

#### **Horizons of Hope**

A Toolkit for Catholic Parishes on Palliative Care

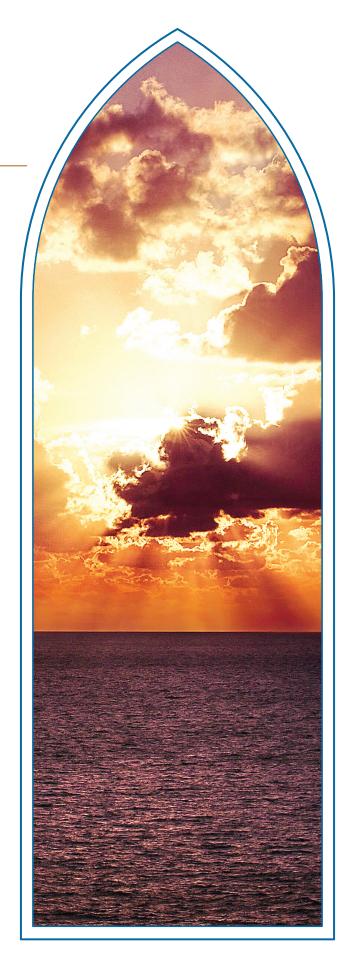
# Introduction and Facilitator's guide











# Table of Contents

Backg	round	L	2
Memb	er org	ganizations	2
Ackno	wledg	gements	3
Ration	ale	•••••	4
	1.	For whom is the program designed?	6
	2.	What are the roles and responsibilities of my parish community for the facilitation of this toolkit?	6
	3.	What are the components of the Horizons of Hope: A Toolkit for Catholic Parishes on Palliative Care?	8
	4.	What do I, as a facilitator, need to know about palliative care?	8
	5.	What are some key things to know about how adults learn?	9
	6.	What is the process for delivering each Module?	10
	7.	What can I do to prepare for each Module?	13
	8.	What preparation is required immediately before the sessions begin?	13
	9.	What materials will be helpful?	14
	10.	How are the sessions scheduled?	15
	11.	Why are norms for conversation helpful?	17
	12.	What is the optimal size of discussion groups?	18
	13	What can I do if the table conversations become difficult?	18

14.	How do I facilitate this program online?	20
15.	Suggested guidelines for online participants:	21
Appendix 1		23
Appendix 2		24
Appendix 3		25

# Introduction

# Background

The Canadian Conference of Catholic Bishops (CCCB) formed a Joint *Ad hoc* Committee on Palliative Care with a variety of partners and experts to address the increasing complexities regarding end of life issues in Canada.

In response, the *Ad hoc* Committee has developed a resource kit on palliative care and end-of-life issues for Catholic parishes. The toolkit seeks to empower and educate parishioners and address questions surrounding palliative care, dying, death, suffering and bereavement in a holistic fashion. The content includes Catholic moral and pastoral theology, medical expertise and the *Compassionate Community* model. The toolkit is available for use in Catholic parish settings and other appropriate venues. English and French versions are available.

For generations, Catholic dioceses and religious orders in Canada have been significant contributors to the development and delivery of health care services and formation in Canada. This resource honours and continues that legacy.

The CCCB Joint *Ad hoc* Committee, comprised of the following members, made an invaluable contribution of expertise to the development of this toolkit.

# Member organizations











## Acknowledgements

The CCCB Joint *Ad hoc* Committee on Palliative Care acknowledges with deep gratitude the following organizations, which have generously provided donations to support the development of this kit.

- Archdiocese of Toronto
- Congregation of the Most Holy Redeemer (Redemptorists)
- Congregation of St. Basil (Basilian Fathers)
- Ex Corde Foundation (Diocese of Hamilton)
- Grey Sisters of the Immaculate Conception
- Institute of the Blessed Virgin Mary (Loretto Sisters)
- Religieuses Hospitalières de Saint-Joseph
- Sisters of Providence of Saint Vincent de Paul
- Sisters of Saint Anne / Soeurs de Sainte-Anne du Québec
- Sisters of St. Joseph in Canada
- Sisters of Saint Joseph of Sault Ste. Marie
- Sisters of St. Ann
- Soeurs de la Charité d'Ottawa
- Soeurs de Saint-Joseph de Saint-Hyacinthe
- Soeurs du Sacré-Coeur de Jésus
- St. Mary Catholic Women's League, Beaverlodge, AB
- The Catholic Women's League of Canada

Introduction 3

### Rationale

When confronted with a sudden and unexpected diagnosis with a poor prognosis, we find ourselves in an unfamiliar and even frightening situation. It is a time that can be marked by sadness, confusion, anxiety and fear. When faced with an onslaught of medical appointments, tests, surgeries and treatment plans, we can find ourselves navigating new and challenging terrain. These moments are often marked by numerous practical decisions surrounding care and support for loved ones and ourselves. For example, we find ourselves thinking about decisions regarding finances, wills, power of attorney, advance care directives and funeral plans, to mention but a few.

Medically, we are faced with treatment-related decisions that can change depending on what stage of the illness trajectory we find ourselves in. More often than not, such decisions require moral discernment through the lens of our faith tradition. We believe in the dignity and sacredness of human persons at all stages of life, conception to natural death. At the same time, our faith does not demand that life is to be sustained at all costs.

As Catholics, our faith in Jesus Christ has much to teach us about living well until the end of life. Horizons of Hope: A Toolkit for Catholic Parishes on Palliative Care is designed to help each of us—caregivers, the sick and dying and family members—to find support and concrete assistance.

The Catholic teaching on end of life from a theological and pastoral perspective, combined with medical expertise and a *Compassionate Community* model, are explored in the four modules of this toolkit. It invites us to reflect on the benefits and importance of palliative care.

#### 1. For whom is the program designed?

- Those seeking to learn more about palliative care and Catholic Church teaching on end-of-life;
- Caregivers;
- Persons who have recently been diagnosed with a terminal illness;
- Family members who need resources and guidance as they journey with a loved one who is seriously or terminally ill; and
- Parishioners and pastoral care teams who want to form a *Compassionate Community* program.

## 2. What are the roles and responsibilities of my parish community for the facilitation of this toolkit?

The toolkit is intended for use in parishes. Ideally, community members will gather in small groups to explore palliative care in the context of a prayerful, caring community. Recognition of the various roles and responsibilities that parishioners play will ensure the program's success.

#### Roles and responsibilities:

- **Parish Priest:** As the spiritual leader of the parish community, the parish priest brings his pastoral, sacramental and theological expertise to support and facilitate learning about palliative care. His experience of journeying with the members of the community who are ill, dying and bereaved is invaluable. The priest plays a crucial role in comforting and consoling those who are suffering to help them see how God is with them.
  - As a champion of the Horizons of Hope: A Toolkit for Catholic Parishes on Palliative Care, the parish priest ensures that time and resources are provided to the program. He may facilitate the program himself or call on the appropriate members of a parish pastoral team or volunteers to do so. His presence at some or all of the sessions will witness to the importance of palliative care in our time.
- **Facilitator:** If the parish priest wishes, he may ask a staff person or a volunteer to cofacilitate or facilitate the Parish Palliative Care program.
- **Parish Pastoral Care Team:** Many parishes have teams that accompany and provide spiritual support to shut-ins, palliative care patients and the elderly. These teams are an invaluable resource to the community and can be helpful in delivering this program.

- **Parish Volunteers:** It is well known that dedicated volunteers are essential to parish life. Very often, the pastoral care team is comprised mainly of volunteers. They play a vital role in ensuring the excellent delivery of the toolkit. Functions may include:
  - o serving as facilitators of the programs,
  - o providing hospitality and setting up a welcoming environment,
  - o offering technological assistance especially if programs are delivered online,
  - o providing one-on-one support to parishioners who are grieving or caring for a loved one, and
  - o promoting and communicating about the program to fellow parishioners and family members.
- Parish Community: Participants in the program will most often be members of the parish community. Some will be interested in it because they want to know more about palliative care, and some will come because they are journeying with someone who is ill or has recently died. They may come with questions about what our faith teaches about end-of life issues. Others will participate because they want to know if the decisions they have made about the care of a loved one were the 'right' decisions.
  - Hospitality is an essential part of every gathering. It helps people to feel welcomed! Members of the parish community can support the facilitator by volunteering to set up the meeting space and arrange for coffee, tea, water and snacks.
- Extended Community: There are many resources available to us within our parishes, neighbourhoods, towns and cities. Perhaps a parishioner is a palliative care doctor or a nurse who could help facilitate the sessions. Many agencies provide resources to assist those who are seriously or terminally ill. An excellent source for finding regional resources across Canada is the website <a href="https://documents.com/211.ca">211.ca</a>. Often the parish priest and other leaders in the parish community have a wider network of contacts and supports to help direct you to partners in the community. If there is a local hospice in your community consider inviting a staff member to your sessions.

## 3. What are the components of the Horizons of Hope: A Toolkit for Catholic Parishes on Palliative Care?

- Introduction
- Facilitator's Guide
- Four Modules
- Videos (embedded)
- Reflection Sheets Appendices
- Resource Lists Appendices
- Links to external resources

The toolkit creates opportunities for learning and reflection on palliative care. Each Module provides participants with opportunities to reflect on the proclamation of a Gospel narrative and hear presentations by theological and medical experts. Participants can engage in meaningful reflection and conversation to understand the experience of dying and the end of life.

#### 4. What do I, as a facilitator, need to know about palliative care?

• Horizons of Hope: A Toolkit for Catholic Parishes on Palliative Care is organized so it can be delivered with ease. The instructions and content are embedded within the kit. While expertise is not necessary, experience facilitating groups, using the required technology, and having experienced the palliative care journey will be helpful.

#### 5. What are some key things to know about how adults learn?

Adults choose learning opportunities based on their own needs. For example, a parishioner may be interested in the topic of palliative care because:

- A loved one was recently diagnosed with a chronic or life-threatening illness;
- Caregivers and family members may wonder if they made good decisions regarding the care of a person who has recently died;
- Caregivers and family members are grieving the death of a loved one and are seeking a supportive community that they can learn with;
- They want to understand how palliative care is different from euthanasia and assisted suicide, which in Canada is called Medical Assistance in Dying (MAiD);
- They want to understand the Church's teaching on end-of-life care questions;
- They are trying to discern their gifts to accompany, care for and support caregivers and the person who is ill;
- They simply want to learn more about palliative care.

Adults have particular learning needs:

- Adults require time for reflection and discussion on what they are learning;
- Adults need opportunities to ask questions, challenge new ideas and integrate learning;
- Adults want their ideas and opinions to be validated;
- Adults appreciate having resources to extend learning beyond the sessions.

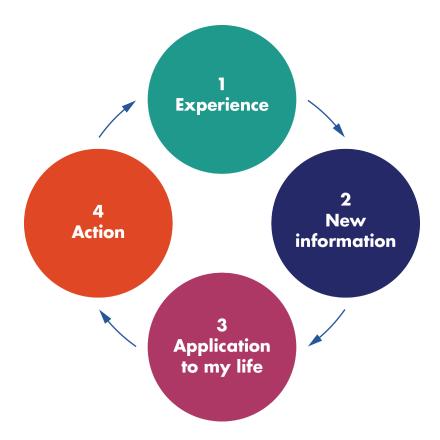
#### 6. What is the process for delivering each Module?

Horizons of Hope: A Toolkit for Catholic Parishes on Palliative Care consists of four Modules:

- Module 1 Understanding the Human Experience of Dying and Death
- Module 2 Discerning and Making Decisions at the End of Life
- Module 3 Accompanying those at the End of Life
- Module 4 Supporting and Integrating within the Wider Community

Each Module will be delivered by following experience-based learning cycle:

#### **Adult Learning Process**



#### **Movement one: Experience**

"Learning is the process whereby knowledge is created through the transformation of experience."

Adult learners seek answers to questions that are particularly relevant to their lives. They want to know if their experience and what they know resonates with current thinking on a subject. The adult learner is self-directed, so learning begins by examining their experience as a way to identify the questions they have. This can come about by having participants share anecdotes on a particular experience as it relates to the topic. We may also hear the experiences from other sources that might speak to our own.

In the *Experience* section of the toolkit, we begin by proclaiming a Gospel story that is related the theme of the Module. Participants then have an opportunity to reflect and consider how the Scripture passage resonates with their personal experience of illness and death.

#### **Movement two: New information**

The participants' experience is broadened through new insights offered in expert-specific video content, which helps to inform and expand the participants' understanding of the theme.

Theological and ethical content is provided by video to address the Christian perspective on illness, dying and death. In a particular way, it provides information on the moral teaching of the Catholic Church as it relates to the benefits of the palliative care journey, the withdrawal or withholding of treatment and nutrition, and the response to suffering. An emphasis is placed on the importance of spiritual discernment and accompaniment when making decisions related to medical and end-of-life care.

Medical information is provided by video and addresses specific clinical factors related to suffering, death and dying. This includes a thorough explanation of the medical benefits of palliative care, treatment options and pain management at the end of life.

<sup>1</sup> Kolb, David, *Experiential Learning: Experience as the Source of Learning and Development*, Prentice Hall. 1984, p. 38.

#### Movement three: Application to my life

Having considered the theme through the lens of our experience and the new information provided, we ask ourselves questions such as:

- How does the new information help me to understand my experience?
- In what aspects of my own life will this new information be helpful?
- How will the new information, as it relates to my experience, assist me going forward?

#### **Movement four: Action**

As a result of reflecting on our experience, new information and how it applies in our lives, we are ready to consider actions or steps we can take as we go forward. The key question here is:

• What concrete actions can I take in my personal life and my community when I am faced with end-of-life issues?

An Action Appendix with take-home resources such as Q & A guides, links to helpful websites and suggestions for next steps is included in each of the four Modules. These can be emailed to participants or made available in print format. Review the contents of the Action Appendix with participants before the end of the session.

#### 7. What can I do to prepare for each Module?

It is important that you:

- View the training webinar available on the CCCB website (cccb.ca). The medical and theological experts who developed the program will guide you through the Modules and their content.
- Read and review the Facilitator's Guide and become familiar with the learning process and the content of each Module.
- Consult with your parish priest about the involvement of nurses, doctors or hospice staff who are parishioners and might wish to assist with the delivery of the program.
- See yourself as one who is guiding the process to promote learning together. The idea of being the "guide on the side" instead of the "sage on the stage" illustrates this role.

#### 8. What preparation is required immediately before the sessions begin?

- Work with your parish pastor to advertise the program and invite parishioners to register for it. See suggestions for bulletin inserts in **Appendix 3**.
- There is no minimum or maximum number of participants required to offer a successful program. However, the number of participants will determine the requirements for setting up, hospitality and the number of volunteers you will want to have on hand.
- Ensure that the technical requirements for viewing the videos are set up and cued before the session begins.
- Videos can be accessed in the following ways:
  - Stream them directly from the CCCB website (cccb.ca), where the videos are embedded, or from the CCCB YouTube channel (www.youtube.com/ CCCBCECC); or
  - Download the video files from the CCCB website and save them to your computer. This option is suitable for unstable internet connections.

- Decide how to make documents from the appendices available. Possible options include:
  - Using a projector screen and PowerPoint presentation;
  - Viewing them directly on a personal computer—attaching a large monitor is recommended to improve visibility;
  - o Posting or writing them on a whiteboard;
  - Sending an email to participants with the links to the required documents in advance of each session; or
  - o As a last resort, copying and printing the resources.

All participants must have access to the take-home appendices for each Module.

#### 9. What materials will be helpful?

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



Holy Bible (New Revised Standard Version)



Flip chart/whiteboard/chalkboard



Laptop



Masking tape



Projector



Markers



Speakers



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



Screen



Pencils or pens



Paper for taking notes



Items needed for hospitality: coffee pot/teapot, coffee, tea, juice, cups, glasses, napkins, serving plates, fruit, cheese and crackers, cookies, etc.

#### 10. How are the sessions scheduled?

#### a) Organization of sessions

- Given the sensitive nature of the topic, it is recommended that Modules be scheduled one at a time: for example, four Tuesday afternoons or evenings.
- It is possible to adapt this approach based on your community's needs. For example, hold two one-day sessions where two Modules are completed each day: one in the morning one in the afternoon.

#### b) Timing

- Each session is designed to last for 120 minutes. The facilitator is the timekeeper.
- This timing may vary depending on the number of participants and the delivery model you choose.
- For example:
- If you have a small number of participants, you may decide to facilitate the sessions online. This may mean that you will not need 120 minutes to complete each Module.
- o If you have a small number of participants in person at the parish, less time may be required to complete each Module.
- o If you have a large group, you will likely need the entire 120 minutes.
- o Allow flexibility for extended conversations, questions and answers.

**IMPORTANT NOTE:** Communicate the start and end times for each session to participants and volunteers. Respect the time allotted to avoid going overtime.

#### Sample Module Timing Chart — 120 minutes

Module	Time
Experience	Total time 25 minutes
1. Proclamation of the Word of God	2 minutes
2. Guided Personal Reflection	10 minutes
3. Table Conversations	10 minutes
4. Large Group Focus	3 minutes
New Information and Application — Theological and Ethical	Total time 45 minutes
1. Video	5 minutes
2. Guided Personal Reflection	15 minutes
3. Table Conversations	20 minutes
4. Large Group Focus	5 minutes
Break	10 minutes
New Information and Application — Medical	Total time 45 minutes
1. Video	5 minutes
2. Guided Personal Reflection	15 minutes
3. Table Conversations	20 minutes
4. Large Group Focus	5 minutes
Action — Take-Home Resource	Total time 5 minutes
1. Overview of Take-Home Resource	

#### 1. Why are norms for conversation helpful?

Throughout the Module, there will be many opportunities for table discussions. The sensitive nature of the topic of end of life requires that facilitators be attentive to the possibility that some conversations may become emotionally charged and complex. At the beginning of each session, it is always helpful to identify, with the participants, some norms or guidelines to help facilitate a healthy conversation space. These may include:

- All participants are allowed to speak in the group; some may choose not to speak. The group must respect the person's decision.
- One person speaks at a time.
- Participants, if they choose, may respond to the speaker in a helpful yet 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 may offer to speak one on one during a break or after the session.

**NOTE:** These norms may be projected on a screen, printed and placed on the tables, posted to the wall or written on a whiteboard. (For a printable copy of the Norms for Conversation see **Appendix I.**)

#### 2. What is the optimal size of discussion groups?

This depends on how many people are participating in the program:

- If only four or five people are registered, there is no need to break into smaller groups. You could break into "pair and share" mode. If there is an odd number of participants, such as five, the facilitator could participate, making three groups of two.
- If the group is larger than five people, break into smaller groups, to a maximum of five people each. Groups of three to a maximum of five people are optimal. Table groups of more than five people can become challenging to manage timewise. Smaller discussion groups will ensure that everyone has an opportunity to speak if they wish.

#### 3. What can I do if the table conversations become difficult?

When speaking with others about complex topics such as palliative care, end of life, decision-making, and so on, emotions can be triggered.

A person may:

- Cry;
- Disagree with or be offended by something another person has said; or
- Dominate the conversation by telling his or her story without letting others speak.

Such moments can be uncomfortable and difficult for people.

#### **Tips**

#### Acknowledge

o Acknowledge the person's feelings – sadness, anger, fear, hurt, etc.

#### Gently take control

- o Guide the conversation by focusing on the topic and the questions.
- o "[Insert name], I understand that this is a difficult topic. I wonder if we could come back to the original topic and find some common ground there."
- Redirect the person who is dominating the conversation by thanking them for their contribution. Then invite another person in the group to offer their comments.
   Say something like "Thank you for your perspective and sharing, [insert name].
   Now let's hear from others in the group."

#### Offer support

- o Invite individuals to speak with the parish priest or the facilitator at the break or another appropriate time.
- o Provide the contact information for the pastor, pastoral animator or pastoral care team leader or a community bereavement organization so that if a person becomes distressed following the session, they will have support.
- The phone number(s) of these support contacts may be shared at the beginning of each Module session.

**NOTE:** Ensure that you have the consent of the person(s) whose phone numbers are shared.

#### • Take a break or move on

o Sometimes the best way to address a difficult situation is to call for a break or move on to the next step in the Module.

#### 4. How do I facilitate this program online?

For many reasons, you may wish to run the program online by using video conferencing or other various online communication platforms. Here are some tips to assist you.

- **Hybrid:** Consider running the program by using a "hybrid" approach. Gather together sometimes online and other times in-person. Taking time for these meaningful conversations face-to-face cannot always be replaced in the virtual context. While at the same time, the convenience of meeting online can widen your audience and participation.
- **Timing:** The allotted time is designed for in-person gatherings. You will likely need to adjust the timings for each step. If possible, the online meeting per course should not last more than 1.5 hours. Fatigue from video calls is an important consideration.
- **Choosing a video platform:** When hosting a virtual meeting, select the platform that works best for you. If you do not have access to paid subscription accounts like Zoom, Webex, Microsoft Teams, some free services, such as Google Meets and Skype, are available. It is best practice to run the meetings through a secure and private site.
- **Before the meeting:** Communicate well with your participants and ensure to provide a link with clear instructions on how to join the video call. Depending on the video platform service you are using, participants may be required to create an account. If this is the case, provide instructions on how to do so successfully.
- **Technical support:** Coordinating both the program facilitation and the technical aspects of a meeting is challenging. Consider inviting someone to be responsible for "hosting" the session from a technical point of view. This person would be accountable for "screen sharing" of the video content, helping participants if they have technical issues, organizing small group breakout rooms, etc. This will allow you, the facilitator, to be present with the participants and to the program details.
- **Test your tech:** Ensure your internet connection is excellent cable hook-ups (ethernet cables) are best. Test your camera, sound, microphone. Make sure participants can see your face. Look often at the camera when speaking to connect with your audience.

#### 5. Suggested guidelines for online participants:

See **Appendix 2** for a copy of these guidelines.

- Sign in to the meeting 15 minutes early. You will be placed in a Waiting Room, and the host will let you into the meeting at the appointed time.
- You will require a desktop, tablet, or phone with an enabled camera (embedded or external), a microphone and speakers. If possible, use a headset or earbuds.
- The facilitator will give you instructions regarding unmuting at the appropriate times.
- If you have questions during the event, please use the in-meeting chat.

#### Please remember to:

- Situate yourself in a room where there will be minimal distractions.
- Optimize your meeting space for video. Lighting should be bright, even and come from in front of you.
- Your background can be interesting but not distracting—you may consider using the Virtual Backgrounds feature.
- Remove any images in your background that are personal and important for privacy.

#### Please do not:

- Share the link to the meeting with others. Only those registered and approved may participate.
- Take screenshots. Privacy and consent are important in this case. It is not appropriate to take screenshots of participants, nor is it appropriate to share these on the internet with others.
- Failure to comply with the above may result in removal from the session.

# Appendices

# Appendix 1

#### Norms for conversation

- All participants are allowed to speak in the group; some may choose not to speak. The group must respect the person's decision.
- One person speaks at a time.
- Participants, if they choose, may respond to the speaker in a helpful yet 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 may offer to speak one-on-one during a break or after the session.

# Appendix 2

#### Suggested guidelines for online participants:

- Sign in to the meeting 15 minutes early. You will be placed in a Waiting Room, and the host will let you into the meeting at the appointed time.
- You will require a desktop, tablet, or phone with an enabled camera (embedded or external), a microphone and speakers. If possible, use a headset or earbuds.
- The facilitator will give you instructions regarding unmuting at the appropriate times.
- If you have questions during the event, please use the in-meeting chat.

#### Please remember to:

- Situate yourself in a room where there will be minimal distractions.
- Optimize your meeting space for video. Lighting should be bright, even and come from in front of you.
- Your background can be interesting but not distracting—you may consider using the Virtual Backgrounds feature.
- Remove any images in your background that are personal and important for privacy.

#### Please do not:

- Share the link to the meeting with others. Only those registered and approved may participate.
- Take screenshots. Privacy and consent are important in this case. It is not appropriate to take screenshots of participants, nor is it appropriate to share these on the internet with others.
- Failure to comply with the above may result in removal from the session.

# Appendix 3

#### Sample bulletin notice

#### Do you want to know more about palliative care?

We (Parish Priest, Pastoral Care Team, CWL, Parish Council etc.) invite you to participate in learning sessions on Horizons of Hope: A Toolkit for Catholic Parishes on Palliative Care. Our faith in Jesus Christ has much to teach us about living well until the end of life. The program will help parishioners, caregivers, and family members facing a terminal illness to learn more about palliative care. Throughout four modules, the learning and discussion sessions address themes such as understanding the dying process, discernment and decision-making at the end of life, accompaniment and the importance of building Compassionate Communities.

The four-module program will take place in the Parish Hall. (Insert actual dates).

- Module 1: January 5th from 7:00 pm to 9:00 pm
- Module 2: January 12th from 7:00 pm to 9:00 pm
- Module 3: January 19th from 7:00 pm to 9:00 pm
- Module 4: January 26th from 7:00 pm to 9:00 pm

To register call or emai	l (the parish	office, pastor,	facilitator, o	etc.) or register	online
at www.					

NOTES:	

NOTES:		

NOTES:		

NOTES:		

Horizons of Hope: A Toolkit for Catholic Parishes on Palliative Care: Facilitator's Guide © Joint Ad Hoc Committee on Palliative Care, 2021. Some rights reserved.

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

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

Code: 185-177

ISBN: 978-0-88997-925-3

Legal Deposit: Library and Archives Canada



#### cccb.ca





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