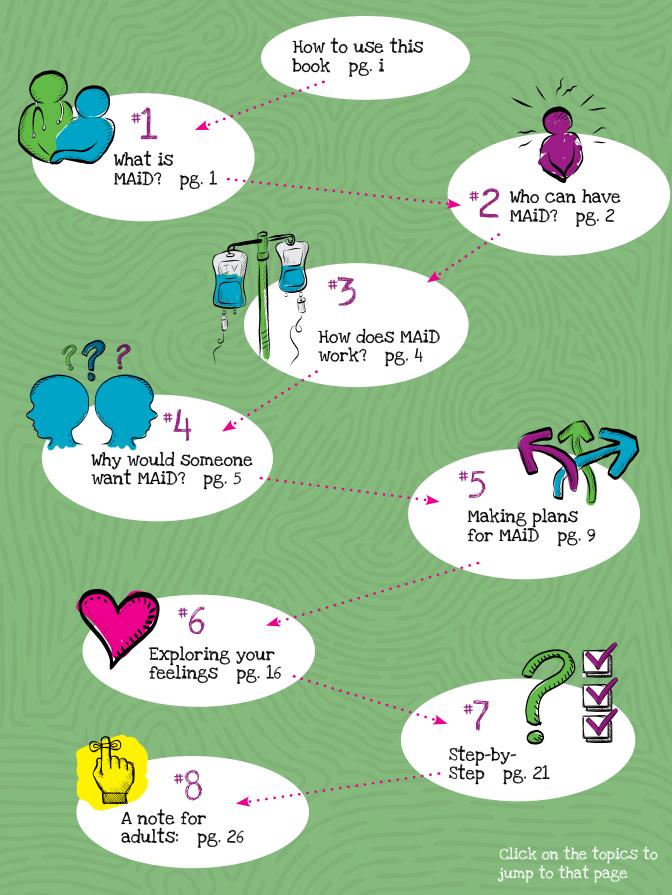


Medical Assistance in Dying (MAiD) Activity Book

Welcome! These activities will help you think about Medical Assistance in Dying by Someone in your life.

Start Here!



Adults – please read "Information for adults" on page 24

How you can use this book

Instructions

This book was created for young people, like you, who have someone in their life who may have MAiD. Before you start, check out the "My life, their illness" book. That book talks about the person's illness and how it might be affecting their body and mind, what you might be thinking or feeling, your family and your day-to-day life. Then come back to this book to learn more about MAiD, the questions, thoughts and feelings you might have about it, and ideas for things that might be helpful for you.

Use this book any way you want to! Since we made this book for people dealing with lots of different situations, some parts may feel useful, and others may not. That is okay! You can do, change, or skip any parts you choose. You can:

• Work at your own speed

Skip sections

- O Come back to sections later
- O Do the activities in your own way
- O Save your answers
- ^O Work with a parent or health care provider

You may have lots of different questions, feelings, and ideas as you go through this book. If you can talk about or do the activities in this book with a parent, healthcare provider, counsellor, or another adult who you trust, they can try to help you with hard questions and your feelings.

You might want to do some activities by yourself, or with someone's help but without talking about your feelings. That is okay, too. If there is an adult helping you with some parts of the book, tell them which parts you want help with, and how they can help. You might say:

- "Can we do this part together?"
- "Can you keep me company while I do this part by myself?"
- "I'd like to be alone while I do this part."
- "Can you stay with me while I do this part, but without talking about my feelings?"



what is MAiD?

The term "MAiD" is short for: Medical Assistance in Dying.

The word "medical" means the science of medicine, and "assistance" means help. So MAiD means that medicine is used to help someone with their death. A doctor or nurse practitioner (a nurse with special training) uses medicines to stop the person's body from working. When their body stops working, the person dies.

This is done in a way that does not hurt the person. The medicines help them feel comfortable and peaceful. A person has to ask for MAiD and then go through a bunch of steps before it can happen. The steps are described below in this book.

Who can have MAiD?

If someone wants MAiD, they have to ask for it themselves. No one can ask for someone else to have MAiD. The person asking for MAiD has to fill out a form and then they can meet with two or three members of their health care team (called "MAiD assessors") who will check to make sure that the person has everything that they need to be allowed (or "eligible") to have MAiD. They all have to agree that the person is eligible, or the person will not be able to have MAiD.

> A person can only have MAiD if they are at least 18 years old, and if:



They have a serious illness, disease, or disability that hurts their body or their mind so much that it feels too hard to keep living.



Medicines have not been able to help their body or mind feel better, and



There is no cure; nothing can make the illness or disability go away, even if the person and their health care team have tried everything they could.

The person also has to be able to understand:



their illness or disability, AND

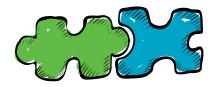


all of the medicines and other treatments, resources, and supports that they could choose, AND



what MAiD is and how it works.

If all of these things are true, a person may be allowed (or "eligible") to have MAiD.



The person having MAiD will get three different medicines. They are usually given in an IV. IV stands for "intra-venous" and means "in the vein." A very small needle is used to place a small plastic straw that goes into a person's vein. Then the needle is taken out and the straw can be used to send medicine straight into a person's body in their blood.

The three medicines work like this:

The first medicine makes the person feel very relaxed and fall asleep. They may yawn or snore or mumble.

How does MAiD work?

The second medicine causes a "coma." A coma looks like sleep but is much deeper than regular sleep. The person will not wake up or be bothered by noise or touch.

3

The third medicine makes the person's lungs stop breathing and then their heart stops beating. Because of the coma, the person does not notice this happening and **it does not hurt**. When their heart and lungs stop working, their body dies. It will not start working again. This often happens in just a few minutes, but sometimes (rarely) it can take hours.



Why would Someone want MAiD?

Most people who ask for MAiD have an illness that will cause their body to die no matter what. They are not choosing to die instead of live.

They are choosing **what** will make their body die, **when** and **where** it will happen, and **who** they spend that time with.



Other people might ask for MAiD if their illness or disability will not cause their body to die, but it causes too much pain or suffering for them to keep living with it,

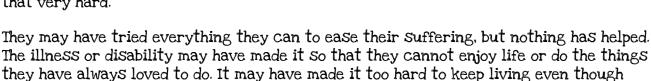
and there is no way to make the illness or disability get better or go away.



Sometimes when a person asks for MAiD, people wonder:

"Why do they want to die?" or "Why would they leave me/us?"

It is natural to have feelings and questions like this. People who ask for MAiD are not choosing MAiD because they want to die and leave their families and friends. They would rather keep living, be healthy, and enjoy more time with the people they care about, but the way they feel because of this illness or disability makes that very hard.



"Is it because of me? Could I have made things better?"

These are natural questions and worries to have when we wish we could change what is happening. No one can cause another person to have so much pain and suffering that they choose MAID. No one has the power to stop another person's suffering or cure their illness, no matter how badly they want to. Health care

providers and researchers around the world are working to find cures and to help people in every way that they can, but some things still cannot be cured, and some pain and suffering cannot be taken away. This is no one's fault.

"Could I change their mind?"

they care a lot about the people in their lives.

As much as other people may want to change their mind, the person who is choosing MAiD probably wishes just as strongly that they could change their illness or condition and how it is affecting their life. When someone decides to ask for MAiD, it is usually after thinking very carefully and having very hard feelings for a long time. They may feel that nothing will change their mind because there is nothing that can help their body or their suffering get better.



What if I (or someone else) don't want them to have MAiD?

MAID is a personal choice. That means that no one can decide for another person. Each person has to decide for themselves.

It is natural for people to have different ideas or feelings about MAiD, just like everyone has their own thoughts and feelings about the illness or disability and about death. Even people within the same family can feel very differently. Sometimes these differences feel okay, but other times it can be very hard. People may argue or feel hurt or upset.

It is okay to feel angry, sad, confused, or upset about the person dying, or about them choosing MAID. Being upset about what is happening, or disagreeing with their choice, does not mean that you do not love or care about the person. You might even have different thoughts and feelings at the same time. You can be upset about it at the same time that you understand or want to support them.

It can be very hard to hear other people disagree or even argue about MAiD. Sometimes people feel like they need to choose whose "side" they're on, or they feel bad about agreeing with one person and not another. They may feel stuck in the middle or wish they could fix it, even though no one can make another person change their mind or their feelings.

If you feel like this, try talking with someone you trust about what is happening and how you're feeling. They may be able to help you think of something you can say when it happens, like, "I'd rather not talk about this right now," or "please don't talk about that in front of me."



Activity:

Draw or write about your ideas and feelings about the person in your life who is choosing MAiD. You can share this sheet with someone in your family or a health care team member who can help you with your questions, ideas, and feelings. You can always come back to this page and build another sheet.

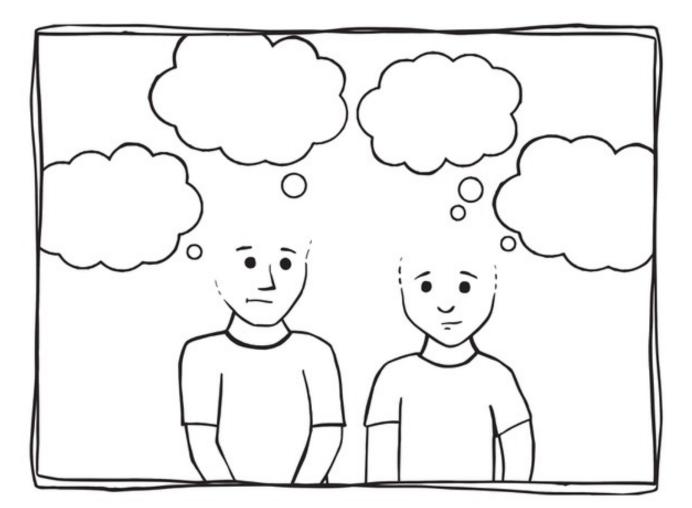
Have you ever wondered why the person in your life is asking about MAiD?

Do you have ideas about why they might want MAiD?

What questions do you have about the person's choices or wishes?

What other questions do you have?

Using blank paper or the picture below, decorate it to look like you and the person. Write or draw what you think they think or feel about choosing MAiD in the space around them. Then, write or draw what you think, feel, and Wonder about in the space around you.





Making plans for MAiD

Who decides when and where the person will have MAiD?

After a person has been told that they can have MAiD, they will talk with the doctor or nurse practitioner who will be their MAID provider. The provider, along with other the health care team members, will help give the person the medicines that make their body stop working.



The providers will ask the person about where and when they would like that to happen (like at a hospital, in hospice, or at home), and they will make a plan together. If the person's disease will not make their body stop working very soon, the person may need to wait 3 months to meet with health care team again to make sure they still want to choose MAID. If they still do, then they can choose a date together.

What else can the person decide about MAiD?



Most of the time, people can decide where they want to be, who they would like to have with them, and choose things like music they would like to listen to and pictures they would like around them.

They might also decide they want prayers, a ceremony, or other things that are special to them. They can talk with the MAiD provider about their wishes and choices.

It can be a very hard decision to make, and they can change their mind ANY TIME if they decide they do not want MAiD anymore, even right before they get the medicine.

What choices do I have?

Some choices will be made by the person who will be having MAID, like where and when it will happen, and whether they want other people to be there.

Parents or caregivers might make some choices, like when or where to spend time with the person. Other choices might only be possible in some situations and not others, like if the person is in a hospital or hospice with rules about visiting.





There are other important choices for you to make. Ask a parent or caregiver to look at this list with you to see what choices you can make. It is okay to choose something different from other people in your family, and it is okay to change your mind. The most important thing is to do what feels the most comfortable, safe, and "right" for you.

Choices you could make about when the person is having MAiD: Think about what different choices you have and which ones might feel best for you.

Think about what different choices you have and which ones might feel best for you. First, ask a parent or caregiver to go through the list and cross out anything that is not possible in your situation. Then you can look at the rest of the list together and choose the things you would like to do or think about. There are no right or wrong choices, and you can change your mind about your choices anytime. If you have other ideas about things that you would like to do that are not on this list, share those ideas with your parent or caregiver to see if they would be possible.

Would you like to spend time with them before they have MAiD?

⊘yes ⊘No

Where would you like to be when the person is having MAiD?

- ${\mathcal O}$ in the room with the person
- ${\ensuremath{\mathcal{O}}}$ nearby but not in the room (another room in the hospital/hospice/home)
- O somewhere else that feels familiar (school, camp, a friend or family member's home)

If you are going visit them, would you like to bring something:

- It to hold onto to help you feel comfortable, like a special blanket, jewellery, photo, or toy?
- It to do to help you feel comfortable or to pass the time, like a book to read, crayons and a colouring book, or music to listen to?
- to give to the person?
- O Other: _____







MAID Activity Book

If you are not going to be there:

• would you like to have a phone or video call so that you can see or say something to the person before they die?

- would you like to send them something to let them know you are thinking of them, or that you are with them in a different way?
- I how would you want to find out that the person had died? Would you like someone to call or send a message, or would you prefer to wait until they are picking you up to go home.

Wherever you choose to be:

I how long would you like to stay there before you go home?

Would you like to have someone or something with you for company or comfort?

♀ Yes ♀ No ♀ Not sure right now

Would you like to see the person's body after they have died?

○ Yes ○ No ○ Not sure right now

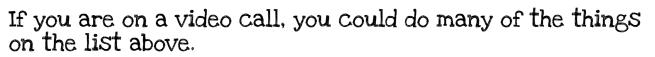




If you are there in person, would you like to:

I read them a message, poem, or short story?

- whisper something to them?
- I hold their hand?
- O give them something special?
- I think or talk about time you spent together?
- give them a kiss goodbye (in person or by phone or video)?
- O say a prayer or make a wish?



Would	you	like	to	have	Someone	take	а
photo	for ;	you?					
Q Yes	QNo						

Is there anything else you would like to do?"





Ideas about things you could do, bring, or send to the person



Is there something that you would like to do, or that you think might make the person feel more comfortable when they are having MAiD?

These are things that you could bring if you were going to be with them, or things that you could send to them so that you could be with them in a different way.

Here are some ideas:



Choosing a song or music to be played for the person



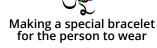
Drawing a picture to be placed near the person



Writing or recording a message for them to hear (even if the person is not awake)



Choosing a blanket, pillow, stuffed animal, or piece of clothing to put near the person





Telling or reading the person a story in-person, over the phone, or on a recording



Choosing a candle, flowers, incense, or aromatherapy oils that the person might like to see or smell



Drawing your "hug" on a piece of fabric

Circle the ideas you would like to try.

Do you have other ideas?



When someone is asking for MAiD, you might have lots of strong feelings. Having different feelings at the same time can be confusing and can make it even harder to know how to help yourself feel better.

Sometimes people say, "I feel this thing that's hard but I don't know what it is or how to explain it." That is okay. You don't have to know what you're feeling or thinking about, or what you want to talk about. Sometimes it helps to tell someone, "I'm full of feelings but I don't know what they are or what to say."

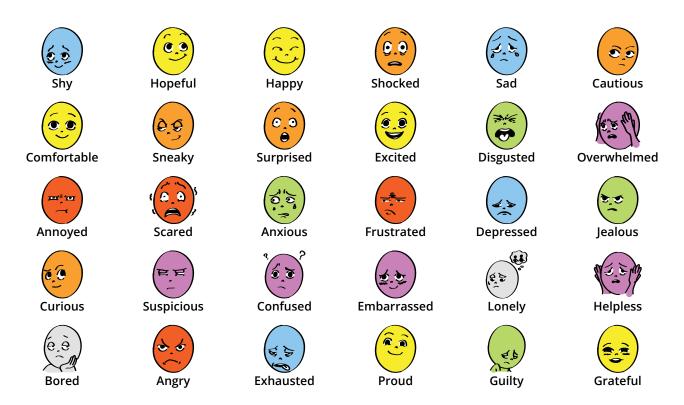
Activity:

Choose feelings that you have had before and write or draw what those feelings were about. There may be some feelings that you've had but you don't know when or why. That's okay. Circle these feelings, write or draw what they felt like, or put a question mark beside them.

Making this list can help you figure out what you're feeling, and what your feelings are about. Then you can use this list to talk with other people in your life about how you feel and what you need.

Feelings

Here is a list of some feelings. You might have some and not others. You may feel some of them a lot, a little, or not at all. They may change after a short or a longer time. Some of these emotions feel good inside, and others are hard.



Feeling faces adapted from Eaton Russell, C. (2019) *Staying Connected: Family Communication When a Sick Child has Trouble Speaking,* with permission from BrainChild.

I feel	About	It might help to
Worried	What will happen next	Find out more about the person's plans
Jealous	People who don't have anyone in their life who is dying	Spend time with someone you can talk to, or who knows what you're going through
~~~~~		
~~~~~~		

Activity:

Build a **question and answer sheet** that you can share with anyone you choose. Your parent or caregiver can help you answer these questions, or they can help you email (or print and send) the sheet to someone who might be able to help you find the answers you need. If you have more questions, you can always come back to this page and build another sheet

Build your question and answer sheet

Choose the questions you want to ask from the list below.



Why does this person want MAiD?
How do they feel about having MAiD?
What else has been tried to make the person's suffering or their life better?
When and where do they want to have MAiD?
What else have they planned? (for example, who will be there and what will happen?)
Can I spend time with them before they have MAiD (in person or another way)?
Can I be there when they are having MAiD (in person or another way)?
Can I see them/their body after MAiD has happened?
Is there something I can make, send, or do to help them feel cared for, or to let them know that I'm thinking about them?

Add your own questions here:



Step-by-Step

Asking for MAiD

First, a person who has a serious illness, disease, or disability asks if they can have MAiD.

Deciding if a person can have MAiD

Next, two or three "MAiD assessors" meet with the person. These are members of the person's health care team who carefully decide if they are "eligible" to have MAiD. ("Eligible" means that they have everything they need to be allowed to have something in this case, MAiD.)

A person can only have MAiD if they are at least 18 years old, and if:



They have a serious illness, disease, or disability that hurts their body or their mind so much that it feels too hard to keep living.



Medicines have not been able to help their body or mind feel better, and



There is no cure; nothing can make the illness or disability go away, even if the person and their health care team have tried everything they could.

The "MAID assessors" also have to make sure the person understands:

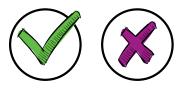
- 1. their illness or disability,
- 2. all of the medicines they could choose,
- 3. what MAID is and how it works.





Finding out if they CAN or CANNOT have MAiD

1. If the person is NOT eligible (meaning that they are NOT allowed to have MAiD), they can talk with their doctor and health care team members about what other choices they have. They can also ask for MAiD again another time, if they want.



- 2. If the person IS eligible (meaning that they ARE allowed to have MAiD), they will meet with a "MAID provider." This is a doctor, or nurse practitioner who will work with other health care team members to help them have MAiD.
- 3. If they have a serious illness or condition that might make their body stop working soon, they can talk with their MAiD provider to plan where and when they would like to have MAiD.
- 4. If they do not have an illness or condition that will make their body stop working soon, the person may need to wait 3 months and meet with the health care team members again to make sure they still want to choose MAiD. If they still do, then they can choose a date together.

What to expect on the day of MAiD



On the chosen day, the MAiD provider will come to see the person at the time and place that they had planned. That might be a room in a hospital or hospice, the person's home, or another special place.

1. They will

check with the person to make sure they still want to have MAID. The MAID provider will only continue if the person does still want MAiD.

- 2. Next the MAID provider will get the medicines ready and make sure that the person has everything they wanted, like music, candles, or people in the room.
- 3. The MAID provider will make sure that the person is ready for the medicines. If they are not ready, the MAiD provider will wait until they are.
- 4. When the person is ready, the MAID provider will give them the first medicine, which will help them feel very relaxed and fall asleep.
- 5. Then the MAiD provider will give the person the second medicine that will make their body and their brain go into a "coma" - this looks like sleep but is much deeper than regular sleep. The person will not be woken up or bothered by noise or touch. Sometimes this medication stops the person's breathing or heart beating and causes the person to die. When this drug is being given, the person's colour may change and they become pale. The person will not move after this drug is given.



- 6. Next, the MAiD provider will give the person the third medicine, which blocks the brain from sending messages to the person's organs. That makes their heart and lungs stop working. Because of the coma, the person does not notice this happening, and **it does not hurt**. When their heart and lungs stop working, their body dies. It will not start working again. Most of the time a person's body stops working a few minutes after the third medicine is given, but sometimes it takes longer.
- 7. Next, the MAiD provider will make sure that the person has died. They do this by listening for a heartbeat using a stethoscope and feeling for the person's pulse in their wrist or the side of their neck. They may also check that the person's brain has stopped working by looking at the person's eyes to make sure the eyes are still and the pupils do not react to light.
- 8. Once the MAiD provider has checked everything and they are sure that the person has died, they will leave the room to fill out some papers. Then they will pack up their supplies and leave so that the person's family or friends can spend some time with the person's body.
- 9. What happens after that depends on what the person and their family wanted and planned. The person's family may be able to spend some time with the person's body, if they want to. After a while, someone will come to move the person's body out of the room. They may be taken somewhere for a funeral, memorial, or other special ceremony or ritual to be held if that is what they wanted.

You can talk with someone in your family to answer any questions you have about what will happen next.

Remember that even though the person has died, we can keep their memory close to us by thinking and talking about them, or by doing things that they enjoyed or wanted to do.



Information for adults

Who is this book for?

This activity book has been designed for young people who have someone in their life who may have MAiD. It is best suited to children aged 6–12, but it may also be helpful for younger or older children. Parents, guardians, and clinicians are encouraged to review the book in advance. This way you can be familiar with the content if your child asks questions, and you can think about their ability to complete the book on their own or with your help.

The workbook is available in a printable PDF and an interactive version. <<links>>

How do I use this book?

This book is meant to be used as an extra "chapter" AFTER the activity book called, "My life, their illness." <u><<links>></u> By starting with that book, the child may have a better understanding of the person's illness and treatment, and their own thoughts and feelings. It will also give you a chance to hear what the child knows, and what they might wonder or worry about, so that you can build on that when you talk about MAiD together.

This book does not need to be read from start to finish, all at once. You can work through it together in smaller 'chunks'. Try to let the child's attention or feelings let you know when they need a break, or to skip parts of it. The child may find those parts helpful at another time, or they may not. That is okay. Use this book in whatever way feels right for your child.

What is the purpose of these activity books?

Families often say that there are things that feel important to talk about, but they worry about

how, or don't know how to talk about these things. These books were written to help guide parents, caregivers, or healthcare providers explore some of these topics together with children when someone in their life has a serious illness, and is considering an assisted death. These books are tools to help start, or guide a conversation. They should not be used *instead of* a conversation.

Sometimes people think, "there's nothing anyone can say to 'fix' what's happening, so what's the point of talking about it?" Although talking cannot cure an illness, it can help people:

- understand what is happening now;
- understand what might happen in the future;
- understand how they are each feeling and what they are thinking about;
- Ind ways of helping each other; know that they are not alone.

How can I prepare to use these activity books?

Review the activity books in advance so that you know what the child will be reading and thinking about. This will help you:

- Decide how you want to be involved;
- Identify topics that you or the child might need more help with, or want to save for later;
- Prepare for conversations or questions that may come up;
- O Decide where to start.

Will they complete these activity books on their own or with help?

Most children and teenagers will find it helpful to have an adult work on these books with them. That person might be a parent, caregiver, healthcare provider, counsellor, or anyone who can talk with them about their questions, worries, and feelings.

Children may want to do some activities by themselves. They may want to keep their thoughts private, or they may want to talk about it or show someone when they are finished. For other activities, they may want help, or an adult's company or encouragement. It is okay to use these books in any of these ways. Try to give children as much control, privacy, and independence as they want (or as much as possible), while letting them know that they are welcome to talk about any of the content with you. That will help them to think about and let out their thoughts, feelings, and questions in a way that feels comfortable.

Will the content be "right" for this child?

Each child and situation is unique, so these books can be used and adapted in different ways. The activities explore a wide range of topics, and some may be a better fit than others for a child's situation, needs, and interests. Here are some ideas for adapting these books to your situation:

- You can do the activities anywhere: on a computer or on printed copies.
- You can adapt the activities to fit the child's situation.
- You or the child can decide to skip or spend less time on some topics, and to focus on others.

Talking, listening and doing

Some children are comfortable talking about their feelings and worries, but just like adults, they may need time to "warm up" first. Others prefer to listen, point at pictures, or show their thoughts and feelings through art or play instead of talking. All of these are natural and healthy ways of expressing themselves. Try to check in often, like at the beginning of a new section or activity, to see what would be most comfortable for them.

Strong feelings and big reactions

These activity books include topics that can stir up strong feelings. Children may cry or become upset, or they may not seem to react at all. Some children need some time before they let their feelings out, and others may react right away. All of these are natural reactions.

Sometimes when a child has a big emotional reaction, adults wonder if that means they should not be talking about these things. The opposite is often true — a child may have had these feelings for a while and this is the first time they have expressed them. This can be hard for adults to see, but it is helpful for the child to be able to let those feelings out rather than trying to hold them inside. That gives adults a chance to reassure the child that their feelings are natural and that they do not have to go through this alone.

More support

If you have questions about this workbook, you can contact us at <u>info@virtualhospice.ca</u>.

For more information about caring for a child with a life-limiting illness, please visit: <u>CaringTogether.life</u>.

For more information about supporting children and talking about illness, dying and grief, please visit: <u>kidsgrief.ca</u>



www.virtualhospice.ca

A NOTE FOR ADULTS:

Children naturally have many different questions about illness, dying, and MAiD. Some of these questions can be very hard to know how to answer, and the questions are often very hard for young people to ask. Adults sometimes worry that the answers to these questions may be "too scary," but if the child has asked the question, they have often imagined what the answer might be. Imagining different possibilities can be scarier than reality, and talking with a trusted adult offers children the comfort of knowing that they are not alone with their thoughts and feelings. Try to answer in a clear and honest way using words that the child can understand, and check in by asking, "did that answer your question?" It is okay not to have all the answers and to say, "I don't know." Thank children for asking their questions, even the ones you can't answer.

For more information and guidance about exploring children's questions, about dying, death and grief, visit: <u>www.KidsGrief.ca</u>, <u>Module 2 –</u> <u>Talking about dying and death</u>

For more information about supporting children with MAiD, visit: <u>www.KidsGrief.ca</u>, <u>Module 2</u>, <u>Chapter 7: Preparing for a medically assisted death</u>

Children and young people may have the same kinds of questions, feelings, and struggles as adults do when a family member is choosing MAiD. For information about MAiD that might help you talk about some of these difficult topics, visit: Resources on Medical Assistance in Dying (MAiD)



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