Walter and Joanne's dying?*
- *Do you have a memory of a loved one who has died? What did you learn from that experience?*
- *What is most important to you about your physical or mental well-being? How would that influence decisions you might make for your own time of illness or dying?*
- *What makes each day meaningful to you?*

Autonomy

Walter and Joanne are voicing their wishes for dying and death. The right to self determination is a strong ethical principle in Canada. The word autonomy comes from the Greek "autos-nomos" meaning self-rule or determination. This principle is based on the belief that each human being has the capacity and the right to direct their own life, make their own decisions. In health-care the principle of self-determination means that the individual takes responsibility for their own decisions and bears the consequences of those decisions while the role of the health-care providers is to respect those decisions and thus uphold the dignity of the person. The decision of the Supreme Court (Bill C-14) upholds the rights of the individual, in certain circumstances, to make choices regarding *medical assistance in dying*.



35

Let us look at the four-quadrant grid for a moment. Here we see that there are many ways to consider a situation and the decisions we make each day about life choices including health care decisions. In the “I” quadrant, we use our feelings, including our “gut” instincts, to aid us in making decisions. In the case of Walter, his feelings of uselessness and despair, his perception of being a burden to his family are a large part of his wish to die. He is largely influenced by his interior world of self-reflection but has not tested his perceptions out with his family, friends or pastor. The quadrant of IT invites the individual, Walter, to engage with facts and thinking not just on his feelings but also on his experience. He could consider how his physical condition is changing and the impact this has on his own sense of well-being and quality of life.

Recognizing that we, and Walter, are also communal beings, we consider the lower two quadrants which invite us to consider the wider community we are part of. The “WE” quadrant invites us to consider the shared values of our family, cultural group and faith community. Walter has a working assumption regarding Martha and his children’s experience of his decline without having discussed this with them. The “ITS” quadrant refers to the authority of the system. In health-care this largely means the health care practitioners, such as physicians, and the government. We might also include the church in this category. Walter is fearful of judgment and so maintains a pretense with his clergy in order to shield himself. Unfortunately, this action cuts him off from the very community that desires to support him.

Many hospitals and health-care centres in Canada have developed a patient’s *Bill of Rights* based on the principle of autonomy. Some have paired it with a *Bill of Responsibilities* document. Together, these express the value and right of the individual to make their own choices while acknowledging the decisions of one person impact the lives of the many. Congregations that engage in discussions such as this one, reflect the call we have to share life together and consider ways we can support each other

35 Diagram is from *The End of Life and the Right to Die: A Conversation Starter*, Christ Church Cathedral, Vancouver, 2014, page 7. Used with permission.

<http://thecathedral.ca/wp-content/uploads/2014/09/COMBINED-DOCUMENT-TEXT-AND-COMMENTS-2.pdf>

when life is difficult. We are a community of faith who acknowledge in baptism that we are brothers and sisters in the body of Christ. *If one member suffers, all suffer together; if one member is honored, all rejoice together with it.* (1 Cor. 12:26.) A gift of the community is the collective wisdom of diverse and shared experience. Valuing the wisdom, insights and experience of the community can aid us in our own decision-making processes while not binding us to one decision thus preserving our autonomy.

Discussion

- *As I reflect on different decisions I make in life (travel plans, when to buy a home, when to retire etc.) which quadrant do I most often use to consider my action?*
- *What am I understanding or not understanding about the 4 quadrants?*
- *In this moment as I consider medical assistance in dying, which quadrant do I find myself reflecting from?*
- *What other quadrant do I need to consider to expand or deepen my reflection?*

Theological Considerations

Walter's wish to have his suffering over with and to die is not new. Throughout the ages some people have wished to die, expressed in a prayer such as "I hope I don't wake-up tomorrow". The decision of the Supreme Court and the subsequent legislation has radically altered this making it a possibility for those who meet the criteria for a medically assisted death. Many older adults and those living with the burden (weight) of chronic illness consider assisted dying believing that the decision to die is theirs. Unlike Christians of the 3rd century for whom the threat of death was real, today the threat may well be life. "Christians are not facing the question of what kind of death does God ask us to endure, but what kind of life."³⁶ Quantity of life and the quality of those days of life need to be carefully considered.

Given that we are children of God in our baptism, we then live our lives in relationship to the Creator. We have been given full agency over our lives to become the people God has created us to be. "In giving us full agency in our lives, God gives us the privileges and responsibilities to make decisions about our lives and our deaths."³⁷ As human beings we are constantly making choices about life and death—the death of a relationship, for example, through divorce, or through choosing life through sobriety. "While the finality of choosing physical death seems to surpass the deaths of our other choices in this world, it is no more 'final' to our Easter God than any other form of death."³⁸ In contrast, the church has long been influenced by Aquinas, who instructed that only God had the power of life and death. Relational theology offers us a different lens to consider *medical assistance in dying*. "In giving us the freedom to live, God also gives us the freedom to die."³⁹ Whatever decisions we make in our dying we are asked to consider if we are making choices from a place of fear, love and trust of God that move us towards the one who created and loves us.

36 Driedger Hesslein, unpublished paper submitted to the Task Force on Decisions at the End of Life, page 5.

37 Driedger Hesslein, unpublished paper submitted to the Task Force on Decisions at the End of Life, page 7.

38 Driedger Hesslein, unpublished paper submitted to the Task Force on Decisions at the End of Life, page 7.

39 Driedger Hesslein, unpublished paper submitted to the Task Force on Decisions at the End of Life, page 7.

Discussion

- *What factors have influenced or shaped your own health care decisions?*
- *In the case of Walter, what might he consider from the “WE” quadrant as he considers his own end of life issues/concerns/wishes.*
- *How important to you is the principle of self-determination?*
- *As people of faith how do we measure and balance (?) the quality and quantity of life with each other? Does one have more weight than another for you?*
- *Under what circumstances might an individual feel that life is no longer worth living?*

Case Study

ALS was the diagnosis for Donna at the age of 47 years. Now 51, Donna is having significant communication and swallowing issues due to the disease process. Eating is very difficult and she eats a modified diet, no more steak from the BBQ! Her husband and daughter are encouraging Donna to have a feeding tube placed in her stomach so that she can continue to live. As Donna reflects on her physical losses—the ability to walk and feed herself, the loss of her career as a teacher and the inevitability of her own death, Donna is considering making a request for *medical assistance in dying*.

“I’m done. I cannot endure anymore especially when I know that my future holds more loss, more suffering and in the end, death.” As a person of faith, Donna has spent many hours awake at night asking how much God expects her to endure. On her best days Donna believes that her baptism assures her that there is indeed life after death and she longs to surrender into God’s loving care, confident in the promises made by God in her baptism.

- *Can you imagine circumstances where you might want to discuss MAID or request MAID for yourself? For a loved one?*
- *What questions do you have about it?*
- *How would your congregation accompany a parishioner like Donna? Her family?*

A Word of Wisdom

We do not see things as they are. We see them as we are. (The Talmud)

The faith community is called to support people in times of dying and death. The new reality in our context is that some sick people are going to die. And some sick people who are going to die will ask for *medical assistance in dying*. People of faith will offer care and guidance in this new and ethically-complex reality. Along with the ministry we offer, our conversations, actions and reflections will cause us to discover things about ourselves.

Discussion

- *What does the above saying from The Talmud mean to you?*
- *In the Small Catechism, Luther begins his explanations of the Ten Commandments with the words, “we are to fear, love and trust God above all things.” As we consider our living and our dying, what it is that you fear, love and trust?*

Review

Consider what happened for you during this session.

- What did you hear during this session?
- What questions arise?

Take home: reflecting and digging deeper

In the next session, we will be considering how the church articulates its values.

As you prepare for the next session, consider:

- *What guidance would you like from our church?*
- *What is God calling us to do as people of faith?*
- *Read the ELCIC’s current policy Resolution on Decisions-At-The-End-of-Life (Appendix 2)*

Concluding Prayer

O God, you have called your servants to ventures of which we cannot see the ending, by paths as yet untrodden, through perils unknown. Give us faith to go out with good courage, not knowing where we go, but only that your hand is leading us and your love supporting us; through Jesus Christ our Lord. Amen.⁴⁰

ELCIC Study Guide for Conversations on Medical Assistance in Dying

SESSION 4

What Values Guide our Work as People of Faith?

Introduction

By participating in previous sessions, you have had a chance to participate in conversations regarding:

Session 1: Where Are We Now? And How Did We Get Here?

Session 2: A Good Death?.

Session 3: Rights and Responsibilities, Autonomy and Community

The Task Force on Decisions at the End of Life was given two assignments:

1. To prepare this to study to encourage discussion across this church on the needs of people in times of dying.
2. To review the ELCIC's current policy *Resolution on Decisions-At-The-End-of-Life* (1997) (appendix 2)

The Task Force hopes to receive input from individuals and groups who have participated in these conversations. The purpose of this is to reflect on what you have discovered on this journey, and to reflect on what input you might wish to offer to the Task Force. Input received from across the church will be a valuable part of the review of the ELCIC's current policy. The Task Force will be submitting its recommendations to the National Church Council (NCC) in September, 2018. After reviewing the recommendations, the NCC will make proposals for the National Convention to consider in 2019.

In this session, we will consider:

- Local mission
- Public statements in the ELCIC
- The ELCIC's *Resolution on Decisions-At-The-End-of-Life* (1997)
- Theological considerations
- Input you may wish to offer the Task Force.
- An expression of gratitude

Reading from Scripture

Which of these three, do you think, was a neighbour to the man who fell into the hands of the robbers?" He said, "The one who showed him mercy." Jesus said to him, "Go and do likewise." (Luke 10:36–37)

Opening Prayer

Compassionate God, we ask for your presence in our midst for our discussion today. Give us open and fearless hearts and minds, knowing you are with us as we live and as we die. Amen ⁴¹

Local Mission

What is God calling us to do as people of faith? The ELCIC's vision is to be a church *In Mission for Others*. The majority of mission happens at the local level, as members of this church live by making faith active in love.

The needs of people in times of death and dying are holistic: physical, emotional, social, mental and spiritual. Local faith communities are on the front lines of addressing these needs. In times of illness, dying and grieving, Christians have the opportunity show care by visiting, listening, cooking meals and praying.

In the book of James, the prayers of the faith community are part of addressing illness.

Are any among you sick? They should call for the elders of the church and have them pray over them, anointing them with oil in the name of the Lord. (James 5:14)

Similarly, taking care of the sick is one of the ways of the righteous mentioned in the well know passage from Matthew 25. The call to care for one another is a calling from our baptism.

It is the sincere desire of the Task Force that ELCIC communities would embrace a variety of ways to show care and promote dignity. This includes respecting people's autonomy in decision-making, being a supportive community, offering spiritual care and giving people permission to die. It also includes encouraging discussion of death, dying, advance care directives, and faith questions.

Any Christian, sometimes quite suddenly, can find themselves called upon to be a caring, supportive, faithful presence for a family, friends, neighbours, co-workers and/or community members who are encountering treatment, dying and/or death. People such as health care professionals, social workers, counsellors and institutional administrators have vocations which may present repeated opportunities to address the needs of the dying. Pastor and diaconal ministers have a public ministry on behalf of the church that includes both the provision of spiritual care and the equipping of the church for spiritual care.

What are your reflections on the role that spiritual care plays in addressing the needs of the dying?

Discussion

- *What role do you see for your faith community in supporting people who are dying and their families?*
- *What role does spiritual care play in addressing the needs of the dying?*
- *What values guide our work as people of faith?*

Public Statements in the ELCIC

What is God calling us to do as people of faith? The ELCIC Constitution describes addressing social issues as part of the mission of the church.

In seeking to achieve its mission, this church shall :... Study issues in contemporary society in the light of the Word of God and respond publicly to social and moral issues as an advocate for justice and as an agent for reconciliation;⁴²

Public statements are one way that ELCIC addresses social issues. The purpose of public statements is:

- 1) To serve as teaching opportunities for the people of God;
- 2) To guide the internal life of the ELCIC and support its corporate public witness to society; and
- 3) To support individual Christians in their respective vocations.

The ELCIC makes public statements with a sense of humility regarding how we address complex issues.

The ELCIC's public statements are always proximate answers to the ever changing reality of God's world. While hoping to encourage responsible Christian discipleship, such public statements do not obligate all members of the ELCIC to agree. Honest disagreement should not be seen as a sign of disunity, but as a means of forcing the ELCIC to new understandings and insights. After such debate and discussion, those delegates to a convention and members of Boards, who in conscience cannot subscribe to an adopted policy statement, should always be allowed to register their disagreement in the official record of the proceedings. However, once adopted the Social Statements, Position Resolutions and Policy Resolutions are normative for the elected officers, staff and elected or appointed representatives of the church in representing the ELCIC.⁴³

It is good to remember that the study and conversation that precede the issuing of a public statement are as important as the document.

Decisions at the End of Life

The ELCIC's current policy document is entitled *An ELCIC Resolution On Decisions–At–The–End–Of–Life*, adopted by the ELCIC in Convention in 1997. (Appendix 2.)

If you have not already done so, you may wish to read over the 1997 resolution.

42 ELCIC Constitution, Article IV, Section 2.d.

43 *The Public Witness of the Evangelical Lutheran Church in Canada: A Policy on How the Church Addresses Social Issues*, Adopted by National Church Council, April 1, 1991.

www.elcic.ca/Public-Policy/documents/1991-ThePublicWitnessoftheEvangelicalLutheranChurchinCanada.pdf

Some things to consider

This document is in two parts: the resolution itself, followed by “Background Information.” The resolution part is the official ELCIC policy, adopted by convention. The background information was, and is, for providing context on why the resolution came forward.

The background information makes reference to the *Lutheran Social Statement On Death and Dying*, which was adopted by one of the ELCIC’s predecessor bodies. Statements from predecessor bodies are regarded as “a resource for instruction and guidance for the life and witness of the ELIC.”⁴⁴

A previous draft of the Resolution On Decisions at the End of Life was first presented to the 1995 National Convention, where delegates voted to refer it back to the National Church for further consultation and review. Subsequently, the Resolution, in its current form, was adopted by the 1997 convention. Which is to say the church has long understood that decisions at the end of life are complex and difficult matters, and it takes time for discussion and prayerful reflection when refining public statements.

Public statements in the ELCIC are an effort by the church to address issues in contemporary society. In the 1990’s, some of the issues being discussed were:

- Advances in medical sciences,
- Growing awareness of hospice and palliative care
- The right of persons to determine their own treatment, including the right to refuse treatment.

In addition, in 1993, the Supreme Court of Canada heard a case (Rodriguez v. British Columbia (Attorney General)) in which Sue Rodriguez, a terminally ill woman, challenged the prohibition of assisted suicide as contrary to the *Canadian Charter of Rights and Freedoms*. In a 5 to 4 decision, the Court upheld the provision in the *Criminal Code of Canada*⁴⁵. Similar to today, a court decision has generated discussion in society and in the church.

The 2015 ELCIC National Convention passed the following motion:

That in light of advances in medical science and the recent Supreme Court of Canada’s ruling decriminalizing doctor assisted death the National Church Council be directed to review our current Resolutions on Decisions-At-The-End-Of-Life approved at the Sixth Biennial Convention of the Evangelical Lutheran Church in Canada (1997).

44 *The Public Witness of the Evangelical Lutheran Church in Canada: A Policy on How the Church Addresses Social Issues*, Adopted by National Church Council, April 1, 1991.

www.elcic.ca/Public-Policy/documents/1991-ThePublicWitnessoftheEvangelicalLutheranChurchinCanada.pdf

45 https://en.wikipedia.org/wiki/Assisted_suicide#Canada

When National Church Council (NCC) reviewed the 1997 *Resolution on Decisions at the End of Life* and the 2015 call for a review, they had meaningful and personal conversations regarding the needs of people in times of dying and death. They also noticed that some of language in the 1997 resolution seemed out of date. In creating the Task Force, NCC assigned a dual mandate:

1. To encourage conversations across our church regarding the needs of people in times of death and dying; and
2. To review our current Resolution on Decisions-At-The-End-Of-Life (1997).

Discussion

- *What do you find helpful about the 1997 resolution?*
- *What would you change in the resolution?*
- *What is missing?*

Medical Assistance in Dying

What is God calling us to do as people of faith? As noted in Session One of this study, on February 6, 2015 the Supreme Court of Canada ruled that sections of the Criminal Code that had prohibited physician assisted death were no longer in force and that a medically assisted death could be allowed, but under strict criteria of protection.⁴⁶ This decision has generated a new set of conversations in the public square and in the church.

As chronic, life-threatening illnesses progress, a person nearing the end of life has the following options to consider:

Continue treatment: For some people, continuing treatment feels like the best way to fight disease and to honour the gift of life.

Stop treatment: Respect for a person's rights, dignity and freedom means that an individual always has the right to refuse treatment. For some people, there comes a point when stopping treatment becomes the best way to honour the gift of life.

Palliative Care: *Excellent palliative care promotes early identification, comprehensive assessment and treatment of all pain including physical, psychosocial and spiritual issues.*⁴⁷ Over the last half-century in Canada, there has been a growing awareness of the importance of palliative care. At the same time, awareness of, and access to, effective palliative care remains an important element in addressing the needs of people in times of dying and death.

Hastened Death: The legalization of *medical assistance in dying* means that people will have decisions to make regarding this option. For some, choosing assisted death may be the way they feel called to best honour the gift of life.

46 Quoted from Session 1 of this study.

47 (CHPCA, 2014, p.20) As quoted in the Glossary of the Study Guide.

The ELCIC's current policy states that *we do not support the legalization of "physician assisted" death or "mercy killing" in which the purpose of medical treatment or private action is the deliberate taking of a life which has been created in God's image.*"

Now that medically assisted death has been legalized, and is accessible, in Canada, this statement does not adequately address our current context. Certainly, the church's perspective does not need to change simply because of a change in legislation or public opinion. Nevertheless, this critical moment calls us to review our whole perspective, and to find effective ways to communicate our perspective.

Even if the church were to remain completely opposed to *medical assistance in dying*, there are questions to be addressed in this context:

- Do we actively seek to reverse the legislation or do we simply ask members to refrain from this choice?
- What implications does medical assistance in dying have for Lutheran medical professionals and Lutheran health-care facilities?
- How do we respect the choice that people are legally free to make?

Moreover, some things have changed:

- Advances in treatment means people can survive longer during terminal illness.
- Public opinion has shifted on *medical assistance in dying*.
- Our own sense of what it means to preserve dignity may have changed.
- The legislation has changed so that *medical assistance in dying* will be an option available to people.

Can medical assistance in dying ever be part of a good death? is an honest question. This moment has called our church to wrestle with this question. And we will also need to consider under what circumstances *medical assistance in dying* might be permitted, and/or how to respond to those whom assistance in dying is denied.

Ecumenical Perspectives

This is a brief review of how various churches are engaging questions of decisions at the end of life. It is beyond the capacity of this study to address interfaith perspectives on these matters.

Within the Canadian Council of Churches (CCC), there is no consensus on *medical assistance in dying*. In October of 2016, the CCC did endorse a *Statement of Support for Universal Access to Palliative Care in Canada*.⁴⁸

48 www.councilofchurches.ca/commission-on-faith-witness-releases-statement-of-support-for-universal-access-to-palliative-care/

The Anglican Church of Canada had a Task Force on Physician Assisted Dying from 2013 to 2016. Its final report, *In Sure and Certain Hope: Resources to Assist Pastoral and Theological Approaches to Physician Assisted Dying*, is available online.⁴⁹ It includes the Anglican submission to the Government of Canada which articulates questions in four areas:

1. Dignity, Personhood and Community,
2. Nation to Nation Relationship, (addressing issues around Indigenous culture)
3. Contexts of Care and Access: Grounds for Questions about Coercion and Decision
4. Palliative Care and Hospice

The United Church of Canada has a task force studying this issue. The moderator made a submission to the Government of Canada.⁵⁰

Both the Canadian Conference of Catholic Bishops (CCCB) and the Evangelical Fellowship of Canada (EFC) have been actively opposed to the legalization of *medical assistance in dying* in Canada, and both are supportive of palliative care.⁵¹

Discussion

- *Can medical assistance in dying (MAID) ever be part of a good death? And Why or why not? And in what circumstances?*

Theological Considerations

What is God calling us to do as people of faith? Knowing our theological values helps us to discover opportunities for ministry. It is also important to practice discipline of regularly asking: *What core theological values guide our work?* The process of pondering, articulating, discussing, and even debating these values is an important element in discerning how communities address difficult issues, and a valuable discipline in preparing individuals to support each other in times of crisis. No quick or simple answer to the question will be satisfactory. Rather, communities support each other by carrying this question together.

This reflection is offered as one way to begin your conversation.

But a Samaritan while traveling came near him; and when he saw him, he was moved with pity. He went to him and bandaged his wounds, having poured oil and wine on them. Then he put him on his own animal, brought him to an inn, and took care of him. The next day he took out two denarii, gave them to the innkeeper, and said, 'Take care of him; and when I come back, I will repay you whatever more you spend.'

Which of these three, do you think, was a neighbour to the man who fell into the hands of the robbers?" He said, "The one who showed him mercy." Jesus said to him, "Go and do likewise." (Luke 10:33-37)

49 www.anglican.ca/faith/focus/ethics/pad/

50 www.united-church.ca/news/moderator-physician-assisted-dying

51 www.cccb.ca, www.evangelicalfellowship.ca/euthanasia

What does it mean to love your neighbour? The Good Samaritan went the extra mile to care for one in need. Reaching beyond cultural and ethnic division, he offered his time, effort and resources to act with compassion, commitment, and generosity. Jesus uses this parable to challenge us to show mercy in all circumstances. It is central to our baptismal calling to live as disciples.

Reflecting on these words, and looking back over the sessions in this study, some values that might be articulated are:

Trust in God: We know God as the source of life for all peoples and for each person. We look to God for guidance and direction. We trust in God for forgiveness and support. We trust in God for resurrection.

Sanctity of life: Life is a precious gift from God. We show respect for life by refraining from violence and harm. And we honour the gift by helping and supporting others in times of need.

Compassion: The one who shows mercy is the true neighbour. It is a calling.

Dignity, respect and autonomy: The Good Samaritan directs his attention away from himself and toward another. Helping is about addressing our neighbour's needs, rather than acting based on our perception of someone's else's needs. To help our neighbour we need to listen to our neighbour, and to respect her or his rights and responsibilities.

Community: We love God. Therefore, we are called to show compassion. We need the support of community to live out this calling. The Holy Spirit acts in community to reveal God's guidance.

Reformation People: We are called to help and support in ways that proclaim the gospel in our current context. Our actions need to demonstrate our faith in a loving and gracious God. Life is complex and we don't always know what to do or how to proceed. We are continually asking "what does this mean?" We are continually discovering ways to participate in God's mission to love and save the world.

A Good Death: Life is a gift. Dying and death are the conclusion of each individual life. Caring for our neighbour in times of dying is one element of helping and supporting them in all of life's needs.

Honesty: A Lutheran perspective is that the commandments invite us to examine our lives, know that we cannot fulfill their expectations. We are invited to be honest about our weakness, our sins and our fears because we believe in God's grace, forgiveness, compassion and love.

Discussion

- *What core theological values guide our work?*
- *What guidance would you like from your church?*
- *What questions do you still have?*

Offering Input to the Task Force

While the primary goal of these sessions is for you to have meaningful conversation that is relevant to your local context, the Task Force on Decisions at the End of Life is interested in your insights. The Task Force welcomes, and desires, input from you regarding the needs of people in times of dying and death, and regarding decisions at the end of life.

Appendix 3 is a list of Reflective Question for Input to the Task Force on Decisions at the End of Life.

You are welcome to respond to any or all of these questions. You are welcome to submit responses individually and/or as a group.

Appendix 3 also identifies the options for submitting your responses.

Expression of Gratitude

We do not live to ourselves, and we do not die to ourselves. If we live, we live to the Lord, and if we die, we die to the Lord; so then, whether we live or whether we die, we are the Lord's. For to this end Christ died and lived again, so that he might be the Lord of both the dead and the living. (Romans 14:7–9)

The Task Force is grateful for your participation in this conversation, and for any and all input you choose to forward on to us.

While complex issues have a way of continuing to generate provocative questions and stirring memories of difficult times, we hope that along the way you had meaningful and encouraging conversation. We pray that the question *How might our faith carry us?* might be a blessing to your journey as a disciple and a community.

Discussion

- *Offer each participant an opportunity to express gratitude to each other for being part of this conversation together.*

Concluding Prayer

O GOD the Word that leads all to freedom and the peace that the world cannot give, help us to know that you will call our names, embracing our pain, and that through you we can stand up and walk and live. Help us to believe that you will bring us home because you love us, and we are yours. Amen.⁵²

52 Paraphrased from EvLW Hymn #581. "You Are Mine"

ELCIC Study Guide for Conversations on Medical Assistance in Dying

APPENDIX 1

Medical Assistance In Dying (MAID)

How Have We Gotten Here?

- **Sue Rodriguez** suffered from ALS (Amyotrophic Lateral Sclerosis) and petitioned the B.C. Court of Appeal to have the *Criminal Code* restrictions on physician assisted death struck down. Her challenge moved to the Supreme Court of Canada where she lost her appeal by a vote of 5–4. (circa 1993).
- Many **private member’s bills** in support of physician assisted dying were tabled in the House of Commons: none were successful.(Senate of Canada, June 1995)
- **Gloria Taylor** (suffering from ALS) and Kay Carter (suffering from severe spinal stenosis) brought forward the need for removal of the restriction in 2013-2014 in the B.C. Courts.
- On February 6, 2015 the **Supreme Court of Canada** who heard the Carter case, created an exemption from criminal prosecution for health-care professionals who assist a person to die under set criteria and processes.
- On June 17, 2016 the **House of Commons passed Bill C-14** (An Act to amend the *Criminal Code* and to make amendments to other Acts (*medical assistance in dying*)) giving Canada its assisted dying law.

Relevant Clauses in the *Criminal Code*

The new law created exemptions for *medical assistance in dying* and aiding a practitioner (physicians and nurse practitioners) to provide a person with medical assistance in dying by “**striking down” Sec 14 and Sec 241(b) of the Criminal Code.**

Sec 14. *No person is entitled to have death inflicted upon him.*

Sec 241 (b). States that anyone who *aids or abets a person to commit suicide commits a crime.*

[Sec 241 (a) **remains.** It states: *Everyone who counsels a person to commit suicide...whether suicide ensues or not, is guilty of an indictable offence and liable to imprisonment for a term not exceeding fourteen years.*]

Only 2 forms of MAID are permitted: (1) **administering a substance** to a person, at their request, to cause their death; and (2) the **prescription or provision** of a substance to a person, at their request so that they may self-administer the substance.

Criteria for MAID

To be eligible for *Medical Assistance in Dying* a Person must be:

- Eligible for health services funded by the Government of Canada (Provincial Health Insurance);
- At least **18 years old** and **capable of making decisions** with respect to their health;
- Must have a **grievous and irremediable medical condition**;
- Must have made a **voluntary request** for MAID that, in particular was not made as a result of external pressure;
- Must have given an **informed consent** to receive MAID after having been informed of the means that are available to relieve their suffering, including *palliative care*, and consent is witnessed by two independent witnesses; and
- Whose natural death is **reasonably foreseeable**.

As defined in the legislation, having a ***grievous and irremediable medical condition*** means (a) they have a serious and incurable illness, disease or disability, (b) they are in an advanced state of irreversible decline in capability, (c) that illness, disease or disability or that state of decline causes them enduring physical or psychological suffering that is intolerable to them and that cannot be relieved by conditions that they consider acceptable, and (d) their natural **death has become reasonably foreseeable**, taking into account their medical circumstances, without a prognosis necessarily having been made as to the specific length of time that they have remaining.

Process & Safeguards

A physician or nurse practitioner must ensure that:

- a person meets the criteria;
- the person makes the request in writing, that is signed, dated and witnessed;
- a waiting period of 10 days follows receipt of the written request before the request is implemented;
- the person is informed that they can withdraw consent at any time;
- immediately prior to giving the drug the person is asked if he/she wishes to withdraw consent; and
- two persons must sign and they must be independent from the MD or the NP.

The death certificate must indicate the illness, disease or disability that prompted the request.

www.parl.gc.ca

ELCIC Study Guide for Conversations on Medical Assistance in Dying

APPENDIX 2

An ELCIC Resolution on Decisions-at-the-End-of-Life

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

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

- should seek to provide support and guidance to family, friends, and health care professionals about what treatment and care they would want for the patient in circumstances where the patient may be unable to communicate. Christians should not support any treatment given without the consent of a patient, or if that is not possible, without the witnessed consent of those who have been given authority to speak on behalf of the patient.
- encourage individuals to empower and help alleviate potential guilt of family and friends who may have to make treatment decisions on behalf of the patient by discussing and documenting treatment wishes and the values that inform these wishes.

Background Information

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

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

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

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

Christian Convictions:

A foundation for Christian guidelines in the matter of euthanasia can be found in the *Lutheran Social Statement On Death and Dying*⁵³ adopted by the ELCIC from one of its predecessor bodies. From that document certain affirmations and insights can be drawn which are helpful to our Christian reflection on issues regarding death, dying and euthanasia. These affirmations and insights include:

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

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

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

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

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

53 www.elcic.ca/Public-Policy/documents/500.31982-ASocialStatementonDeathandDying.pdf

ELCIC Study Guide for Conversations on Medical Assistance in Dying

APPENDIX 3

Reflective Questions for Input to the Task Force on Decisions at the End of Life

1. What role does the Christian community play in addressing the needs of the dying?
2. What role does spiritual care play in addressing the needs of the dying?
3. *Can medical assistance in dying (MAID) ever be part of a good death? Why or why not? And in what circumstances?*
4. What core theological values guide our work?
5. What guidance would you like from your church?
6. What questions do you still have?
7. Is there anything else you would like to share with the Task Force?

Ways to submit input

Online: <https://www.surveymonkey.com/r/Taskforcequestions>

Email: electronic document or scan: pgehrs@elcic.ca

Mail: Task Force on Decisions at the End of Life
600—177 Lombard Ave, Winnipeg, MB R3B 0W5

ELCIC Study Guide for Conversations on Medical Assistance in Dying

APPENDIX 4

Glossary

ACCOMPANIMENT/ACCOMPANYING. Means a commitment to stay with another person or family in their time of distress, decision-making and or grief. Sometimes stated as “walking with another.”

ADVANCE DIRECTIVES. A person’s written wishes about how and what decisions should be made if they become incapable of making decisions themselves, in decisions about life-sustaining treatment. Advance directives are meant to assist with decisions about withholding or withdrawing treatment. Also called living wills or personal directives.

AGENCY. The freedom to make our own decisions, either as an individual or as a family unit

ALS. Refers to *Amyotrophic Lateral Sclerosis* which is a progressive neuro-degenerative disease that attacks cells in the brain and the spinal cord needed to keep muscles active. It causes weakness, paralysis, inability to speak or swallow, and ultimately respiratory failure that leads to death. It has been a common disease of individuals seeking *medical assistance in dying*.

AUTONOMY. Means having both the right and the ability to make meaningful choices for oneself; in health care the right to choose what one will or will not do or allow to be done with respect to treatment.

BLANKET OF CONDEMNATION. Refers to statements made by governing bodies or organizations that emphasize their opposition to particular laws, policies or practices.

CONSCIENTIOUS OBJECTION. Refers to the legal right of individual health professionals to decline to participate in a particular medical practice due to matters of personal conscience and/or religious beliefs.

CONVENTION RESOLUTION. With reference to this Study Guide means a decision passed by the Evangelical Lutheran Church of Canada meeting in convention, normally every two years, whose decisions are binding on members.

CREATED IN GOD’S IMAGE. Comes from Genesis 1:26-27 and is used as foundation for various doctrines in various faith communities. One common implication is that God bestows value and dignity on each person, which informs God’s expectations of human behaviour.

DIGNITY. Is the quality or state of being worthy, honoured or esteemed; behaviour that accords with self-respect or with regard to due seriousness. (Oberle & Raffin 2009.)

ETHIC OF ACCOMPANIMENT. See Accompaniment above. People are urged, as a matter of ethics, to be with people in their time of distress, decision-making, and grief.

ECUMENICAL. Refers to the Christian church as a whole.

GRIEVOUS AND IRREMIABLE. Is a term used in the *Parliament of Canada Act* legislating *medical assistance in dying*. This medical condition is defined as being serious and incurable, an advanced state of irreversible decline, causing enduring suffering intolerable to an individual and whose death is reasonable foreseeable. (Statutes of Canada 2016, chapter 3.)

MAID. A commonly used short term for *medical assistance in dying*. See below.

MEDICAL ASSISTANCE IN DYING (MAID). Means (a) administering by a medical practitioner or nurse practitioner of a substance to a person, at their request, that causes their death; or (b) the prescribing or providing by a medical practitioner or a nurse practitioner of a substance to a person, at their request so that they may self-administer the substance and in doing so cause their own death. (Statutes of Canada 2016, chapter 3.)

NURSE PRACTITIONER. Refers to a registered nurse who under Provincial law is entitled to practice as an advanced practitioner, autonomously diagnosing, ordering, interpreting diagnostic tests, prescribing substances and treating patients.

PALLIATIVE CARE. Is care given to improve the quality of life of those facing challenges of 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. (CHPCA 2014.)

POLICY. A principle, plan or course of action as pursued by a government, organization or individual.

REFLECTION. Means the fixing of the mind on some subject, serious thought or contemplation.

REFORMATION PEOPLE. Refers to Lutherans and others who commit to being Christians willing to continue to examine their faith and faithful practices, and to change positions or practices that are not in keeping with a reflection of Christian love and compassion.

RESPECT. Involves recognition of an individual's right to make choices according to their values and beliefs.

SANCTITY OF LIFE. Is a principle based on either religious or secular beliefs. The religious argument is based on the view that life is sacred, is a gift from God and is protected by divine commandments; the secular argument is based on the Kantian view that there is a rule that killing is wrong. (Downie 2004).

SOCIAL STATEMENT. Refers to a well thought-out document that provides guidance for individuals on a particular matter or area of interest.

SPIRITUAL CARE. refers to the activity of chaplains, community clergy, faith leaders and laity in helping persons to discover and deepen life and give expression to their spirituality and/or religion. (CHAC 2012).

SPIRITUALITY. Means the search for the sacred. A conscious striving to move beyond isolation and self-absorption to a deeper awareness of interconnectedness with the self, other human beings and the transcendent. (CHAC 2012).

SUICIDE. Involves the taking of one's own life

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

THEOLOGIAN. Means as student of or specialist in the study of God and the relations between God, mankind and the universe. In this study guide it means a pastor who has gone on for further theological study normally at a doctoral degree level.

WITHDRAWAL OF TREATMENT. In this context means a patient's decision to discontinue life-saving treatment to allow for an earlier death (e.g. discontinuing kidney dialysis or discontinuing a respirator). This should not be confused with *medical assistance in dying*.

APPENDIX

Sources

Session 1

Downie, J. (2004). *Dying Justice: A Case for Decriminalizing Euthanasia & Assisted Suicide in Canada*. Toronto: University of Toronto Press.

In this book, written over a decade ago, Downie presents evidence for why a law permitting physician assisted suicide/death should be developed in Canada.

Martin, Sandra (2016) *A Good Death: Making the Most of our Final Choices*. Toronto: HarperCollins Publishers Limited.

Martin provides a detailed account of how our Medical Assistance in Dying law developed and highlights some of the key individuals noted in this lesson who were instrumental in moving it forward.

College of Family Physicians of Canada. (2015). *A Guide for reflection on ethical issues concerning assisted suicide and voluntary euthanasia*. Ottawa: CFPC Task Force on End of Life Care.

Fletcher, J. (1954) *Morals and medicine*. Princeton, N.J.: Princeton University Press.

Norlander, L. (2014) *To comfort always: a nurses guide to end-of-life care* (2nd ed). Indianapolis IN: Sigma Theta Tau International.

Senate of Canada. (1995). *On life and death*. Report of the Special Senate Committee on Euthanasia and Assisted Suicide.

Statutes of Canada 2016. Chapter 3. *An Act to amend the Criminal Code and make related amendments to other Acts (medical assistance in dying)*. Assented to June 17, 2016. Bill C-14.

Session 2

Driedger Hesslein, K. (2016) *"Theological Reflection on Physician-Assisted Death" for the ELCIC Task Force on Decisions at the End of Life*.

Knudson Munholland, L. (2016) *Response to the Request – Decisions at the End of Life*.

Kuhnert, P. (2016) *ELCIC Task Force on Decisions at the End of Life. A Medical-Theological Response*.

McNabb, K. (2016) *Theological Reflection Re: ELCIC Task Force on Decisions at the End of Life*.

Nouwen, H. (1997). *Bread for the journey*. New York: HarperColl