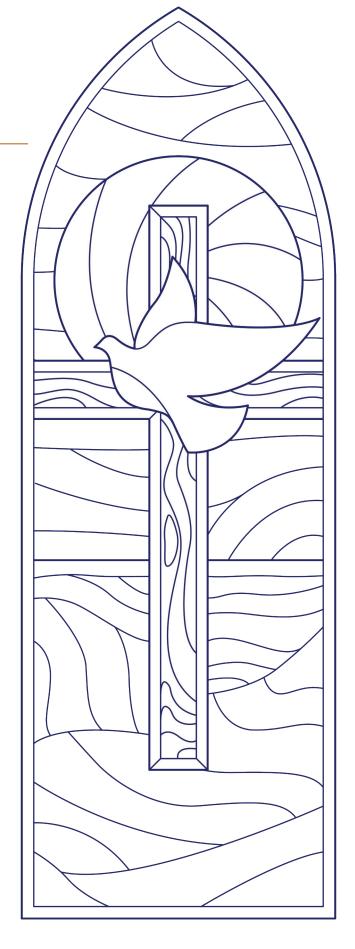


### **Horizons of Hope**

A Toolkit for Catholic Parishes on Palliative Care

### **MODULE 02**

Discerning and making decisions at the end of life



# Table of contents

| Tips for the | e facilitator   | 2   |
|--------------|---|-----|
| Helpful ma   | terials   | 2   |
| Norms for o  | conversation  | 3   |
| Part 1: Exp  | erience   | 6   |
| 1.           | Preparing our hearts  | 6   |
| 2.           | Proclamation of the Word of God   | 6   |
| 3.           | Guided personal reflection  | 6   |
| 4.           | Table conversations   | 7   |
| 5.           | Large group focus   | 7   |
| Part 2: New  | v information   | 10  |
| Section      | A: Medical perspective  | 10  |
| 1.           | Video — Medical perspective on discernment and decision-making at the end of life | 10  |
|              | Video script — Medical perspective  | 11  |
| 2.           | Application to my life: Medical perspective                                       | 14  |
| 3.           | Table conversations   | 15  |
| 4.           | Large group focus   | 15  |
| 5            | Break   | 1.5 |

| Section        | B: Theological and ethical perspective  | 16 |
|----------------|---|----|
| 1.             | Video — Theological and ethical reflections on discernment and decision-making at the end of life | 16 |
|                | Video script — Theological and ethical reflection   | 17 |
| 2.             | Application to my life: Theological and ethical perspective                                       | 20 |
| 3.             | Tables conversations  | 21 |
| 4.             | Large group focus   | 21 |
| Part 3: Action | on  | 24 |
| 1.             | Going Forth   | 24 |
| Endnotes       |   | 25 |
| Appendices     |   | 27 |
| Арр            | pendix 1  | 28 |
| Арр            | pendix 2  | 29 |
| Арр            | pendix 3  | 33 |
| Арр            | pendix 4  | 34 |
| Арр            | pendix 5  | 37 |
| Арр            | pendix 6  | 38 |
| Арр            | pendix 7  | 40 |

### **MODULE 02**

# Discerning and making decisions at the end of life

# Tips for the facilitator



Module 2 is designed to help participants understand the experience of death and dying. Participants will reflect on the proclamation of a Gospel narrative and hear presentations by theological and medical experts. In particular, the focus is on **discernment and decision-making** when faced with serious illness and dying. This will enable participants to engage in meaningful reflection and conversation to better understand the experience of death and dying.

# Helpful materials

Depending on the group and the availability of resources, the following items may be of assistance.



Holy Bible

(New Revised Standard Version)



Paper for taking notes



Laptop



Flip chart/whiteboard/chalkboard



Projector



Masking tape



Speakers



Markers



Screen



Participants are encouraged to bring notebooks/paper/journals for recording their insights and thoughts during the session



Pencils or pens

# Norms for conversation



Throughout the module, there will be many opportunities for table discussions. The sensitive nature of the topic "end-of-life" requires that facilitators be especially attentive to the possibility that some discussions may become emotionally charged and difficult. It is always helpful to identify, with the participants, some norms for conversation at the beginning of each session. These may include:

- All participants will be given an opportunity to speak in the group; some may choose not to. The group will respect the person's decision.
- One person speaks at a time.
- Participants, if they choose, may respond to the speaker in a helpful but non-judgmental/non-confrontational way.
- Respect each other and commit to confidentiality to promote trust.
- Sometimes a person requires more time to tell their story than is allotted in the discussion. The facilitator will gently redirect the person so that he or she may speak one on one with another person during a break or after the session.

**NOTE:** These norms may be projected on the screen, printed and posted on the wall, placed on the tables or written on a whiteboard. **See Appendix 1 in the Facilitator's Guide.** 

### PART 1

# Experience

Your word is a lamp to my feet and a light to my path.

Psalm 119:105

# Part 1: Experience

© 25 minutes



### 1. Preparing our hearts

As Christians, we look to the Gospel to guide us, inspire us and help us to grow in our relationship with Jesus. When we reflect on the Gospel stories, they help us understand the experiences we are going through in our lives. Let us quiet ourselves to hear the Word of God.



### 2. Proclamation of the Word of God



Proclaim the Scripture passage Deuteronomy 30:15–20 aloud. Please use a bible or lectionary for this proclamation.



### 3. Guided personal reflection

① 10 minutes

**Invite participants** to take a few minutes in silence to respond to some guiding questions *individually* in their journals/notebooks. The guiding questions may be projected on the screen, printed and posted on the wall, placed on the tables or written on a whiteboard. See **Appendix 1** for a copy of the guiding questions.

### **Guiding Questions:**

- 1. Deuteronomy 30:15-20 implores us to choose life. This may seem paradoxical when we are faced with illness, dying and death. What value does life always have, even in these situations?
- 2. Is it easy to choose life, or does the alternative sometimes seem less burdensome?
- 3. What does it mean to choose life in the midst of pain and suffering?



### 4. Table conversations



This is an opportunity for individuals to have conversations in small groups to share their responses to the guiding questions.

**Ask the participants** to share **a word**, **a phrase** or **an image** from the Gospel that struck them or reminded them or spoke to their lived experience.

**NOTE:** Participants may wish to tell their own stories very briefly in this context: allow for this, but monitor the tables to ensure that everyone has an opportunity to speak if they wish.

Depending on the number of participants, the facilitator may circulate to each table and listen to the conversations to identify common themes in the discussion. If there is only one table group, the facilitator should join the group as an interested listener.



### 5. Large group focus



**Gather the participants** together in a large group. The facilitator brings the *experience* portion to a close by identifying one or two points they heard during the table discussions.

**Wrap up** by introducing the next section of the module.

### PART 2

# New information

Conscience is the most secret core and sanctuary of the human person. There he is alone with God, whose voice echoes in his depths.

Pope Paul VI, Gaudium et spes.

### Part 2: New information

### **Section A: Medical perspective**

**(1)** 45 minutes



### Video – Medical perspective on discernment and decision-making at the end of life



This video will introduce participants to medical questions about palliative care. Topics to be explored include these:

- 1. How much information do people want or need about their illness or the process of dying?
- 2. What are "care and treatment" options?
- 3. What is meant by "goals of care"?
- 4. Why is "advance care planning" important?

**NOTE TO FACILITATOR:** This video can be viewed on YouTube at <a href="https://youtu.be/yf5QRluD6WQ">https://youtu.be/yf5QRluD6WQ</a>. For direct download of the video files, visit <a href="cccb.ca">cccb.ca</a>. To help you become familiar with the core content of this video, we have included the script below. See <a href="https://www.appendix.2">Appendix 2</a> for a take-home version of the script.



### Video script — Medical perspective

Hi again. I am Dr. Jose Pereira ... and I am professor and director of the Division of Palliative Care in the Department of Family Medicine at McMaster University.

It is difficult to make decisions without information, especially when one is also experiencing very strong emotions when facing a serious illness. In this video, we will provide some information that may help you when facing a serious illness.

#### How much information do we need?

People have different preferences about this. Some people want lots of information, some not too much. Some want all the information up front, while others prefer to get it in chunks over time. Let your doctors and family know what your preferences are.

Most people want a fair amount of information—enough to help them understand the illness, what is happening, what treatments are available, and what the pros and cons of the various treatments are and what care options are available.

Sometimes we hear some people say that "in our culture" or "in that culture," people don't want to know what is happening, especially if it is a serious illness. The family may even ask that doctors not tell their loved ones that they have a serious illness or that there is a serious complication, for fear that it will depress them. We need to challenge this way of thinking.

Research across many countries and cultures shows that in most cases, people want to have information about their illness. Withholding information from patients is unethical, unless the patient has clearly said that they don't want information or only want limited information. At the very least, we need to ask patients what information they want, no matter what culture or background they are from.

Think about it yourself: "What type of information would I want when facing an illness?" Most patients find information about the following most useful and often want someone with them when receiving it:

- The disease and the extent of the disease, also known as the "stage" of the disease;
- The treatment options available;
- The anticipated benefits as well as possible side effects of each treatment;
- Where the best place for care would be.

Dr. Elizabeth Latimer, a Canadian pioneer of palliative care, once wrote that there are **little**, **medium** and **big questions** that arise when facing serious illness. The little questions are the easiest to ask and also the easiest to answer, such as "What test is being done and why? Where will I get the treatment? Can I still travel?" Medium questions are important questions that are easy to ask, but may not be so easy to answer. They include "What is the illness and at what stage is it? What results will different treatments produce?" The big questions are the ones that worry us the most, that keep us from sleeping, that we are often afraid of asking, but they are important questions to ask and discuss. These are questions like "How serious is my illness? Will I be cured? How long do I have to live?"

Now, you are probably wondering why we talk of "care and treatment approaches." Are these not the same? We use these words to make the point that the type of treatments we choose at any given time depends on the overall goals of care. During the course of an illness, and especially at diagnosis or when the disease recurs, there may be treatments that can control or even cure a disease. Other times, however, a potential treatment may not help control the disease or prolong life much, but may cause severe side effects and discomfort. In these cases, it may be a better option to forgo such treatments and focus rather on a palliative care approach, where treatments are used that can improve pain and symptoms and maximize comfort, without causing bad side effects. But remember, in all cases, whether treatments to control the disease are possible or not, one can always do supportive and palliative care to improve the life that is still to be lived.

The discussions and decisions about what care or treatment plan to do whenever things change are called "goals of care" discussions and decisions. In addition to having information about the disease and possible treatments, other important things also need to be considered. One of them is asking oneself, "What is most important for me now ... living longer or living better in the time that I have?" If the treatments do not cause a lot of side effects or lots of burden, such as needing special tubes or frequent visits to hospitals or labs and even hospitalizations, then the decision may be easier to go with the treatment. However, when the treatments do not prolong life and come with lots of serious side effects, one may opt to focus on quality of life instead of going through the treatments. It is important to be honest with oneself and to make sure that your family understands your wishes and goals. Sometimes patients may appropriately opt to not proceed with treatments, but families become upset by that, thinking that patients are giving up. Families need to understand these dynamics and what is important for the patient.

Additionally, we can conclude from what we have heard that the trust between doctor and patient forms the basis for a fruitful dialogue on how to balance appropriate and futile interventions. As our Church teaches, "... for such a decision to be made, account will have to be taken of the reasonable wishes of the patient and the patient's family, and also of the advice of the doctors who are especially competent in the matter."

Advance care planning is a very, very important topic, one of the most important pieces of information of this video. Advance care planning is a reflection on what is important for us at the end of our lives. It also includes identifying someone who knows us well to make health decisions on our behalf if we are not able to make those decisions ourselves. Advance care planning is about planning ahead to make sure that if we are too sick to make decisions for ourselves, the care we receive is what we would have wanted. It provides the person or persons we have identified to make decisions on our behalf with the information they need. If there has been no advance care planning, we can end up receiving care and treatments that are not what we want. In the absence of advance planning, we also end up putting a lot of pressure on our family or friends who have to make difficult decisions on our behalf, without knowing our wishes.



# 2. Application to my life: Medical perspective



#### Silent individual reflection

Following the instructional video, participants will have an opportunity to consider the *medical* video content.

**Invite participants** to respond to some guiding questions *individually*. The guiding questions may be projected on the screen, printed and posted on the wall, placed on the tables or written on a whiteboard. See **Appendix 3** for a copy of the guiding questions.

Let us reflect on what we heard about advance care planning, goals of care and treatment in the video.

- 1. How do you understand care and treatment approaches?
- 2. How will *goals of care* help me to articulate the ways in which my illness will unfold?
- 3. Why is *advance care planning* so important?



### 3. Table conversations



This is an opportunity for individuals to have conversations in small groups to share their responses to the guiding questions.

**Review the Norms for Conversation**. Participants may wish to tell their own stories very briefly in this context: allow for this, but monitor the tables to ensure that the focus is maintained so everyone has an opportunity to speak if they wish.

**Provide participants** with a time frame in which the table conversations will take place.

Depending on the number of participants, the facilitator may circulate to each table and listen to the conversation to identify common themes in the discussion. If there is only one table group, the facilitator should join the group as an interested listener.



### 4. Large group focus



**Gather the participants** together into a large group. The facilitator will finish the *medical* portion by identifying one or two points they heard during the table discussions.

**Wrap up** by introducing the next section of the module.

### 5. Break

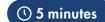


# Section B: Theological and ethical perspective

**45** minutes



### Video — Theological and ethical reflections on discernment and decision-making at the end of life



This video will introduce participants to the topics of discernment and decision-making, and address questions about beginning or withdrawing treatment, pain and suffering, and conscience formation.

**NOTE FOR FACILITATOR:** This video can be viewed on YouTube at <a href="https://youtu.be/jf5rIRc6hBk">https://youtu.be/jf5rIRc6hBk</a>. For direct download of the video files, visit <a href="cccb.ca">cccb.ca</a>. To help you become familiar with the core content of the video, we have included the script below. See <a href="Appendix 4">Appendix 4</a> for a take-home version of the script.



### Video script — Theological and ethical reflection

#### The Gift of Life

As Catholics, we thank God for the gift of life. We are called to develop our talents, to become people who love God and each other, hence our most important Commandment: love God and love your neighbour as yourself. When it comes to end-of-life matters, we want to be sure that we are making good decisions for ourselves and for loved ones. It is reassuring that we do not have to make these decisions alone. Since our faith matters to us, we should turn to it especially in the most difficult of times where we can be assured of Christ's presence and the ministry of His Church.

# The question of beginning or withdrawing of medical treatment

The Church points to some long-standing principles to assist us in our decision-making process. These decisions are not always easy, but should be approached in prayer.

Fundamentally, we must provide and receive what is called "the necessities of life." These are basic forms of care such as: food, water, air, warmth, clothing, etc.

The Church uses the moral categories of ordinary and extraordinary care, now more accurately referred to as proportionate or disproportionate care. These concepts help guide our ethical decision-making at the end-of-life. For example, continuing to use a treatment which has become ineffective in that it cannot cure the patient would count as disproportionate care and is not obligatory to use. Likewise, treatment which a patient experiences as a burden could also be deemed disproportionate, meaning that the person could choose to stop treatment or not even embark on it. For example, a dread of chemotherapy might prevent someone from starting such treatment. It is important to remember that treatment options are the patient's choice, despite others' advice and concerns in some situations.

Some people are worried that, if treatment is withdrawn, they might be guilty of participating in euthanasia. We can reassure them that, in these circumstances, it is the underlying disease that causes death and not one's decision to stop treatment.

It is also important to affirm that the Catholic Church is not what is called "vitalist," meaning human life is to be sustained at all costs. There are situations where it is clearly appropriate to stop futile or overly burdensome treatments.

#### Pain and Suffering: What are the Differences?

Pain can be defined as "An unpleasant sensory and emotional experience associated with, or resembling that associated with, actual or potential tissue damage."<sup>2</sup>

An important task of end-of-life care is to assure patients that their pain levels are managed. Pain, in addition to appropriate medication, can also be controlled in rare cases by deep sedation. Questions are often asked about the morality of deep sedation. Pope Pius XII issued teaching on this as far back as 1957, stating that such procedures were in fact morally licit because the intention is to relieve pain and not cause death.<sup>3</sup>

The term suffering, however, includes enduring the physical woes of sickness or injury as well as the experience of psychological or spiritual distress, which is not so easily medicated, if at all. Suffering comes in many forms, affecting our bodies, minds and spirits. This can be more difficult to treat than physical pain. Pope Francis reminds us that no one is to be abandoned; rather, everyone is to be accompanied and made to feel the dignity of being part of a community as a valued person.

### **Decision-making, Conscience and Discernment**

Each person has the God-given gift and responsibility to make his or her own decisions at the end of life, when still capable and competent. These decisions need to be made in the same way as other decisions, by a conscience informed by Catholic teaching. Most of us need some advice when it comes to medical decision-making. At the same time, we have to pay attention to Church teaching to see if the two sets of advice agree. Conscience formation is the responsibility of each one of us. This includes consulting other sources when we are unsure about medical diagnoses, Church teaching, or even the opinions of our family and loved ones. Experts can provide necessary information for good treatment choices. They can direct us, but the final decision is up to us. As Catholics, we make these decisions in the context of prayer and discernment and guided by Church teaching.

### Living Life to the End

The Catholic Church is strongly committed to helping us live our lives fully, to the very end, when we believe God will take us home. As a community of believers, we do not see death as "the end," but as a transition to fullness of life in God through the power of the Resurrection of Jesus Christ. Our Christian faith gives us a different perspective, even though we naturally experience the same human pain and suffering as everyone else. This difference is captured in St. Pope John Paul's Letter to the Elderly, where he says that, in dying we go "from life to life." He writes: "It is wonderful to be able to give oneself to the very end for the sake of the Kingdom of God!" This message gives us hope that each of us will have the same experience of not just dying, but living life to the very end, in the hope of the Resurrection.



# 2. Application to my life: Theological and ethical perspective



#### **Silent Individual Reflection**

Following the instructional video, participants will have an opportunity to consider the *theological*|*ethical* content of the video.

**Invite participants** to respond to some guiding questions *individually*. The guiding questions may be projected on the screen, printed and posted on the wall, placed on the tables or written on a whiteboard. See **Appendix 5** for a copy of the guiding questions.

### **Guiding questions:**

- 1. What are some examples of ordinary care (i.e., that does not place an undue burden on a person)?
- 2. What are some examples of extraordinary care?
- 3. Ordinary and extraordinary care are sometimes referred to as proportionate and disproportionate means. How would you explain the difference between proportionate and disproportionate means using the examples provided in the video?
- 4. What is the Church's position on treatment at all costs?
- 5. What is the difference between euthanasia and physician-assisted suicide (also called Medical Assistance in Dying, or MAID)?
- 6. How would you explain the difference between pain and suffering to someone who is near the end of life?



### 3. Tables conversations

© 20 minutes

This is an opportunity for individuals to have conversations in small groups to share their responses to the guiding questions.

**Review the Norms for Conversation**. Participants may wish to tell their own stories very briefly in this context: allow for this, but monitor the tables to ensure that the focus is maintained so everyone has an opportunity to speak if they wish.

**Provide a time frame** in which the table conversations will take place.

Depending on the number of participants, the facilitator may circulate to each table and listen to the conversations to identify common themes in the discussion. If there is only one table group, the facilitator should join the group as an interested listener.



### 4. Large group focus



**Gather the participants** together into a large group. The facilitator will finish the *theological* portion by identifying one or two points they heard during the table discussions.

**Wrap up** by introducing the next section of the module.

### PART 3

# Action

Lord, make me an instrument of your peace.

From the prayer of St. Francis of Assisi

# Part 3: Action





### 1. Going Forth

An important part of the learning cycle is the Action component because it allows participants to take the new knowledge they have reflected on and applied during the session into their daily lives.

**NOTE TO FACILITATOR:** To assist participants, we have provided a takehome resource and question-and-answer guide for further reflection at home. Please review the question and answer take-home resource with participants. Provide participants with a copy of **Appendix 6** and **Appendix 7**, either in a digital format or distribute a paper copy.

# **Endnotes**

- Congregation for the Doctrine of the Faith, "Declaration on Euthanasia Iura et Bona", 5 May 1980, para 546. <a href="http://www.vatican.va/roman\_curia/congregations/cfaith/documents/rc\_con\_cfaith\_doc\_19800505\_euthanasia\_en.html">http://www.vatican.va/roman\_curia/congregations/cfaith/documents/rc\_con\_cfaith\_doc\_19800505\_euthanasia\_en.html</a>
- Raja, S. et al. "The revised International Association for the Study of Pain definition of pain: concepts, challenges, and compromises", *PAIN*: September 2020, 161–9, p.1976–1982.
- **3** Cf. Pius XII, "Allocution to the International Society of Anesthesiology". *AAS* 49, 1957. p. 147.
- Pope John Paul II, "Letter to the Elderly", 1991. <a href="https://www.vatican.va/content/">https://www.vatican.va/content/</a>
  john-paul-ii/en/letters/1999/documents/hf jp-ii let 01101999 elderly.html

### **MODULE 02**

# Appendices

# Appendix 1

### **Guiding questions – Reflecting on Scripture**

- 1. Deuteronomy 30:15–20 implores us to choose life. This may seem paradoxical when we are faced with illness, dying and death.

  What value does life always have, even in these situations?
- 2. Is it easy to choose life, or does the alternative sometimes seem less burdensome?
- 3. What does it mean to choose life in the midst of pain and suffering?

# Appendix 2

### Video script - Medical perspective

Hi again. I am Dr. Jose Pereira ... and I am professor and director of the Division of Palliative Care in the Department of Family Medicine at McMaster University.

It is difficult to make decisions without information, especially when one is also experiencing very strong emotions when facing a serious illness. In this video, we will provide some information that may help you when facing a serious illness.

#### How much information do we need?

People have different preferences about this. Some people want lots of information, some not too much. Some want all the information up front, while others prefer to get it in chunks over time. Let your doctors and family know what your preferences are.

Most people want a fair amount of information—enough to help them understand the illness, what is happening, what treatments are available, and what the pros and cons of the various treatments are and what care options are available.

Sometimes we hear some people say that "in our culture" or "in that culture," people don't want to know what is happening, especially if it is a serious illness. The family may even ask that doctors not tell their loved ones that they have a serious illness or that there is a serious complication, for fear that it will depress them. We need to challenge this way of thinking.

Research across many countries and cultures shows that in most cases, people want to have information about their illness. Withholding information from patients is unethical, unless the patient has clearly said that they don't want information or only want limited information. At the very least, we need to ask patients what information they want, no matter what culture or background they are from.

Think about it yourself: "What type of information would I want when facing an illness?" Most patients find information about the following most useful and often want someone with them when receiving it:

- The disease and the extent of the disease, also known as the "stage" of the disease;
- The treatment options available;
- The anticipated benefits as well as possible side effects of each treatment;
- Where the best place for care would be.

Dr. Elizabeth Latimer, a Canadian pioneer of palliative care, once wrote that there are **little**, **medium** and **big questions** that arise when facing serious illness. The little questions are the easiest to ask and also the easiest to answer, such as "What test is being done and why? Where will I get the treatment? Can I still travel?" Medium questions are important questions that are easy to ask, but may not be so easy to answer. They include "What is the illness and at what stage is it? What results will different treatments produce?" The big questions are the ones that worry us the most, that keep us from sleeping, that we are often afraid of asking, but they are important questions to ask and discuss. These are questions like "How serious is my illness? Will I be cured? How long do I have to live?"

Now, you are probably wondering why we talk of "care and treatment approaches." Are these not the same? We use these words to make the point that the type of treatments we choose at any given time depends on the overall goals of care. During the course of an illness, and especially at diagnosis or when the disease recurs, there may be treatments that can control or even cure a disease. Other times, however, a potential treatment may not help control the disease or prolong life much, but may cause severe side effects and discomfort. In these cases, it may be a better option to forgo such treatments and focus rather on a palliative care approach, where treatments are used that can improve pain and symptoms and maximize comfort, without causing bad side effects. But remember, in all cases, whether treatments to control the disease are possible or not, one can always do supportive and palliative care to improve the life that is still to be lived.

The discussions and decisions about what care or treatment plan to do whenever things change are called "goals of care" discussions and decisions. In addition to having information about the disease and possible treatments, other important things also need to be considered. One of them is asking oneself, "What is most important for me now ... living longer or living better in the time that I have?" If the treatments do not cause a lot of side effects or lots of burden, such as needing special tubes or frequent visits to hospitals or labs and even hospitalizations, then the decision may be easier to go with the treatment. However, when the treatments do not prolong life and come with lots of serious side effects, one may opt to focus on quality of life instead of going through the treatments. It is important to be honest with oneself and to make sure that your family understands your wishes and goals. Sometimes patients may appropriately opt to not proceed with treatments, but families become upset by that, thinking that patients are giving up. Families need to understand these dynamics and what is important for the patient.

Additionally, we can conclude from what we have heard that the trust between doctor and patient forms the basis for a fruitful dialogue on how to balance appropriate and futile interventions. As our Church teaches, "... for such a decision to be made, account will have to be taken of the reasonable wishes of the patient and the patient's family, and also of the advice of the doctors who are especially competent in the matter."

**Advance care planning** is a very important topic, one of the most important pieces of information of this video. Advance care planning is a reflection on what is important for us at the end of our lives. It also includes identifying someone who knows us well to make health decisions on our behalf if we are not able to make those decisions ourselves. Advance care planning is about planning ahead to make sure that if we are too sick to make decisions for ourselves, the care we receive is what we would have wanted.

Congregation for the Doctrine of the Faith, Declaration on Euthanasia Iura et Bona (5 May 1980), II: AAS 72 (1980), 546 <a href="http://www.vatican.va/roman\_curia/congregations/cfaith/documents/">http://www.vatican.va/roman\_curia/congregations/cfaith/documents/</a> rc con cfaith doc 19800505 euthanasia en.html

It provides the person or persons we have identified to make decisions on our behalf with the information they need. If there has been no advance care planning, we can end up receiving care and treatments that are not what we want. In the absence of advance planning, we also end up putting a lot of pressure on our family or friends who have to make difficult decisions on our behalf, without knowing our wishes.

### Guiding questions - Medical perspective

Let us reflect on what we heard about advance care planning, goals of care and treatment in the video.

- 1. How do you understand care and treatment approaches?
- 2. How will *goals of care* help me to articulate the ways in which my illness will unfold?
- 3. Why is *advance care planning* so important?

### Video script — Theological and ethical reflection

#### The Gift of Life

As Catholics, we thank God for the gift of life. We are called to develop our talents, to become people who love God and each other, hence our most important Commandment: love God and love your neighbour as yourself. When it comes to end-of-life matters, we want to be sure that we are making good decisions for ourselves and for loved ones. It is reassuring that we do not have to make these decisions alone. Since our faith matters to us, we should turn to it especially in the most difficult of times where we can be assured of Christ's presence and the ministry of His Church.

## The question of beginning or withdrawing of medical treatment

The Church points to some long-standing principles to assist us in our decisions-making process. These decisions are not always easy, but should be approached in prayer.

Fundamentally, we must provide and receive what is called "the necessities of life." These are basic forms of care such as: food, water, air, warmth, clothing, etc.

The Church uses the moral categories of ordinary and extraordinary care, now more accurately referred to as proportionate or disproportionate care. These concepts help guide our ethical decision-making at the end-of-life. For example, continuing to use a treatment which has become ineffective in that it cannot cure the patient would count as disproportionate care and is not obligatory to use. Likewise, treatment which a patient experiences as a burden could also be deemed disproportionate, meaning that the person could choose to stop treatment or not even embark on it. For example, a dread of chemotherapy might prevent someone from starting

such treatment. It is important to remember that treatment options are the patient's choice, despite others' advice and concerns in some situations.

Some people are worried that, if treatment is withdrawn, they might be guilty of participating in euthanasia. We can reassure them that, in these circumstances, it is the underlying disease that causes death and not one's decision to stop treatment.

It is also important to affirm that the Catholic Church is not what is called "vitalist," meaning human life is to be sustained at all costs. There are situations where it is clearly appropriate to stop futile or overly burdensome treatments.

### Pain and Suffering: What are the Differences?

Pain can be defined as "An unpleasant sensory and emotional experience associated with, or resembling that associated with, actual or potential tissue damage."

An important task of end-of-life care is to assure patients that their pain levels are managed. Pain, in addition to appropriate medication, can also be controlled in rare cases by deep sedation. Questions are often asked about the morality of deep sedation. Pope Pius XII issued teaching on this as far back as 1957, stating that such procedures were in fact morally licit because the intention is to relieve pain and not cause death.<sup>2</sup>

The term suffering, however, includes enduring the physical woes of sickness or injury as well as the experience of psychological or spiritual distress, which is not so easily medicated, if at all. Suffering comes in many forms, affecting our bodies, minds and spirits. This can be more difficult to treat than physical pain. Pope Francis reminds us that no one is to be abandoned; rather, everyone is to be accompanied and made to feel the dignity of being part of a community as a valued person.

Raja, S. et al. "The revised International Association for the Study of Pain definition of pain: concepts, challenges, and compromises", PAIN: September 2020, 161–9, p.1976–1982.

<sup>2</sup> Cf. Pius XII, "Allocution to the International Society of Anesthesiology". AAS 49, 1957. p. 147.

### **Decision-making, Conscience and Discernment**

Each person has the God-given gift and responsibility to make his or her own decisions at the end of life, when still capable and competent. These decisions need to be made in the same way as other decisions, by a conscience informed by Catholic teaching. Most of us need some advice when it comes to medical decision-making. At the same time, we have to pay attention to Church teaching to see if the two sets of advice agree.

Conscience formation is the responsibility of each one of us. This includes consulting other sources when we are unsure about medical diagnoses, Church teaching, or even the opinions of our family and loved ones. Experts can provide necessary information for good treatment choices. They can direct us, but the final decision is up to us. As Catholics, we make these decisions in the context of prayer and discernment and guided by Church teaching.

### Living Life to the End

The Catholic Church is strongly committed to helping us live our lives fully, to the very end, when we believe God will take us home. As a community of believers, we do not see death as "the end," but as a transition to fullness of life in God through the power of the Resurrection of Jesus Christ. Our Christian faith gives us a different perspective, even though we naturally experience the same human pain and suffering as everyone else. This difference is captured in St. Pope John Paul's Letter to the Elderly, where he says that, in dying, we go "from life to life." He writes: "It is wonderful to be able to give oneself to the very end for the sake of the Kingdom of God!" This message gives us hope that each of us will have the same experience of not just dying, but living life to the very end, in the hope of the Resurrection.

Pope John Paul II, "Letter to the Elderly", 1991. https://www.vatican.va/content/john-paul-ii/en/letters/1999/documents/hf jp-ii let 01101999 elderly.html

# Guiding questions — Theological and ethical perspective

- 1. What are some examples of ordinary care (i.e., that does not place an undue burden on a person)?
- 2. What are some examples of extraordinary care?
- 3. Ordinary and extraordinary care are sometimes referred to as proportionate and disproportionate means. How would you explain the difference between proportionate and disproportionate means using the examples provided in the video?
- 4. What is the Church's position on treatment at all costs?
- 5. What is the difference between euthanasia and physician-assisted suicide (also called Medical Assistance in Dying, or MAiD)?
- 6. How would you explain the difference between pain and suffering to someone who is near the end of life?

## Discernment and decision-making at the end of life

#### Take-home resource

When confronted by a loved one's illness and dying, people often do not know where to turn for help. It is important for us to realize that within our communities, many people, organizations and online resources are available to assist us as we live this new reality. Below you will find a number of links to organizations that can be very helpful. This page is available at <a href="https://www.cccb.ca">www.cccb.ca</a>.

- Help Starts Here www.211.ca: Looking for help? For assistance finding housing, language training, employment and much more, call 2-1-1. It's free, offered in over 100 languages, and available in most parts of Canada day or night. Click on the map to search for services online in your community.
- Go Wish "Go Wish gives you an easy, even entertaining way to talk about what is most important to you. The cards help you find words to talk about what is important if you were to be living a life that may be shortened by serious illness." <a href="http://www.gowish.org">http://www.gowish.org</a>
- Hello: "The Conversation Game: Hello is a conversation game. It's the easy, non-threatening way to start a conversation with your family and friends about what matters most to you. <a href="https://commonpractice.com/products/hello-game">https://commonpractice.com/products/hello-game</a>
- Speak Up Advance Care Planning: www.advancecareplanning.ca

Look in the Resources tab for the following and more:

- Advance care planning in your province or territory:
   https://www.advancecareplanning.ca/acp-across-canada/
- You and your family: <a href="https://www.advancecareplanning.ca/">https://www.advancecareplanning.ca/</a>
   resource-library/#resource-library | category:you-and-your-family
- Advance Care Planning Workbooks and Quick Guides: <a href="https://www.advancecareplanning.ca/resource-library/">https://www.advancecareplanning.ca/resource-library/</a> #resource-library | category:you-and-your-family
- Conversation starters: <a href="https://www.advancecareplanning.ca/resource/conversation-starters/">https://www.advancecareplanning.ca/resource/conversation-starters/</a>
- Choose a Substitute Decision Maker:
   <a href="https://www.advancecareplanning.ca/resource/choosing-a-substitute-decision-maker/">https://www.advancecareplanning.ca/resource/choosing-a-substitute-decision-maker/</a>
- Speak up Wallet Card: <a href="https://www.advancecareplanning.ca/resource/speak-up-wallet-card-bookmark/">https://www.advancecareplanning.ca/resource/speak-up-wallet-card-bookmark/</a>
- CPR Decision Aids: <a href="https://www.advancecareplanning.ca/resource/cpr-decision-aids/">https://www.advancecareplanning.ca/resource/cpr-decision-aids/</a>
- ICU Workbook: <a href="https://www.advancecareplanning.ca/">https://www.advancecareplanning.ca/</a>
   resource/icu-workbook/
- Cancer Planning Toolkit: <a href="https://www.advancecareplanning.ca/resource/cancer-toolkit/">https://www.advancecareplanning.ca/resource/cancer-toolkit/</a>
- First Nations Resources: <a href="https://www.advancecareplanning.ca/">https://www.advancecareplanning.ca/</a> resource/first-nations-acp-resources/

# Discernment and decision-making at the end of life Question and answer take-home

### 1. What is Catholic teaching on death and dying?

The Catholic Tradition holds the following beliefs:

• All persons are created in the image and likeness of God: therefore, we are called to respect every person and to respect the sanctity of each human life from conception to natural death.

"Human life is sacred because from its beginning it involves the creative action of God and it remains for ever in a special relationship with the Creator, who is its sole end. God alone is the Lord of life from its beginning until its end: no one can under any circumstance claim for himself the right directly to destroy an innocent human being." (Catechism of the Catholic Church, n. 2258)

- We are always called to provide care, compassion and comfort to those who are suffering and/or dying.
- Euthanasia "is understood to be any action or omission which of itself and by intention causes death, with the purpose of eliminating all suffering." (Pope St. John Paul II, *Evangelium Vitae* [The Gospel of Life], 1995, n. 65)
- The Catholic Church opposes euthanasia and assisted suicide (which in Canada is referred to as "Medical Assistance in Dying") in all of its regrettable forms. The Church teaches that "whatever its motives and means, direct euthanasia consists in putting an end to the lives of handicapped, sick, or dying persons. It is morally unacceptable." (Catechism of the Catholic Church, n. 2277)

- Both euthanasia and assisted suicide, while opposed by the Church, are regrettably legal in Canada.
  - Euthanasia is "the administering by a medical practitioner or nurse practitioner of a substance to a person, at their request, that causes their death."
  - Assisted suicide is "the prescribing or providing by a medical practitioner or 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."<sup>2</sup>
- "Treatment decisions, therefore, for a person receiving care are never to include actions or omissions that intentionally cause death." (Catholic Health Alliance of Canada, *Health Ethics Guide* [2012], #87)
- "Intentionally causing one's own death (suicide), or directly assisting another in such an action (assisted suicide), is morally wrong." (Catholic Health Alliance of Canada, *Health Ethics Guide* [2012], #88)
- Even in situations where the state legally endorses assisted suicide and/or euthanasia, as does Canada in legislation known as "Medical Assistance in Dying" (MAiD), Catholics are not to take part in this, either individually or with or for another person.
- Pope Francis has reaffirmed Catholic teaching that euthanasia "is always wrong, in that the intent of euthanasia is to end life and cause death." (Pope Francis, Message to the Participants in the European Regional Meeting of the World Medical Association, November 7, 2017)

Bill C-14. Section (7) Definition. See <a href="https://www.parl.ca/DocumentViewer/en/42-1/bill/C-14/royal-assent">https://www.parl.ca/DocumentViewer/en/42-1/bill/C-14/royal-assent</a>.

<sup>2</sup> Ibid.

- Nonetheless, Pope Francis reiterated Catholic teaching as articulated by Pope Pius XII in 1957, affirming that "there is no obligation to have recourse in all circumstances to every possible remedy" to keep a person alive. "In some specific cases," the Pope said, "it is permissible to refrain from their use." (Pope Francis, Message to the Participants in the European Regional Meeting of the World Medical Association, November 7, 2017)
- The Catechism provides further clarity on this matter by noting: "Discontinuing medical procedures that are burdensome, dangerous, extraordinary, or disproportionate to the expected outcome can be legitimate; it is the refusal of 'over-zealous' treatment. Here one does not will to cause death; one's inability to impede it is merely accepted. The decisions should be made by the patient if he is competent and able or, if not, by those legally entitled to act for the patient, whose reasonable will and legitimate interests must always be respected." (Catechism of the Catholic Church, n. 2278)

## 2. What do I do if someone I love and care for requests euthanasia or assisted suicide (MAiD)?

Affirm and accompany the person with Christian love and truth.

When someone I love and care for requests euthanasia or assisted suicide (MAiD), I should be conscious that this request can be a cry for help. The first thing I should do is remind the person of how much I love them and also how much God loves them. In affirming that they are loved by God and by others, I should also reassure them that they will be accompanied during this difficult and trying time of their life. They are not alone on this journey.

### **Examine and Explore**

Here are some examples of how to engage, in an open manner, someone who might be contemplating a request for euthanasia or assisted suicide. It is important to enter into this conversation as a dialogue. You are certainly not affirming the person's desire for euthanasia or assisted suicide, but trying to understand the reason for the request.

- What I am hearing you say is that you cannot continue living like this in the way you are living now. Would you like to talk more about this? It must be a heavy burden to carry alone.
- I remember seeing other people who have experienced similar health challenges. They mentioned having difficulty with the following issues. Is that true for how you are feeling?

When exploring these sensitive issues with your loved one, you may hear the following responses:

- I am so afraid of being a burden on my family. I looked after them all of their lives and I don't want them to have to look after me now. They can't afford to take time off work—they have their own family to look after now.
- My pain is controlled right now, but I don't want to die in agony or become even more incapacitated than I am now.
- I have no dignity left—I can't walk, eat, stand, go to the toilet without help, etc. I am tired of living.
- It's my life and I have the right to make decisions about how I live and when I will die.
- No one has the right to deny me my legal right to MAiD.
- If I don't make this decision now when I am capable, I may miss the opportunity to make the decision if I become incapable. I will be living "like a vegetable." I don't want this.
- It's time to go. I have had a good life. I am looking forward to seeing God and reuniting with my friends and family who have gone before me.

- I have nothing left to look forward to. My friends are dead. I haven't seen my family in years. I am alone in the world. What's the point in carrying on?
- There is no hope—not even in God.

### **Possible Responses**

- If the person is experiencing physical pain, let them know that you will support them by seeking the advice and the help of their medical advisors to find the best way to alleviate their physical pain, be it through medication or other treatments.
- The majority of people who request euthanasia or assisted suicide (MAiD) do so not because of physical pain but because of suffering due to anxiety and worry about their situation. It is essential to find out the particular cause of the person's suffering. For example, they may feel that they are a burden to others or perceive that their quality of life has diminished. Or they may feel they are losing the ability to make decisions and control their life (their autonomy). These feelings can affect their mental health. This type of suffering can be much more difficult to deal with than physical pain. Just as physical pain can be addressed by medical professionals, mental health professionals can be of great assistance in helping to determine the cause of a person's suffering and in finding the appropriate treatment to ease their suffering.
- If a person feels they are a burden to others, you need to let them know that they are not a burden; their life matters to you and to others. This can be a time to address a person's spiritual well-being. You could call upon a priest or chaplain to speak with the person.
- Even a person who is experiencing great suffering should be told that their life is of inestimable value because it has been given to them as a gift from God. We can take the opportunity to remind them that in the light of our Catholic faith, suffering can be transformed and redeemed when it is seen as a participation in Jesus' saving death and resurrection.

## 3. What about the sacraments and euthanasia (Medical Assistance in Dying)?

How is the Church to respond to people who have requested euthanasia or physician-assisted suicide? May the Church walk with them on that journey, as it is called to do in every other situation? What about reception of the sacraments and funerals for those who follow their own path on this issue, and not that of the Church? If you are facing these difficult situations or have questions on these matters, speak with your parish priest or bishop for guidance.

For further reading, you may wish to consult the September 2020 letter entitled *Samaritanus bonus: On the Care of Persons in the Critical and Terminal Phases of Life*, published by the Congregation for the Doctrine of the Faith on 14 July 2020.

http://www.vatican.va/roman curia/congregations/cfaith/documents/rc con cfaith doc 20200714 samaritanus-bonus en.html

### 4. In what circumstances is it permissible to withhold or withdraw medical treatment?

- As Catholics, we recognize that we have been given the gift of life.
   Therefore, we are obliged to receive medical interventions that can help us.
- However, "Persons are not obliged to seek or accept medical interventions/treatments that will not accomplish the goal for which they are intended or when the burdens (excessive pain, extreme suffering, expense or other serious inconvenience) resulting from the treatment are clearly disproportionate to the benefits hoped for or achievable." (Catholic Health Alliance of Canada, *Health Ethics Guide* [2012], #77)
- Pope St. John Paul II was clear on this point when he stated, "While life is always good it is not an absolute good." (See *Going to the House of My Father: A Statement on the Dignity and Destiny of Human Life*, Ontario Conference of Catholic Bishops, 2007)

• "In principle, there is an obligation to provide food and water to persons, including medically assisted nutrition for those who cannot take food orally. This obligation extends to patients in chronic and presumably irreversible conditions who can reasonably be expected to live indefinitely if given such care. Medically assisted nutrition and hydration become morally optional when they cannot reasonably be expected to prolong life or when they would be 'excessively burdensome for the patient or [would] cause significant physical discomfort'." When decisions regarding the provision of nutrition and hydration are needed, they should take into account the "needs, values and wishes of the person receiving care."

Withholding or withdrawing nutrition and hydration must never be to hasten death. (Catholic Health Alliance of Canada, *Health Ethics Guide* [2012], #84)

| NOTES: |  |
|--------|--|
|        |  |
|        |  |
|        |  |
|        |  |
|        |  |
|        |  |
|        |  |
|        |  |
|        |  |
|        |  |
|        |  |
|        |  |
|        |  |
|        |  |
|        |  |
|        |  |
|        |  |
|        |  |
|        |  |
|        |  |
|        |  |
|        |  |
|        |  |
|        |  |
|        |  |
|        |  |
|        |  |
|        |  |
|        |  |
|        |  |
|        |  |
|        |  |
|        |  |
|        |  |
|        |  |
|        |  |
|        |  |
|        |  |

| NOTES: |  |  |
|--------|--|--|
|        |  |  |
|        |  |  |
|        |  |  |
|        |  |  |
|        |  |  |
|        |  |  |
|        |  |  |
|        |  |  |
|        |  |  |
|        |  |  |
|        |  |  |
|        |  |  |
|        |  |  |
|        |  |  |
|        |  |  |
|        |  |  |
|        |  |  |
|        |  |  |
|        |  |  |
|        |  |  |
|        |  |  |

| NOTES: |  |
|--------|--|
|        |  |
|        |  |
|        |  |
|        |  |
|        |  |
|        |  |
|        |  |
|        |  |
|        |  |
|        |  |
|        |  |
|        |  |
|        |  |
|        |  |
|        |  |
|        |  |
|        |  |
|        |  |
|        |  |
|        |  |
|        |  |
|        |  |
|        |  |
|        |  |
|        |  |
|        |  |
|        |  |
|        |  |
|        |  |
|        |  |
|        |  |
|        |  |
|        |  |
|        |  |
|        |  |
|        |  |
|        |  |
|        |  |

| NOTES: |  |  |
|--------|--|--|
|        |  |  |
|        |  |  |
|        |  |  |
|        |  |  |
|        |  |  |
|        |  |  |
|        |  |  |
|        |  |  |
|        |  |  |
|        |  |  |
|        |  |  |
|        |  |  |
|        |  |  |
|        |  |  |
|        |  |  |
|        |  |  |
|        |  |  |
|        |  |  |
|        |  |  |
|        |  |  |
|        |  |  |

Horizons of Hope: A Toolkit for Catholic Parishes on Palliative Care. Module 2. © Joint Ad hoc Committee on Palliative Care, 2021. Some rights reserved.

(CC) BY-NC-ND Attribution - Non-Commercial - No Derivatives 4.0 International (CC BY-NC-ND 4.0)

For all other usage, please contact <u>permissions@cccb.ca</u>.

Code: 185-167

ISBN: 978-0-88997-914-7

Legal Deposit: Library and Archives Canada



#### cccb.ca





Canadian Conference of Catholic Bishops 2500 Don Reid Drive Ottawa (ON) K1H 2J2 Canada