

TALKING ABOUT END-OF-LIFE: YOUR GUIDE TO STARTING THE CONVERSATION.

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Your guide to starting the conversation about end-of-life.



Please read the following information before getting started.

What is the 'Talking About End-of-Life' conversation guide?

This step-by-step conversation guide is for anyone who is interested in starting the conversation of dying and death.

Prior to using this guide, it is important to speak with a health care professional about your current health status, and the options available to you regarding your care. Once you have a better understanding of your health and prognosis, you may want to talk to others about your feelings, values, and expectations regarding end-of-life. This conversation guide can help you reflect on what you may want to discuss with anyone you choose, and can provide tips on how to start the conversation about dying and death. Please note that this guide is not a replacement for medical advice from a health care professional and should be used alongside appropriate supportive resources.

Having a conversation about end-of-life may feel overwhelming. It is important to take the time to reflect on your own readiness to have this talk. We recommend that you take your time going through this guide, as it is not intended to be completed in one sitting. If ever you feel overwhelmed throughout this process, reach out to your health care provider to request supportive resources that are tailored to your needs.

Why is this guide useful?

Death is often considered to be a 'taboo' topic of discussion. Many people have expressed feeling uncomfortable talking about dying and death, leading them to avoid the subject altogether. Studies have shown that people acknowledge the importance of talking about death, yet the majority will still put off the conversation out of fear and anxiety about this topic. The research has shown that putting off the discussion about death can cause significant distress for both the individual who is dying and for their surrounding support system. As living beings, death is something that we all have in common and that we will all experience. While death is a guaranteed part of life, we acknowledge that everyone has their own experience, and that timing and readiness to discuss the topic is unique to each individual.

Our goal is to help facilitate an open and honest conversation about death with the use of this document, "Talking About End-of-Life: Your Guide to Starting the Conversation". Having a conversation about dying and death can help you identify your wishes for your own end-of-life care, and can help remove the ambiguity that occurs when the topic of death is avoided. Having a conversation about end-of-life allows for the dying person and those around them to develop a mutual understanding. While death is inevitable for all living beings, we acknowledge that death is still a complex and difficult topic. This conversation guide is not an exhaustive resource, but rather it is a tool that can be used in conjunction with trained professionals to help guide you into having these conversations about dying and death at your own pace and on your own time.

Next: Introduction to the Guide

Your guide to starting the conversation about end-of-life.

We will all have to face dying and death at some point in our lives, but for many people, this topic is put off until the very end. We want to give you the tools to break through the stigma of talking about death and gain control over your experience. Talking about dying and death can be scary, and our goal is to help you have the conversation at your own pace and give you the chance to explore what end-of-life means to you.

In this step-by-step guide, we will discuss death anxiety, coping strategies, and options for end-of-life care. We will also provide acknowledgement to cultural differences within the experience of dying.

We will walk you through these end-of-life conversations step-by-step. And remember, take your time; not everything needs to be said all at once!



Download and save this interactive document on your computer to start filling it out. Your answers will be saved, and can be edited and shared at any time. You can also print this document to get started!

With this guide, I hope to...

Next: It's normal to feel scared.

It's normal to feel scared.

What is death anxiety?

Death anxiety is a negative feeling that arises from the thought of you no longer existing.

Death can be a heavy word. When you first start talking about dying and death, it is normal to feel frustration or fear. Anxiety surrounding the topic of death can make it difficult for you to have a conversation about end-of-life. Some people may grieve not only their death, but the years they will lose and the experiences they may never get to have.

It is important that you take the time to explore your own views on dying and death, and reflect on what it is that you may find intimidating.

When you think about dying and death, what thoughts come to mind?

What makes you anxious about death or the conversation of death? (select all that apply)

- Leaving others behind
- The emotional impact on others
- Never getting to experience something you really wanted to do
- Experiencing pain (physical and/or emotional)
- Other:

What motivates you to want to have this conversation?

Example: a sense of relief, making sure your wishes are understood, to start planning your legacy

What are some barriers preventing you from having this conversation?

Example: discussing the unknown, vulnerability, concerns about finances

Have you ever spoken to anyone about dying and death? How did the conversation make you feel?

Coping with Death Anxiety

When reflecting on your answers, was there something that stood out for you? Remember, it is normal to have uncomfortable feelings when talking about dying and death. There are various strategies that can help support you as you process these feelings. Let's take a moment to think about how you deal with stress in your life.

What are some coping strategies that you currently use when you are faced with a challenging situation?

Example: going for a walk, talking with friends, having a cup of tea

Other coping strategies can be found at
Brain Tumour Foundation of Canada's website: www.braintumour.ca



Strategies for Coping with Death Anxiety

- **Creating Meaning**
Clarifying your core values will allow you to be aware of death without constantly fearing it.
- **Setting Priorities**
For example, prioritizing the things you have always wanted to do instead of pushing them aside.
- **Dignity Therapy**
Helps to promote self-expression, connection with loved ones, a sense of purpose and continuity, and a strengthened identity by documenting important memories and messages.
- **Generativity**
Leaving behind a positive legacy for future generations (i.e. volunteering, teaching, being a mentor).

How can you use the above strategies to cope with with death anxiety?

Next: What is important to you?

What is important to you?

Reflecting on what is important to you can help you clarify your values and guide your goals when thinking about end-of-life care. Sharing your thoughts and feelings with others will also ensure they have a better understanding of your concerns, wishes, and beliefs. Your answers to these questions can change over time and that's okay.

What is important to you in terms of your health? (select all that apply)

- Being able to do things on my own
- Spending time with my family and friends
- Being able to express myself and be understood
- Being able to do the things I love (i.e. sports, reading, art)
- Maintaining my dignity
- Other:

What would make you question your quality of life? (select all that apply)

- Not being able to communicate
- Being in pain
- Not being able to live independently
- Changes in behaviour and thinking (i.e. memory, learning, personality, concentration)
- Weakness and paralysis
- Other:

How much medical treatment would be appropriate for you in end-of-life?

Example: extending your life as much as possible with intensive treatment, avoiding intensive treatment that would impair quality of life

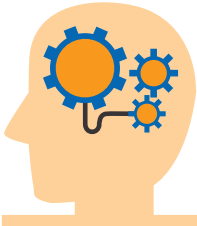
What makes life meaningful to you?

Example: family, travelling, your faith, being active

What are your expectations regarding the presence of spirituality and/or culture in your end-of-life experience?

Example: traditional foods or medicines, religious ceremonies, presence of elders

Next: End-of-Life Learning



End-of-Life Learning

You may hear many terms being used when talking about end-of-life. Learn what they mean here:

End-of-life care: This is exactly how it sounds - the care provided at the end of a person's life. It is for you to decide what kind of care you want and what the focus or priority should be.

Palliative Care: Many people fear the words "palliative care", but these words are not as scary as you think. Palliative care is guided by your goals and wishes, and can be concurrent with other curative treatments. The aim of palliative care is to provide comfort and support, maintain dignity, and optimize your quality of life while you continue to live with a brain tumour. Palliative care can be initiated at any age. Please see the [Additional Resources](#) section at the end of this guide for more information on palliative care and palliative care associations in your province or territory.

Hospice: Hospice is a specific type of palliative care provided at the end-of-life that focuses on promoting comfort and prioritizing quality of life, without any curative or aggressive treatments. The goals are similar to palliative care where comfort and dignity are optimized. This care can be provided at home, in a hospice centre, in long-term care facilities, or in the hospital.

Advanced Medical Directives: Advanced Medical Directives are a legal document that allows you to write down your preferences about end-of-life ahead of time. You can specify your preferences about treatments, CPR, level of care, and the identification of an individual to make medical decisions on your behalf when you are no longer able to do so. This document will be kept in your file and will be accessed when needed. Please see the [Additional Resources](#) section at the end of this guide for more information on Advanced Medical Directives.

Medical Assistance in Dying (MAID): There are two types of Medical Assistance in Dying available to Canadians; self-administered and clinician-administered. Both cases involve the administration of medication at an individual's own request to end their suffering and bring about death. There are specific criteria that must be met for someone to be eligible for this request. Please speak with your health care provider or see the [Additional Resources](#) section at the end of this guide for more information on MAID and applicable legislation.

Contact information for end-of-life services throughout Canada by province and territory:
<https://www.canada.ca/en/health-canada/services/provincial-territorial-contact-information-links-end-life-care.html#a7>

Please speak to a member of your health care team for more information about services in your area.

Next: In my end-of-life, I would want...

In my end-of-life, I would want...

Thinking about end-of-life options can feel overwhelming, but it doesn't always need to be; reflecting on different options that will further support you and those you care about is a good place to start. Remember, just talking about end-of-life options can help ease your fears and anxieties.

Who would you like to keep you company during end-of-life?

What song or type of music would you like to listen to during end-of-life?

If you had one month to live, what would be important for you to do?

What would you like your funeral or end-of-life celebration to look like?

Example: traditional structured service, casual gathering, sharing stories

In my end-of-life, it is important to think about...

- Donating my organs
- Donating my body to medical science
- Burial or cremation options
- My preferred place of death (i.e. home, hospice, hospital, other)



This is just to get you thinking. However, your important preferences, also called 'advanced directives', should be legally documented. Please speak to a member of your health care team about your options.

Next: It's time to plan your talk!

It's time to plan your talk!

Now that you've reflected on what is important to you, it is time to have a conversation with those who are important to you. The thought of this conversation can feel intimidating at first, but when you take the time to plan the process, you can begin to feel a sense of relief knowing that your wishes have been heard.

Who would you like to start the conversation with?

Where would you feel comfortable having this conversation?

Example: in the living room, on a walk, at your place of worship, at a coffee shop

When do you want to have this conversation?

Remember: there is no perfect conversation and not everything needs to be said all at once. Take your time and do what feels right to you! Here are some ideas that can help you start the conversation.

Tips

- Choose an environment where you feel comfortable (i.e. kitchen, coffee shop, on a walk).
- Be prepared for emotions: laughter and tears!
- Remove distractions.
- Have few important points written down and reflect on what you would like to say.

*Friendly Reminder:
Going for a walk or sitting next to each other can feel less intimidating and can help reduce anxiety while having these conversations.*

Talking Points

- Are there important events coming up that you are hoping to be present for?
- What do you need to discuss to help you feel more prepared?
- How do you want others to be involved your care?
- Is there a particular treatment or medical intervention that you would NOT want? (i.e. feeding tube, breathing machine, CPR).
- If your condition were to progressively get worse, what would you like others to know?

Conversation Starters

- "Hey, I have something I want to talk to you about."
- "I would like your help to plan and to make sure that my wishes are respected."
- "I heard that talking about end-of-life can help reduce anxiety."
- "Even though I feel okay right now, do you mind if we take some time to talk about what life may be like when I am no longer here?"

Next: Soaking it all in...

Soaking it all in...

It takes a lot of courage to initiate this conversation. Take some time to reflect on how you feel. Gather your thoughts on what went well and what you may want to talk about next time. Don't forget, the more you talk about dying and death, the easier it gets for you and those you care about.

How did you feel after having this conversation?

What are some of the topics that you talked about?

Is there something that was left unsaid?

What would you like to prioritize in your next conversation?



What's Next?

What's Next?

It's important to share your feelings and wishes with those around you. You can always refer back to this Conversation Guide to help. Remember: having these ongoing discussions with your health care team ensures that your wishes are known and respected.

Other planning documents:

- Living Will
- Power of Attorney
- Advanced Medical Directives
- Other:

Additional Resources:

Death Doulas:

- <https://endoflifedoulaassociation.org/>

Advance Care Planning Kit:

- <https://www.dyingwithdignity.ca/education-resources/advance-care-planning-kit/>

Living Will:

- <https://www.braintumour.ca/ways-to-give/legacy-giving>

Advanced Illness, Palliative Care, and Grief:

- https://www.virtualhospice.ca/en_US/Main+Site+Navigation/Home.aspx

Medical Assistance in Dying (MAID):

- <https://www.canada.ca/en/health-canada/services/medical-assistance-dying.html>



Please note this Conversation Guide was designed by McGill Nursing Students in collaboration with Brain Tumour Foundation of Canada. Although we strive to ensure the products are accurate, ethical, and credible, please let us know if we have inadvertently missed any details you think could be important.

For more information, please visit:

www.braintumour.ca | 1-800-265-5106 |     

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