



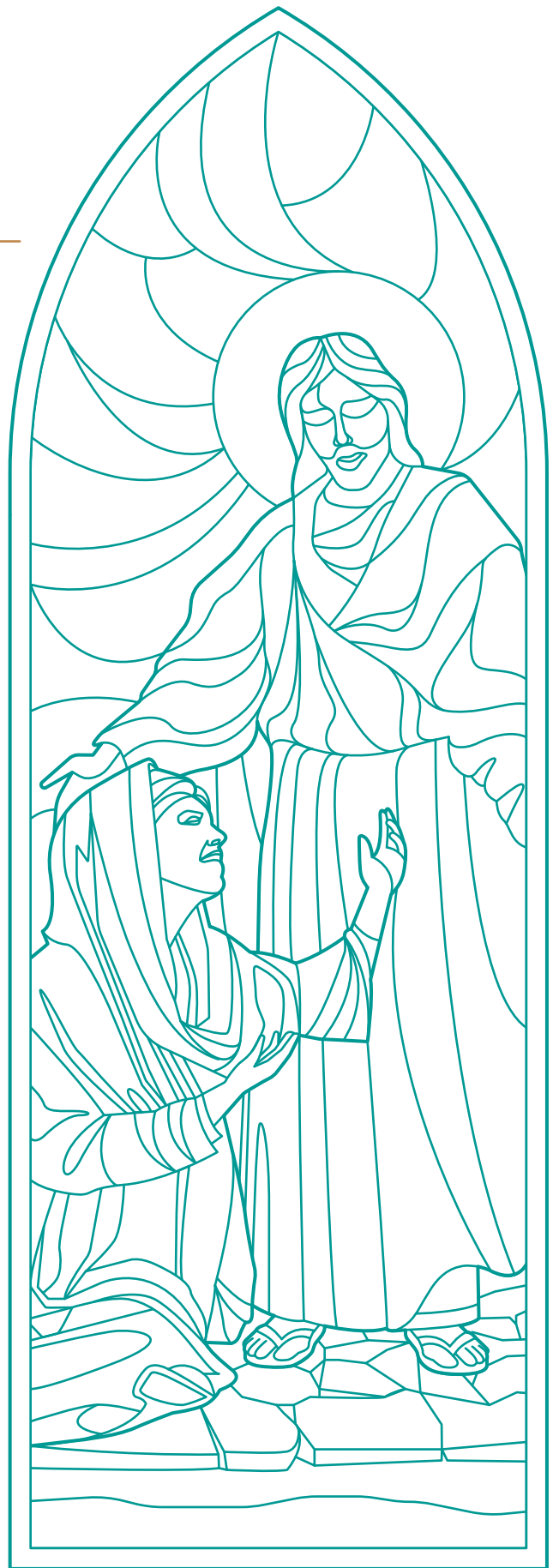
Canadian Conference  
of Catholic Bishops

## Horizons of Hope

A Toolkit for Catholic Parishes  
on Palliative Care

# MODULE 01

Understanding  
the human  
experience of  
dying and death





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## **MODULE 01**

# Understanding the human experience of dying and death

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# Tips for the facilitator



Module 1 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. 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

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# 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 I in the Facilitator’s Guide.**





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## **PART 1**

# Experience

*When the Lord saw her, he had compassion  
for her and said to her, “Do not weep”.*

Luke 7:13

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# 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 **Luke 7:11-13** 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 I](#) for a copy of the guiding questions.

### Guiding questions:

1. How would the widow have been helped by the presence of a supportive and compassionate community during this time of grief?
2. Where do you find hope in this passage?



## 4. Table conversations

🕒 10 minutes

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 could join the group as an interested listener.



## 5. Large group focus

🕒 3 minutes

**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.



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## **PART 2**

# New information

*The gospel of life is a gospel of compassion and mercy directed to actual persons, weak and sinful, to relieve their suffering, to support them in the life of grace, and if possible to heal them from their wounds.*

Congregation for the Doctrine of the Faith, “Samaritanus Bonus”

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# Part 2: New information

## Section A: Theological perspective

🕒 45 minutes



### 1. Video – Theological and ethical reflection on the experience of death and dying

🕒 5 minutes

**NOTE TO FACILITATOR:** This video can be viewed on YouTube at <https://youtu.be/jNTqeFhO4rM>. For direct download of the video files, visit [cccb.ca](http://cccb.ca). To help you become familiar with the core content of the video, we have included the script below. [See Appendix 2](#) for a take-home version of the script.

This video will introduce participants to two important concepts: *A Christian Perspective of Life* and *A Christian Perspective on Death*.



### Video script – Theological and ethical reflection

**Narrator 1:** Often, it can be difficult to see and connect our faith to the end-of-life experience. Seeing family members, good friends, colleagues go through the dying process can challenge our fundamental beliefs and values. While at other times, the end-of-life experience can be an occasion to affirm the hope and trust we hold through faith in Christ.

**Narrator 2:** Since its very beginning, the Christian community has been especially concerned and attentive to the lived experience of illness, suffering, dying and death. While acknowledging the challenges, the Church has developed meaningful resources to help navigate these deeply human realities. Together, we are called to discover that death is a part of life and that there can be life in the dying process.

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## ***A Christian Perspective of Life***

**Narrator 1:** Today, we hear the term “dignity” used and interpreted in many ways, especially in the end-of-life context. Yet our Christian faith has a clear and meaningful way to think about human dignity. Dignity affirms the essential value of the human being. Acknowledging that we are created in the image of God, this dignity is recognized as inherent to every human person. Dignity is irremovable, as it does not depend on a person’s traits or characteristics. Our human condition of fragility and vulnerability needs to be included in this understanding of dignity, as these conditions do not diminish it.

Nevertheless, a person in the midst of suffering, illness or dying can sincerely feel that dignity has been removed or lost. Our belief in inherent dignity is first a call to listen attentively and to be receptive. While at the same time, we must actively create conditions to support the person at the end of life through the establishment of a committed presence and relationship.

**Narrator 2:** Our belief in being created by God leads us also to affirm that life is sacred and to recognize life as a gift from God. Viewing life as both sacred and as a gift reveals the relational nature of our existence with the living God. We, therefore, have a responsibility to take care of this life and to promote it by cultivating our relationship with God and others.

**Narrator 1:** It is also important to remember that for Catholics, earthly life is a central value, but it is not an absolute value. We have a responsibility to respect and to care for life by concretely promoting the quality of life for a person. In this sense, sacredness and quality of life should be viewed as complementary. Recognizing the value of human life calls us to live out a commitment of special attention and care through the dying process of person.

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## ***A Christian Perspective on Death***

**Narrator 1:** From a Christian perspective, aging and dying are viewed as a normal part and process of life. Human fragility and limitations at the end of life do not mean failure. Our limitations are rather an occasion to open this experience of dying to the presence of others, searching for creative ways to share in and live out a meaningful time together.

**Narrator 2:** Our faith does not always remove the feelings of despair, loneliness, powerlessness, brokenness or regret. Nevertheless, our faith in Christ can bring a new light on these experiences. By persevering to hope, to love and to pray together, as a Christian community, faith can trigger unexpected occasions for healing. Faith does not remove the negativity of death, but through support and relationship, it does grant an opening to acknowledge God's presence and his concern for our human distress.

**Narrator 1:** The end of life may no longer be a time for physical curing, but could lead to another way of healing, especially in caring for our relationships with family, friends, God. It can be a time to listen or to be more attentive to the fears and concerns of loved ones — or our own. Since frailty and uncertainty are part of our human condition, we do not have total control of these conditions. Yet, when supported by others, there can become opportunities to grow and heal together.

**Narrator 2:** From a Christian perspective, death does not have the last word. Rather, it is a passage, an opening to the continuation of life. In this sense, death should not be viewed as something purely individual or where we are alone, but should be integrated into a caring community. Approaching death and dying in this way leads to the humanization of end-of-life care and can become an opening to encounter the hope-filled and loving presence of Christ.



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**Narrator 1:** Both through his Incarnation and his attitude, Jesus shows us how God makes himself present in our situations of distress. As described in the various Gospel scenes of encounter, such as the Death of Lazarus or the Widow's Son at Nain, Jesus, by his loving and healing presence, opens a space of extraordinary and unexpected hope for new life.



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

🕒 10 minutes

### 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 a screen, printed and posted on the wall, placed on the tables or written on a whiteboard. [See Appendix 3.](#)

### Guiding Questions:

1. What messages were confirmed for me about the Christian perspectives on life and death?
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

🕒 5 minutes

**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

🕒 10 minutes

## Section B: Medical perspective

🕒 45 minutes



### 1. Video – Medical perspective

🕒 5 minutes

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

1. How do people die?
2. What is palliative care?
3. Illness trajectory (rapid or prolonged decline)
4. Withdrawal and withholding of treatment

**NOTE TO FACILITATOR:** This video can be viewed on YouTube at <https://youtu.be/PqyrW0mJbiY>. For direct download of the video files, visit [cccb.ca](http://cccb.ca). To help you become familiar with the core content of this video, we have included the script below. [See Appendix 4](#) for a take-home version of the script.



## Video script – Medical perspective

Hi, 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.

I would like talk with you about palliative care. Understandably, there is a lot of fear and anxiety about illnesses, death and dying, and so perhaps we do not take enough time in our families to speak about questions related to death and dying, such as palliative care.

The World Health Organization (WHO) defines palliative care as follows:

Palliative care is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.<sup>1</sup>

Palliative care sees dying as a normal process of life; it neither seeks to hasten death or to inappropriately postpone death. This is an important definition, given the realities and confusion around euthanasia and assisted suicide, which is legalized in Canada and referred to as Medical Assistance in Dying or MAiD. Most national and international organizations like the WHO, the World Medical Association and the Canadian Hospice Palliative Care Association do not view MAiD (or euthanasia) as a part of palliative care, but others in Canada and abroad do. Stopping dialysis or stopping chemotherapy when these treatments are inappropriate, not effective and futile are a withdrawal of treatment which is ethically justified and a good end-of-life care for most people. As the Church teaches, “Such a refusal is not the equivalent of suicide; on the contrary, it should be considered as an acceptance of the human condition, or a wish to avoid the application of a medical procedure disproportionate to the results that can be expected.”<sup>2</sup>

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So, there are four points I wish to address:

**First**, contrary to what many people think, palliative care is not only for persons who are at the end of their lives, in the last days or weeks. Palliative care should begin much earlier in the illness. At the very least, it should be started as soon as it appears that a cure is not possible. Imagine, for example, if you were diagnosed recently with cancer and doctors felt that although it is not curable, there is chemotherapy or radiotherapy treatments that could control the disease. Many people in these situations are experiencing pain and other symptoms, including possible worry and fear. These have a negative impact on quality of life. Palliative care can help control these so that you can live better while on the treatments. Unfortunately, for some people, the disease cannot be cured or controlled. Despite treatments, it progresses—sometimes slowly over many months or years, and sometimes more rapidly over weeks and months.

The evolving nature of an illness is technically referred to as “the illness trajectory.” That is what happens along the way in terms of our ability to function, to get on with our daily lives. Clinical experience and research show that there are three main typical illness trajectories: a) the cancer trajectory; b) the trajectory of organ disease or failure; and c) the dementia or frailty trajectory.

I invite you to review in your take-home packet the symptomatology of each type. [See Appendix 5](#) for more on illness trajectories.

Palliative care services are sometimes asked for to help control symptoms in patients who are receiving treatments to cure the disease. When started earlier, palliative care can also be thought of as “supportive care.” Sometimes palliative care is actually referred to as “Supportive and Palliative Care” or “Pain and Symptom Management.” It is important to remember that palliative care is not a “hands-off approach” to illness, but instead is active care which deploys the appropriate levels of care and treatment.

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**Second**, palliative care is not only for the elderly. Many younger people experience serious illnesses, as do babies and children. Palliative care is not only for people with cancer. While cancer accounts for about one third of deaths in Canada, diseases of the heart, lungs, kidney and brain, as well as dementia, account for the majority of the other deaths and can benefit from palliative care.

**Third**, palliative care is not limited to only controlling pain and other symptoms. It includes seeing the person as a whole person, a person made up not only of a physical body, but also with psychological, social, and spiritual and religious needs. It helps to explore all these dimensions of being human, and how they are affected by serious illness.

**Fourth**, palliative care is an approach, and not a service. When people hear “palliative care,” they often think of a palliative doctor or team, or a hospice or a palliative care unit. But the term “palliative care” actually best refers to a care approach. A family doctor, cancer specialist or heart, kidney or lung specialist can also start a palliative care approach while they are treating the diseases. They could say, “Let’s talk about starting a palliative care approach while we treat your disease.” In many cases it means “Let’s improve your quality of life and find out what is important for you while we are treating your disease.”

**In conclusion**, palliative care is not delivered only in hospices or palliative care units in hospitals. In fact, palliative care should be available everywhere where patients with serious illnesses and palliative care needs find themselves. This includes in hospital wards, hospital outpatient clinics, family health clinics, their homes, and long-term care and nursing homes. In every region of Canada, all health care professionals who care for patients with serious illnesses should have good basic training on how to start a palliative care approach.

Unfortunately, many health care professionals don’t have basic palliative care training. There are not enough palliative care specialists in many regions. Some regions don’t have palliative care units. Others don’t have palliative care teams in hospitals or in the community, some don’t have hospices, and many long-term care and nursing homes have not adopted

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a palliative care approach. Yet, with education, building awareness and speaking with our elected leaders in Canada, we can build a stronger, more robust and assessible palliative care system in Canada.



## 2. Application to my life: Medical perspective

🕒 10 minutes

### Silent Individual Reflection

Following the instructional video, participants will have an opportunity to consider the contents of 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 6.](#)

Now that you have heard about what palliative care is, when it is needed, who provides it and where it is provided, let's reflect on the video we have just watched. Here are some questions to help us reflect on this:

1. Were you surprised by anything that was said or shown in the video?
2. How do you feel about palliative care now?



### 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.



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## **PART 3**

# Action

*All grace flows from mercy, and the  
last hour abounds with mercy for us.*

St. Faustina, *Diary*, entry 1507

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# Part 3: Action

🕒 5 minutes



## 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 question-and-answer guide to take home and use for further reflection. Please review the question and answer take home resource with participants. Provide participants with a copy of [Appendix 7](#), either in a digital format or distribute a paper copy.

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# Endnotes

- 1** World Health Organization. “Palliative Care”. Accessed 10 May 2021.  
<https://www.who.int/cancer/palliative/definition/en/>.
- 2** Congregation for the Doctrine of the Faith. *Declaration on Euthanasia* (5 May 1980).  
[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).



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# **MODULE 01**

# Appendices

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# Appendix 1

## **Guiding questions – Reflection on scripture**

1. How would the widow have been helped by the presence of a supportive and compassionate community during this time of grief?
2. Where do you find hope in this passage?

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# Appendix 2

## **Video script – Theological and ethical reflection**

**Narrator 1:** Often, it can be difficult to see and connect our faith to the end-of-life experience. Seeing family members, good friends, colleagues go through the dying process can challenge our fundamental beliefs and values. While at other times, the end-of-life experience can be an occasion to affirm the hope and trust we hold through faith in Christ.

**Narrator 2:** Since its very beginning, the Christian community has been especially concerned and attentive to the lived experience of illness, suffering, dying and death. While acknowledging the challenges, the Church has developed meaningful resources to help navigate these deeply human realities. Together, we are called to discover that death is a part of life and that there can be life in the dying process.

### ***A Christian perspective of life***

**Narrator 1:** Today, we hear the term “dignity” used and interpreted in many ways, especially in the end-of-life context. Yet our Christian faith has a clear and meaningful way to think about human dignity. Dignity affirms the essential value of the human being. Acknowledging that we are created in the image of God, this dignity is recognized as inherent to every human person. Dignity is irremovable, as it does not depend on a person’s traits or characteristics. Our human condition of fragility and vulnerability needs to be included in this understanding of dignity, as these conditions do not diminish it.

Nevertheless, a person in the midst of suffering, illness or dying can sincerely feel that dignity has been removed or lost. Our belief in inherent dignity is first a call to listen attentively and to be receptive. While at the same time, we must actively create conditions to support the person at the end of life through the establishment of a committed presence and relationship.

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**Narrator 2:** Our belief in being created by God leads us also to affirm that life is sacred and to recognize life as a gift from God. Viewing life as both sacred and as a gift reveals the relational nature of our existence with the living God. We, therefore, have a responsibility to take care of this life and to promote it by cultivating our relationship with God and others.

**Narrator 1:** It is also important to remember that for Catholics, earthly life is a central value, but it is not an absolute value. We have a responsibility to respect and to care for life by concretely promoting the quality of life for a person. In this sense, sacredness and quality of life should be viewed as complementary. Recognizing the value of human life calls us to live out a commitment of special attention and care through the dying process of person.

### ***A Christian perspective on death***

**Narrator 1:** From a Christian perspective, aging and dying are viewed as a normal part and process of life. Human fragility and limitations at the end of life do not mean failure. Our limitations are rather an occasion to open this experience of dying to the presence of others, searching for creative ways to share in and live out a meaningful time together.

**Narrator 2:** Our faith does not always remove the feelings of despair, loneliness, powerlessness, brokenness or regret. Nevertheless, our faith in Christ can bring a new light on these experiences. By persevering to hope, to love and to pray together, as a Christian community, faith can trigger unexpected occasions for healing. Faith does not remove the negativity of death, but through support and relationship, it does grant an opening to acknowledge God's presence and his concern for our human distress.

**Narrator 1:** The end of life may no longer be a time for physical curing, but could lead to another way of healing, especially in caring for our relationships with family, friends, God. It can be a time to listen or to be more attentive to the fears and concerns of loved ones – or our own. Since frailty and uncertainty are part of our human condition, we do not have total control of these conditions. Yet, when supported by others, there can become opportunities to grow and heal together.



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**Narrator 2:** From a Christian perspective, death does not have the last word. Rather, it is a passage, an opening to the continuation of life. In this sense, death should not be viewed as something purely individual or where we are alone, but should be integrated into a caring community. Approaching death and dying in this way leads to the humanization of end-of-life care and can become an opening to encounter the hope-filled and loving presence of Christ.

**Narrator 1:** Both through his Incarnation and his attitude, Jesus shows us how God makes himself present in our situations of distress. As described in the various Gospel scenes of encounter, such as the Death of Lazarus or the Widow's Son at Nain, Jesus, by his loving and healing presence, opens a space of extraordinary and unexpected hope for new life.

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# Appendix 3

## **Guiding questions – Theological and ethical reflection**

1. What messages were confirmed for me about the Christian perspectives on life and death?
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?

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# Appendix 4

## Video script – Medical perspective

Hi, 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.

I would like talk with you about palliative care. Understandably, there is a lot of fear and anxiety about illnesses, death and dying, and so perhaps we do not take enough time in our families to speak about questions related to death and dying, such as palliative care.

The World Health Organization (WHO) defines palliative care as follows:

Palliative care is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.<sup>1</sup>

Palliative care sees dying as a normal process of life; it neither seeks to hasten death or to inappropriately postpone death. This is an important definition, given the realities and confusion around euthanasia and assisted suicide, which is legalized in Canada and referred to as Medical Assistance in Dying or MAiD. Most national and international organizations like the WHO, the World Medical Association and the Canadian Hospice Palliative Care Association do not view MAiD (or euthanasia) as a part of palliative care, but others in Canada and abroad do. Stopping dialysis or stopping chemotherapy when these treatments are inappropriate, not effective and futile are a withdrawal of treatment which is ethically justified and a good

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1 World Health Organization. “Palliative Care”. Accessed 10 May 2021.  
<https://www.who.int/cancer/palliative/definition/en/>.

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end-of-life care for most people. As the Church teaches, ‘Such a refusal is not the equivalent of suicide; on the contrary, it should be considered as an acceptance of the human condition, or a wish to avoid the application of a medical procedure disproportionate to the results that can be expected’<sup>2</sup>

So, there are four points I wish to address:

**First**, contrary to what many people think, palliative care is not only for persons who are at the end of their lives, in the last days or weeks. Palliative care should begin much earlier in the illness. At the very least, it should be started as soon as it appears that a cure is not possible. Imagine, for example, if you were diagnosed recently with cancer and doctors felt that although it is not curable, there is chemotherapy or radiotherapy treatments that could control the disease. Many people in these situations are experiencing pain and other symptoms, including possible worry and fear. These have a negative impact on quality of life. Palliative care can help control these so that you can live better while on the treatments. Unfortunately, for some people, the disease cannot be cured or controlled. Despite treatments, it progresses — sometimes slowly over many months or years, and sometimes more rapidly over weeks and months.

The evolving nature of an illness is technically referred to as “the illness trajectory.” That is what happens along the way in terms of our ability to function, to get on with our daily lives. Clinical experience and research show that there are three main typical illness trajectories: a) the cancer trajectory; b) the trajectory of organ disease or failure; and c) the dementia or frailty trajectory.

I invite you to review in your take-home packet the symptomatology of each type. [See Appendix 5](#) for more on illness trajectories.

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2 Congregation for the Doctrine of the Faith. *Declaration on Euthanasia* (5 May 1980) [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).

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Palliative care services are sometimes asked for to help control symptoms in patients who are receiving treatments to cure the disease. When started earlier, palliative care can also be thought of as “supportive care.” Sometimes palliative care is actually referred to as “Supportive and Palliative Care” or “Pain and Symptom Management.” It is important to remember that palliative care is not a “hands-off approach” to illness, but instead is active care which deploys the appropriate levels of care and treatment.

**Second**, palliative care is not only for the elderly. Many younger people experience serious illnesses, as do babies and children. Palliative care is not only for people with cancer. While cancer accounts for about one third of deaths in Canada, diseases of the heart, lungs, kidney and brain, as well as dementia, account for the majority of the other deaths and can benefit from palliative care.

**Third**, palliative care is not limited to only controlling pain and other symptoms. It includes seeing the person as a whole person, a person made up not only of a physical body, but also with psychological, social, and spiritual and religious needs. It helps to explore all these dimensions of being human, and how they are affected by serious illness.

**Fourth**, palliative care is an approach, and not a service. When people hear “palliative care,” they often think of a palliative doctor or team, or a hospice or a palliative care unit. But the term “palliative care” actually best refers to a care approach. A family doctor, cancer specialist or heart, kidney or lung specialist can also start a palliative care approach while they are treating the diseases. They could say, “Let’s talk about starting a palliative care approach while we treat your disease.” In many cases it means “Let’s improve your quality of life and find out what is important for you while we are treating your disease.”

**In conclusion**, palliative care is not delivered only in hospices or palliative care units in hospitals. In fact, palliative care should be available everywhere where patients with serious illnesses and palliative care needs find themselves. This includes in hospital wards, hospital outpatient clinics, family health clinics, their homes, and long-term care and nursing homes.

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In every region of Canada, all health care professionals who care for patients with serious illnesses should have good basic training on how to start a palliative care approach.

Unfortunately, many health care professionals don't have basic palliative care training. There are not enough palliative care specialists in many regions. Some regions don't have palliative care units. Others don't have palliative care teams in hospitals or in the community, some don't have hospices, and many long-term care and nursing homes have not adopted a palliative care approach. Yet, with education, building awareness and speaking with our elected leaders in Canada, we can build a stronger, more robust and assessible palliative care system in Canada.

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# Appendix 5

## **Information on illness trajectories**

**How, you may ask, do people die?** Let's explore that question. Once we have done that, we will explore "How can people live as well as possible while journeying with a serious illness?"

About 10% of us, one in ten, will die suddenly and unexpectedly, often through an accident or a sudden medical event like a heart attack or major stroke. The rest of us will live with one condition or another for many weeks, many months or many years, and we will eventually die from it. These include conditions like a cancer that cannot be cured; advanced diseases of the heart, lungs, kidneys and brain; and conditions like dementia, or even just old age and frailty.

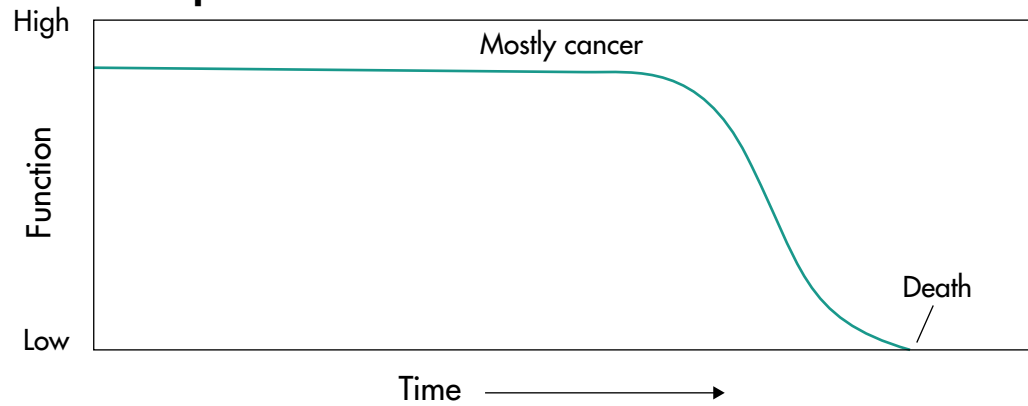
**Let's look at the illness journeys of these various diseases.** The technical term is "illness trajectories." That is, "What happens along the way in terms of our ability to function, to get on with our daily lives, our normal activities." Clinical experience and research show that there are three main typical trajectories:

1. the cancer trajectory;
2. the trajectory of organ disease or failure; and
3. the dementia or frailty trajectory.

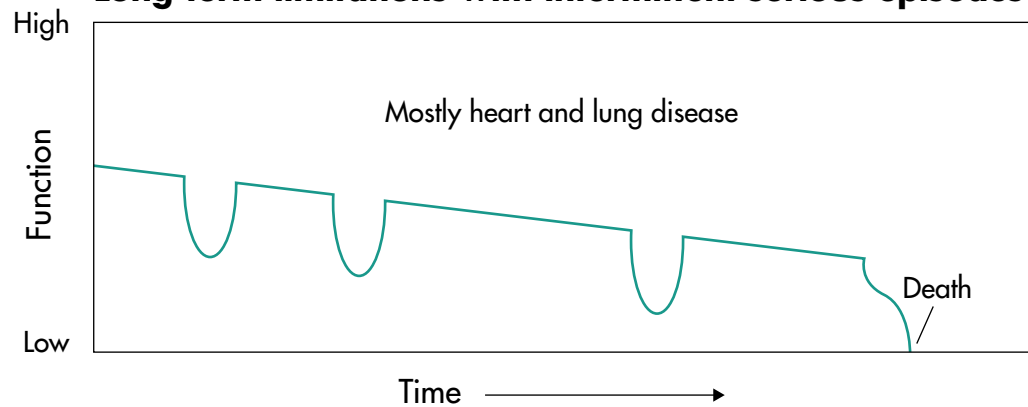
We will now take a closer look at each of these. But remember: these three "typical" trajectories are average ones that most people with these conditions may experience, but they can vary from person to person. So, it does not mean that everyone with these diseases will necessarily follow these journeys or trajectories.

## Illness trajectories – Learning Essential Approaches to Palliative Care (LEAP)

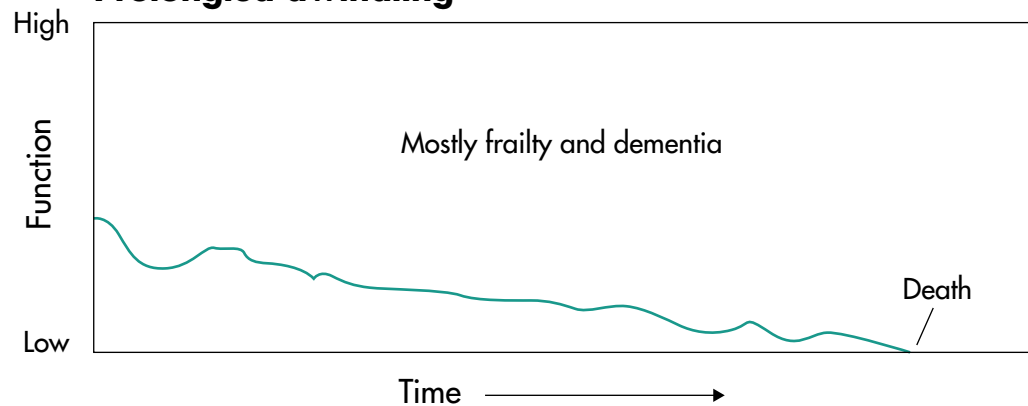
### Short period of evident decline



### Long-term limitations with intermittent serious episodes



### Prolonged dwindling



Jynn J. Perspectives on care at the close of life. *JAMA* 2001;285 (7):925–932

Murray S, et al. Illness trajectories and palliative care. *BMJ* 2005;330(7498):1007–1011



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## **The cancer trajectory**

There are two cancer trajectories.

- One is where a person is diagnosed with cancer, undergoes treatments, and the cancer is cured or goes into remission. This happens with a lot of cancers these days—much more often than, say, 20 or 30 years ago, especially if they are diagnosed early.
- If the disease is not curable, we notice a gradual decline or reduction in what we can do on this trajectory or journey. Over months or years (or sometimes weeks), we notice that we are not able to do what we used to do before. We get progressively more fatigued, spending more time resting. At one point we may find that our appetite starts decreasing, we start eating and drinking less, and we spend more time sitting or resting. We notice that we are losing weight. There may be an unexpected complication, like a lung infection or side effect to a treatment, which makes us feel very sick and perhaps even has us in bed or in hospital. With treatments, we rebound, but not to the same level of activity as before. This journey is gradual, with increasing dependency on others for what we call “activities of daily living.” Then, in the last months or weeks, the progression can be more rapid. Within weeks we may find ourselves having to spend most of the time resting. We may experience rapid weight loss. Some symptoms may worsen, such as shortness of breath or pain. We will need more help doing things like bathing. We will eat less and spend more time sleeping.

## **The trajectory of organ disease or failure**

The second trajectory is often called the “chronic disease” trajectory or journey. This is more often seen in patients with serious heart, lung, liver and kidney diseases. In these trajectories, patients experience very gradual declines in their functioning, often over many years or many months. However, they experience occasional serious complications or events, such as a sudden reduction in their heart function (in medical terms, we call it decompensation of the heart) or a lung infection in a patient with chronic lung disease that reduces their functional level quickly and dramatically,

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sometimes even to the point that they need to be hospitalized. However, with treatment of the disease or the complication, they rebound and regain strength. However, when they rebound, they do not reach the same levels of functioning as before. Then, over time, they start needing more and more help with their daily activities, they start eating less and then, in the last weeks and months, they may have to spend most or all of the time resting or in bed.

Some cancers, such as breast and prostate cancer, are increasingly responding well to new treatments. This allows the disease to slow down or even reverse for a while, resulting in an illness trajectory that looks more like the chronic disease journey.

### **The dementia or frailty trajectory**

Lastly, there is the journey that is typical for dementia or frailty. It declines very gradually, over many years. Occasionally, there may be complications, as in the previous journey, from which people can rebound. With some rarer types of dementia, the decline may be a lot more rapid, within a few years. Sometimes a complication can occur that can speed up the decline and frailty, such as a fall with a hip fracture or new heart disease or stroke.

Now that we know about these journeys, let's look at how we can live as best we can if we are to find ourselves on one of them.

By recognizing these journeys, we can start the discussion. We could, for example, say, "I have a feeling that things are changing. I cannot do what I used to be able to do. Can we talk about this, please?"

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# Appendix 6

## **Guiding questions – Medical perspective**

1. Were you surprised by anything that was said or shown in the video?
2. How do you feel about palliative care now?

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# Appendix 7

## Being Comforted at the End of Life

### Question-and-answer take-home resource

*“Dying is not fundamentally a medical event, but rather a social event that happens in the family and the community.”*

— Dr. Mary Kelly

As Christians, each of us is called to respect the dignity of all persons and the sacredness of human life. In a spirit of love, we are also called to be present to those who suffer, to care with them and for them and to comfort them, especially at the end of life’s journey. The Catholic Church, in imitation of her Lord, “Christ the Physician,” is called to accompany the sick and the dying:

*Christ’s compassion toward the sick and his many healings of every kind of infirmity are a resplendent sign that “God has visited his people” (Lk 7:16; cf. Mt 4:24) and that the Kingdom of God is close at hand. Jesus has the power not only to heal, but also to forgive sins (cf. Mk 2:5-12); he has come to heal the whole man, soul and body; he is the physician the sick have need of (cf. Mk 2:17). His compassion toward all who suffer goes so far that he identifies himself with them: “I was sick and you visited me” (Mt 25:36). His preferential love for the sick has not ceased through the centuries to draw the very special attention of Christians toward all those who suffer in body and soul. It is the source of tireless efforts to comfort them.<sup>1</sup>*

To fulfill this call, there are some things we need to know and some reflections that are important. We hope that the following questions and answers may be helpful to you.

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1 Catholic Church. *Catechism of the Catholic Church: Revised in Accordance with the Official Latin Text Promulgated by Pope John Paul II.* Vatican City: Libreria Editrice Vaticana, 1997, n. 1503.

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The Catholic Tradition faces the reality of suffering and death with the confidence of faith. In the face of death, the Church witnesses to her belief that God has created each person for eternal life. Suffering and death are not the final end, but rather a passage transformed by the promise of the resurrection.<sup>2</sup>

## **What are our responsibilities as Christians to support and care for those who are dying?**

- We are always called to care, to relieve suffering whenever possible in ways that are faithful to Catholic teaching, to be present to the person in a loving manner, and never to abandon him/her. We are reminded by the teaching of the Catholic Church that “The duty of making oneself a neighbor to others and actively serving them becomes even more urgent when it involves the disadvantaged, in whatever area this may be. ‘As you did it to one of the least of these my brethren, you did it to me.’”<sup>3</sup>
- Form and become compassionate communities of support. Each parish should be encouraged to set up a team to help those who are dying and to support their caregivers.
- Provide caregivers and the members of the community with appropriate pastoral training.
- Pray with and for those who are dying, and for their caregivers.
- Provide practical help according to our gifts and abilities (such as personal care, sensitive and timely visits or phone calls, helping with shopping, providing meals as needed).
- Recognize the value of being present to the person who is dying and to his/her family and friends.

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2 Catholic Health Alliance of Canada. *Health Ethics Guide*. Ottawa: Catholic Health Alliance, Third Edition, 2012. p. 55.

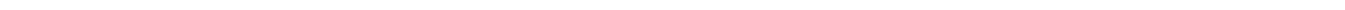
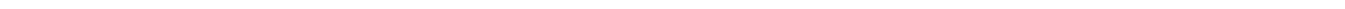
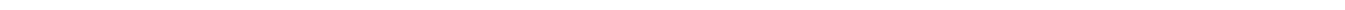
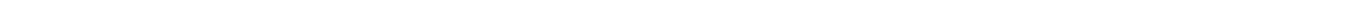
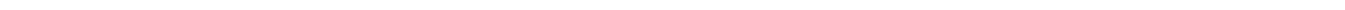
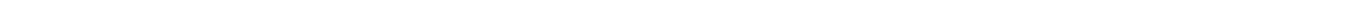
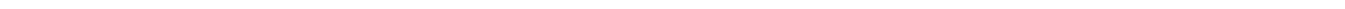
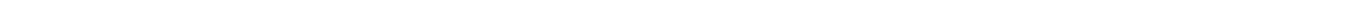
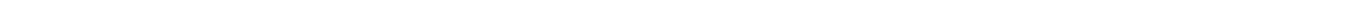
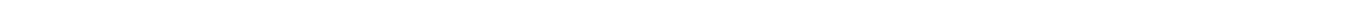
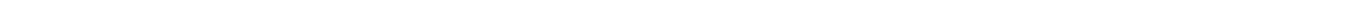
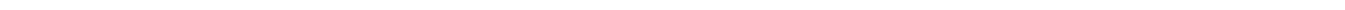
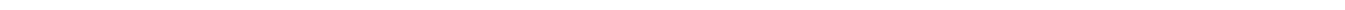
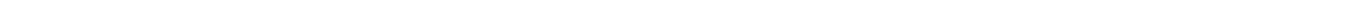
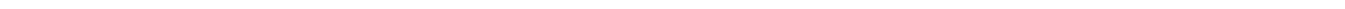
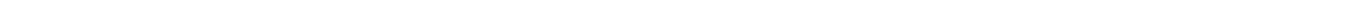
3 Catholic Church. *Catechism of the Catholic Church: Revised in Accordance with the Official Latin Text Promulgated by Pope John Paul II*. Vatican City: Libreria Editrice Vaticana, 1997, n. 1932.

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- Help the person to find meaning at this time in their life.
  - Encourage healing of relationships that may be broken.
  - Help the person to seek appropriate spiritual care and enable arrangements for the person to receive the Sacraments, as appropriate.





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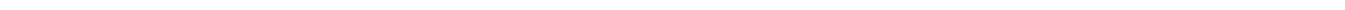
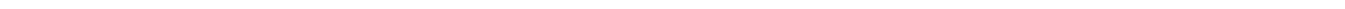
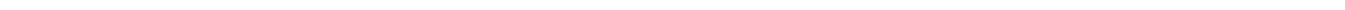
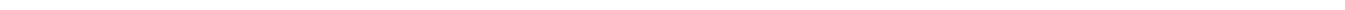
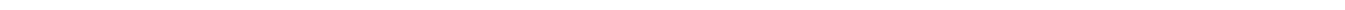
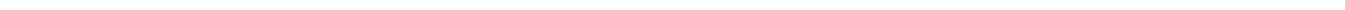
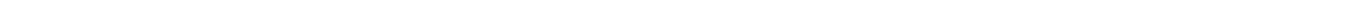
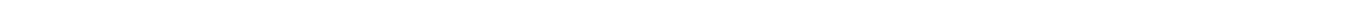
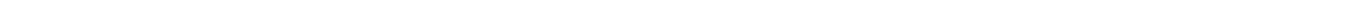
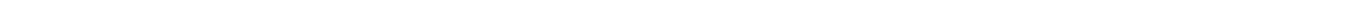
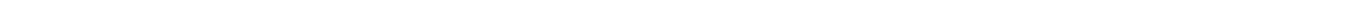
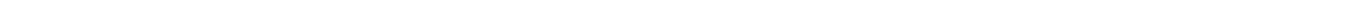
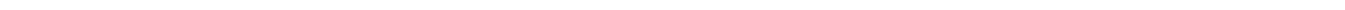
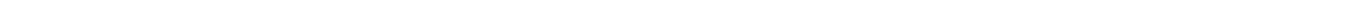
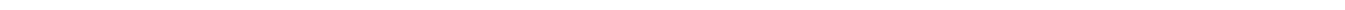
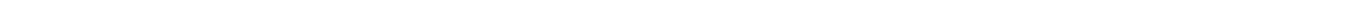
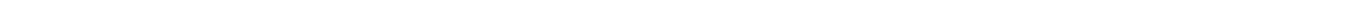
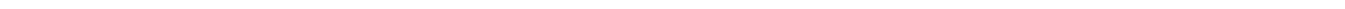








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