

Horizons of Hope

A Toolkit for Catholic Parishes on Palliative Care

MODULE 03

Accompanying those at the end of life

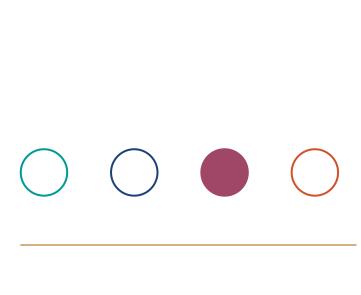




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MODULE 03

Accompanying those at the end of life

Tips for the facilitator



Module 3 focuses on the nature and importance of **accompaniment** as we journey with loved ones who are ill and dying. Participants will reflect on the proclamation of a Gospel narrative and hear presentations by theological and medical experts. In particular, the module will explore how we are called to accompany and the importance of ensuring that the caregiver is also accompanied and receives support and respite when needed.

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 of the Facilitator's Guide.**

PART 1

Experience

Truly I tell you, just as you did it to one of the least of these who are members of my family, you did it to me.

Matthew 25:40

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

(2 minutes

Proclaim the Scripture passage **John 19:25–27** aloud. Please use a bible or lectionary for this proclamation.



3. Guided personal reflection

🕔 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. John 19:25–27 depicts a very poignant moment between Jesus and his Mother Mary. She had accompanied him and been present at the most significant times in his life up to and including his crucifixion. Now Jesus, out of his deep love for Mary, his Mother, places her into the care of John: it is here that she becomes known as Mother of the Church. What feelings or emotions surface for you as you consider this passage?
- 2. Describe a time when someone you were accompanying reached out to accompany you.

3. Does this scripture help you to see that even in the most painful of times we are not alone, but rather we are surrounded by a community that loves and cares for us?



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

All are called to give witness at the side of the sick person and to become a "healing community" in order to actualize concretely the desire of Jesus that, beginning with the most weak and vulnerable, all may be one flesh.

Congregation for the Doctrine of the Faith, "Samaritanus Bonus"

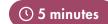
Part 2: New information

Section A: Theological and Ethical Perspective





Video – Theological and ethical reflection on accompanying those at the end of life



This video will introduce participants to the topics of supporting the sick and the dying, using Jesus as a model for accompanying others, and how to accompany well.

NOTE TO FACILITATOR: This video can be viewed on YouTube at https://youtu.be/hBW5NwdSrgU. For direct download of the video files, visit cccb.ca. To help you become familiar with the core content of this video, we have included the script below. See Appendix 2 for a take-home version of the script.



Video Script — Theological and ethical reflection

Accompanying and supporting the sick and the dying

When we hear that a loved one is nearing his or her end of life, it can bring heartache, anger, anxiety and deep sadness. Sometimes the news is unexpected and sudden. Other times, a friend, a parent, a child or a grandparent has been deteriorating for some time, and the approaching end brings feelings of grief coupled with relief or peace.

While each end-of-life experience is unique and can bring about challenges in our families and friendships, it can also be an opportunity to make Christ's presence known in the world.

As Christians, we are to journey beside loved ones and community members at the final stages of life. No one should have to experience dying alone. When reflecting on the end of life, we hope that the reflex in our Christian contexts seeks to accompany and support the sick and dying.

Let us be present, physically, emotionally and spiritually, so that we may be attentive and attuned to those we encounter.

The experience of dying is complex. It affects us in so many ways. We can think about how it affects us physically. We sense that our bodies are weak and in pain; this can change how we see ourselves and affects our self-confidence. Often, we can do less and less by ourselves, depending more and more on others.

We can also reflect on how the dying experience affects how we act and how we speak. The experience of pain and suffering makes communication very strenuous. We may have difficulty sharing what we're going through; this can lead to a deep feeling of loneliness or a sense of being trapped. We might feel that "nobody understands what I am going through." If we try to converse with those around us, it can be frustrating or tiresome and can lead to misunderstandings, irritations and sometimes rejections.

We can also reflect on time. Typically, we approach death with a great deal of uncertainty. It may challenge our ability to be genuinely present, disrupt how we foresee ourselves in the future, or how we remember our past. When diagnosed with a terminal illness, there can be a sense of "a loss of life," that "I had a life before, but now I've lost it." The time that remains is viewed as useless, even sometimes leading to a desire to end it as quickly as possible. This shift in how we see ourselves in the past, present and future can generate a lot of fear and anguish about what will come.

To be challenged by our human limitations at the end of life is normal. However, we cannot shoulder our fragility and vulnerability without the support, care and accompaniment of others. Only together can we ensure that the suffering does not become all-consuming.

Let us be attentive to the many sources of suffering in those we accompany. Let us listen with a steady and patient presence.

Jesus shows us how to journey with others

As Christians, the model to help us walk through the end-of-life experience is in God, who made himself human.

How does Jesus respond to the sick and dying person? In the Gospels, Jesus encounters people who face illness, pain and suffering. Jesus is never indifferent and is powerfully present during these encounters. He models profound compassion and does not abandon the struggling person. He does not explain suffering, and he does not give value to suffering in itself. Jesus shows us concretely how God is present to the sick and dying. In this sense, human fragility supported through the lens of faith can become an experience of salvation.

"In my own life, how can the example of Jesus inspire me, teach me, to approach the person at the end of life, in the process of respect, mercy and compassion?"

How do we accompany well?

Journeying with someone at the end of life is often referred to as accompaniment. Human suffering calls for a response that engages us to be a consoling presence. How do we accompany well?

First, let us be attentive to the one living through the vulnerable experience of dying. We must be physically and emotionally present to build a strong sense of sharing in the trials. It's the opposite of staying away or being distant from the person and their experience. Individually and as a community, we must not be indifferent to the challenge of human vulnerability and fragility at the end of life.

When someone has difficulty expressing their suffering, let us enter into an attentive listening attitude. A welcoming and open presence can receive what the person is trying to communicate. We can then create occasions for the person to express themselves and, later, engage in a dialogue. With a humble discerning spirit, offer words of consolation to bring comfort and encouragement. We must avoid forcing or controlling these conversations, but instead be steadfast, docile, patient and prayerful.

In front of uncertainty at the end of life, let us find new ways of living in the present. Accompaniment opens this time to remember and share our life stories. It's also about creating new and meaningful memories in the present. Accompaniment encourages the person to connect meaningfully to their lives: past, present and future. The accompaniment of palliative care can be seen as a space for creative work on time. As individuals and as a community, let us discover ways to share our time in solidarity by recognizing our shared vulnerability. We don't need to be experts to have the ability to accompany, because we accompany through our very own fragility and openness to the other.

Christ carries our burdens and encourages us to be beacons of light for our families, our friends, our colleagues, our fellow parishioners. Let us walk with one another in the hope of everlasting life in the world to come.



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 3** for a copy of the guiding questions.

Guiding questions:

- 1. What messages were confirmed for me about the Christian perspectives on accompanying at the end of life?
- 2. What was new for me?
- 3. What do I still want to know?
- 4. How can I relate this new information to past experiences?



3. Table 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.



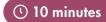
4. Large group focus



Gather the participants together into a large group. The facilitator will bring the *theological* 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.

5. Break



Section B: Medical perspective

U 45 minutes



1. Video — Medical perspective on accompanying those at the end of life

© 5 minutes

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

- 1. the process and signs of dying;
- 2. planning how to respond when death is imminent or has happened, especially in a home setting.

NOTE TO FACILITATOR: This video can be viewed on YouTube at https://youtu.be/zGGtGFn8y-A. For direct download of the video files, visit cccb.ca. To help you become familiar with the core content of this video, we have included the script below. See Appendix4 for a take-home version of the script.



Video script — Medical perspective

The natural dying process

Many of us, in our modern world, have never seen anyone dying and don't know what it looks like. Many people are fearful that death is inevitably accompanied by suffering. This fear may be increased by what one hears in the media, which makes it sound as if dying is not natural and that it is something that always causes suffering and should be feared.

Most deaths are very comfortable, especially with palliative care interventions. People start getting weaker and weaker, start resting more and eating and drinking less, and then start sleeping more. Then they stop eating or drinking, and finally slip into unconsciousness. They can be in a state of partial consciousness or total unconsciousness for hours or days to many days. This is followed by a peaceful death.

Some patients may experience confusion or agitation at the very end of life, in the last hours or days. If this happens, we have medications to control the agitation and confusion, so that they are not agitated by sleeping and resting. If pain or shortness of breath were to worsen in the last hours or days, we have pain medications that can help, and we can adjust the doses to have the patients comfortable.

Sometimes, death may come quicker than expected, or a person may be awake and go into a breathing or pain crisis suddenly. This, for example, can happen if there are large blood clots that go to the lungs. Again, in these cases, there are palliative care interventions to reduce suffering.

It is important to know that at the end of life, one's breathing patterns may change; these are generally normal, and not necessarily signs of suffering. One of the most common normal patterns in the last days or hours of life is called "Cheyne Stokes" breathing. In this pattern, the breathing slows down, becomes shallower, and then seems to stop for a long time. It then starts up again, speeds up, and then slows down again and stops. This cycle repeats itself. Another normal pattern is called "agonal" breathing.

In this pattern, the breathing stops for many seconds, and then the person takes a sudden deep breath, and then stops again for many seconds. This cycle continues until the breathing stops for the last time.

When this is happening, [supplemental] oxygen is not needed if the patient was not experiencing shortness of breath before and was not requiring oxygen. In patients who were requiring oxygen because of shortness of breath, we continue the oxygen during these cycles.

Other signs that death is coming soon, within hours or days, is coldness of the hands and feet, and mottling, blue markings, of the skin. The pulse become very weak, and patients lose consciousness. Some patients experience what we call airway secretions. These are generally mild gurgling sounds that come from the throat. They are caused by phlegm building up in the back of the throat. We all produce phlegm on an ongoing basis, and we swallow this. At the very end of life, when death is near and the person is too weak to swallow, the phlegm builds up in the back of the throat, causing these sounds. It is sometimes referred to as the "death rattle," but we prefer to use the term "airway secretions." Most of the time, they are mild or moderate. They don't cause suffocation. They are like snoring; they are bothersome to the persons listening, but not bothersome to the person sleeping. So when they are mild, they do not need any treatment. If they are moderate, simply placing someone a little on their side can help. If they are severe, we have medications that can reduce the secretions.

Preparing for the End of Life and Preventing Crises

Since most patients will not be able to eat or drink in the last days or weeks of life, and some may experience complications like confusion or inability to urinate, it is important that we prepare for these possibilities, especially if the patient is being cared for at home.

Most important—to prevent crises and to avoid rushing a patient to an emergency department or hospital if this is not preferred—is to plan ahead with one's doctors and nurses. Find out who to call and what the 24/7 telephone numbers are to reach the home care nurse and the doctor if help is needed. Also ensure that a "do not resuscitate" order—

known as a DNR or AND—is in place and that all health care providers and the family are aware of it so that at the end, 911 is not called. If 911 is called, they will proceed to do CPR and intubate and administer electrical shocks, even if this is not the goal of care.

With planning, one can avoid crises and also deal with them better should they occur.



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*. Provide the guiding questions in a reflection page/booklet format so participants can keep their notes together. See **Appendix 5** for a copy of the guiding questions.

Let's reflect upon what you have heard about the process and signs of dying and death in the video we have just watched. Here are some questions to help us reflect on this:

Guiding questions:

- 1. Are you comforted in knowing that your loved one will be able to die peacefully and without pain with good palliative care?
- 2. How does understanding the process of death help you when you are accompanying someone as they are dying?
- 3. Why is it important to have a plan prepared for the time when death comes? Who will you call to avoid a crisis?



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



4. Large group focus

© 5 minutes

Gather the participants together into a large group. The facilitator can bring the *medical* portion to closure 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

My life is but an instant, a passing hour.

My life is but a day that escapes and flies away.

O my God! You know that to love you on earth I only have today!

St. Thérèse of Lisieux

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 take-home resource and question-and-answer guide for further reflection at home. Please review the question and answer take-home resource below with participants. Provide participants with a copy of **Appendix 6**, either in a digital format or distribute a paper copy.

MODULE 03

Appendices

Appendix 1

Guiding questions — Reflecting on scripture

- 1. John 19:25–27 depicts a very poignant moment between Jesus and his Mother Mary. She had accompanied him and been present at the most significant times in his life up to and including his. Now Jesus, out of his deep love for Mary, places her into the care of John; it is here that she becomes known as Mother of the Church. What feelings or emotions surface for you as you consider this passage?
- 2. Describe a time when someone you were accompanying reached back to accompany you.
- 3. Does this scripture help you to see that even in the most painful of times we are not alone, but rather we are surrounded by a community that loves and cares for us?

Appendix 2

Video Script — Theological and ethical reflection

Accompanying and supporting the sick and the dying

When we hear that a loved one is nearing his or her end of life, it can bring heartache, anger, anxiety and deep sadness. Sometimes the news is unexpected and sudden. Other times, a friend, a parent, a child or a grandparent has been deteriorating for some time, and the approaching end brings feelings of grief coupled with relief or peace.

While each end-of-life experience is unique and can bring about challenges in our families and friendships, it can also be an opportunity to make Christ's presence known in the world.

As Christians, we are to journey beside loved ones and community members at the final stages of life. No one should have to experience dying alone. When reflecting on the end of life, we hope that the reflex in our Christian contexts seeks to accompany and support the sick and dying.

Let us be present, physically, emotionally and spiritually, so that we may be attentive and attuned to those we encounter.

The experience of dying is complex. It affects us in so many ways. We can think about how it affects us physically. We sense that our bodies are weak and in pain; this can change how we see ourselves and affects our self-confidence. Often, we can do less and less by ourselves, depending more and more on others.

We can also reflect on how the dying experience affects how we act and how we speak. The experience of pain and suffering makes communication very strenuous. We may have difficulty sharing what we're going through; this can lead to a deep feeling of loneliness or a sense of being trapped. We might feel that "nobody understands what I am going through." If we try to converse with those around us, it can be frustrating or tiresome and can lead to misunderstandings, irritations and sometimes rejections.

We can also reflect on time. Typically, we approach death with a great deal of uncertainty. It may challenge our ability to be genuinely present, disrupt how we foresee ourselves in the future, or how we remember our past. When diagnosed with a terminal illness, there can be a sense of "a loss of life," that "I had a life before, but now I've lost it." The time that remains is viewed as useless, even sometimes leading to a desire to end it as quickly as possible. This shift in how we see ourselves in the past, present and future can generate a lot of fear and anguish about what will come.

To be challenged by our human limitations at the end of life is normal. However, we cannot shoulder our fragility and vulnerability without the support, care and accompaniment of others. Only together can we ensure that the suffering does not become all-consuming.

Let us be attentive to the many sources of suffering in those we accompany. Let us listen with a steady and patient presence.

Jesus shows us how to journey with others

As Christians, the model to help us walk through the end-of-life experience is in God, who made himself human.

How does Jesus respond to the sick and dying person? In the Gospels, Jesus encounters people who face illness, pain and suffering. Jesus is never indifferent and is powerfully present during these encounters. He models profound compassion and does not abandon the struggling person. He does not explain suffering, and he does not give value to suffering in itself. Jesus shows us concretely how God is present to the sick and dying. In this sense, human fragility supported through the lens of faith can become an experience of salvation.

"In my own life, how can the example of Jesus inspire me, teach me, to approach the person at the end of life, in the process of respect, mercy and compassion?"

How do we accompany well?

Journeying with someone at the end of life is often referred to as accompaniment. Human suffering calls for a response that engages us to be a consoling presence. How do we accompany well?

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When someone has difficulty expressing their suffering, let us enter into an attentive listening attitude. A welcoming and open presence can receive what the person is trying to communicate. We can then create occasions for the person to express themselves and, later, engage in a dialogue. With a humble discerning spirit, offer words of consolation to bring comfort and encouragement. We must avoid forcing or controlling these conversations, but instead be steadfast, docile, patient and prayerful.

In front of uncertainty at the end of life, let us find new ways of living in the present. Accompaniment opens this time to remember and share our life stories. It's also about creating new and meaningful memories in the present. Accompaniment encourages the person to connect meaningfully to their lives: past, present and future. The accompaniment of palliative care can be seen as a space for creative work on time. As individuals and as a community, let us discover ways to share our time in solidarity by recognizing our shared vulnerability. We don't need to be experts to have the ability to accompany, because we accompany through our very own fragility and openness to the other.

Christ carries our burdens and encourages us to be beacons of light for our families, our friends, our colleagues, our fellow parishioners. Let us walk with one another in the hope of everlasting life in the world to come.

Appendix 3

Guiding questions — Theological and ethical perspective

- 1. What messages were confirmed for me about the Christian perspectives on accompanying at the end of life?
- 2. What was new for me?
- 3. What do I still want to know?
- 4. How can I relate this new information to past experiences?

Appendix 4

Video script — Medical perspective

The natural dying process

Many of us, in our modern world, have never seen anyone dying and don't know what it looks like. Many people are fearful that death is inevitably accompanied by suffering. This fear may be increased by what one hears in the media, which makes it sound as if dying is not natural and that it is something that always causes suffering and should be feared.

Most deaths are very comfortable, especially with palliative care interventions. People start getting weaker and weaker, start resting more and eating and drinking less, and then start sleeping more. Then they stop eating or drinking, and finally slip into unconsciousness. They can be in a state of partial consciousness or total unconsciousness for hours or days to many days. This is followed by a peaceful death.

Some patients may experience confusion or agitation at the very end of life, in the last hours or days. If this happens, we have medications to control the agitation and confusion, so that they are not agitated by sleeping and resting. If pain or shortness of breath were to worsen in the last hours or days, we have pain medications that can help, and we can adjust the doses to have the patients comfortable.

Sometimes, death may come quicker than expected, or a person may be awake and go into a breathing or pain crisis suddenly. This, for example, can happen if there are large blood clots that go to the lungs. Again, in these cases, there are palliative care interventions to reduce suffering.

It is important to know that at the end of life, one's breathing patterns may change; these are generally normal, and not necessarily signs of suffering. One of the most common normal patterns in the last days or hours of life is called "Cheyne Stokes" breathing. In this pattern, the breathing slows down, becomes shallower, and then seems to stop for a long time.

It then starts up again, speeds up, and then slows down again and stops. This cycle repeats itself. Another normal pattern is called "agonal" breathing. In this pattern, the breathing stops for many seconds, and then the person takes a sudden deep breath, and then stops again for many seconds. This cycle continues until the breathing stops for the last time.

When this is happening, [supplemental] oxygen is not needed if the patient was not experiencing shortness of breath before and was not requiring oxygen. In patients who were requiring oxygen because of shortness of breath, we continue the oxygen during these cycles.

Other signs that death is coming soon, within hours or days, is coldness of the hands and feet, and mottling, blue markings, of the skin. The pulse become very weak, and patients lose consciousness. Some patients experience what we call airway secretions. These are generally mild gurgling sounds that come from the throat. They are caused by phlegm building up in the back of the throat. We all produce phlegm on an ongoing basis, and we swallow this. At the very end of life, when death is near and the person is too weak to swallow, the phlegm builds up in the back of the throat, causing these sounds. It is sometimes referred to as the "death rattle," but we prefer to use the term "airway secretions." Most of the time, they are mild or moderate. They don't cause suffocation. They are like snoring; they are bothersome to the persons listening, but not bothersome to the person sleeping. So when they are mild, they do not need any treatment. If they are moderate, simply placing someone a little on their side can help. If they are severe, we have medications that can reduce the secretions.

Preparing for the End of Life and Preventing Crises

Since most patients will not be able to eat or drink in the last days or weeks of life, and some may experience complications like confusion or inability to urinate, it is important that we prepare for these possibilities, especially if the patient is being cared for at home.

Most important—to prevent crises and to avoid rushing a patient to an emergency department or hospital if this is not preferred—is to plan ahead with one's doctors and nurses. Find out who to call and what the

24/7 telephone numbers are to reach the home care nurse and the doctor if help is needed. Also ensure that a "do not resuscitate" order—known as a DNR or AND—is in place and that all health care providers and the family are aware of it so that at the end, 911 is not called. If 911 is called, they will proceed to do CPR and intubate and administer electrical shocks, even if this is not the goal of care.

With planning, one can avoid crises and also deal with them better should they occur.

Appendix 5

Guiding questions — Medical perspective

Let's reflect upon what you have heard about the process and signs of dying and death in the video we have just watched. Here are some questions to help us reflect on this:

- 1. Are you comforted in knowing that your loved one will be able to die peacefully and without pain with good palliative care?
- 2. How does understanding the process of death help you when you are accompanying someone as they are dying?
- 3. Why is it important to have a plan prepared for the time when death comes? Who will you call to avoid a crisis?

Appendix 6

Accompanying and supporting at the end of life Take-home resource

- 1. What are some tips to help me to accompany and support at the end of life?
 - Have conversations with the person who is dying and his/her loved ones about their goals of care.
 - Resources on decision making are available at https://www.advancecareplanning.ca/resources-and-tools/#resource-library | category:you-and-your-family
 - Take respectful account of the hopes and values of the person who is dying.
 - Reflect on the gifts of the faith tradition and Church teaching.
 - Obtain clear and relevant medical information and seek help from competent health professionals to understand it.
 - Offer to pray with your loved one.
 - Create opportunities for the dying person to receive the sacraments and other spiritual resources.
 - Seek help and consult with others. For example:
 - Medical professionals who are Catholic or those who understand and are respectful toward Catholic teaching on dying and death
 - Questions that the person you are accompanying could ask their doctor might include: Do you think I could die within the next year? If yes, what can we do to prepare for my death? Should I be receiving palliative care support?
 - Catholic chaplains or pastors

- Ethics personnel working in health care settings
- The Canadian Catholic Bioethics Institute (<u>https://www.ccbi-utoronto.ca/</u>)
- CCCB Office for Family and Life https://www.cccb.ca/about/secretariat-offices-and-services/ office-for-family-and-life/.
- Parish pastoral care teams
- Hospice personnel
- Family and friends of the person who is dying
- The dying person's Power of Attorney for Personal Care
- The Catechism of the Catholic Church, speaking of human freedom, states:

Freedom is the power, rooted in reason and will, to act or not to act, to do this or that, and so to perform deliberate actions on one's own responsibility. By free will one shapes one's own life. Human freedom is a force for growth and maturity in truth and goodness; it attains its perfection when directed toward God, our beatitude. (CCC n. 1731)

Freedom is exercised in relationships between human beings. Every human person, created in the image of God, has the natural right to be recognized as a free and responsible being. All owe to each other this duty of respect. (CCC n. 1738)

"Even the weakest and most vulnerable, the sick, the old, the unborn and the poor are MASTERPIECES OF GOD'S CREATION, made in his own image, destined to live forever, and deserving of the utmost reverence and respect."

— Pope Francis, Day for Life Greeting, July 7, 2013

2. How do I talk with someone I love about dying and death?

- Illness, suffering and dying are inevitable parts of human existence. The time of death is unpredictable. Decisions at the end of life are often difficult and complex for both the person who is dying and for their family and friends. It is always helpful if we can talk openly with someone we love and trust about our fears and wishes around dying. The following points may be helpful when having such conversations.
- Enter into conversation about the person's life. Games can often assist in directing the conversation.
 - **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." http://www.gowish.org
 - 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." https://commonpractice.com/products/hello-game
 - Now and Then Game: "The perfect entry point for someone new to the conversation. The Starter Pack is a deck of 25 cards, and each card has a question that one should have at least considered before going too deep into the end of life planning process." https://www.after.community/products

- Explore grief as the dying person and their loved ones are grieving before and after the death. MyGrief.ca is an excellent online resource from Canadian Virtual Hospice: https://www.mygrief.ca/
- The online resources available from Canadian Virtual Hospice at https://kidsgrief.ca/ can be very helpful when assisting children and youth with grief related to illness and death.
- Ask questions such as these:
 - What brings you joy?
 - What values are most important to you?
 - What aspects of your life have you found difficult or painful?
 - What fears do you have?
 - Do you have any unresolved relationship struggles?
 - Do you have any financial or practical worries?
 - What spiritual resources might you find helpful?
- Here are some things a person who is reaching the end of life could do:
 - Write a journal or a biographical letter that expresses important aspects of their life that could be shared with loved ones and caregivers.
 - Prepare an advance care directive (including the designation of a Power of Attorney for Personal Care and a Power of Attorney for Property).
 - Have open and honest conversations with those who hold Power of Attorney.
 - Prepare a will (if this is not already done), keeping in mind the legacy of relationships they wish to leave. Although a will is usually prepared by a lawyer, some funeral homes have kits available to help you to write a will on your own. Please note: wills may be governed by provincial requirements, depending on where you live.

- Plan and discuss funeral arrangements with those who will be responsible for making these when the time comes. This is especially important for those who wish to have a Catholic funeral, including the celebration of the Eucharist, if family members no longer practise the Catholic faith.
- Communicate to family members the desire to receive the sacrament of the Anointing of the Sick from a Catholic priest. The Catholic Church "believes and confesses that among the seven sacraments there is one especially intended to strengthen those who are being tried by illness, the Anointing of the Sick." (Catechism of the Catholic Church, n. 1511)

3. If I am caring for someone who is very ill or dying and I am finding it difficult or stressful, where might I turn for help?

- First, recognize and accept your personal limitations (have self-compassion).
 - Pray specifically for help.
 - Seek physical, emotional and spiritual support from family, friends and your local parish. This support is important for both the person who is dying and the caregiver.
 - Talk to the physician about whom to call after hours in case additional care is required. Only call 911 in an emergency.
 - Create a Care Map to help define the role of the caregiver and to ensure that family and friends look after simple tasks.
 This will allow you (the caregiver) to focus on your loved one and feel less stretched.
 - Consult regional caregiver organizations in your community.
 There are many in Canada, and they are steadily increasing in light of the desire to better support caregivers.

1. Canadian Caregiving Associations

Carers Canada : https://www.carerscanada.ca/

2. Provincial Caregiving Associations

- Ontario: The Ontario Caregiver Organization: https://ontariocaregiver.ca/
- Québec: L'Appui : https://www.lappui.org/en
- Nova Scotia: Caregivers Nova Scotia: https://www.caregiversns.org/
- Alberta: Caregivers Alberta:
 https://www.caregiversalberta.ca/
- British Columbia: Family Caregivers of British Columbia: https://www.familycaregiversbc.ca/
- Take time for rest and respite so you can continue journeying with your loved one.
- Reach out to local resources to find support from health professionals, pastors and pastoral workers, parish or other community organizations, and palliative care staff: https://211.ca/.

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Code: 185-168

ISBN: 978-0-88997-915-4

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