



Me and My Illness

Activity Book


Welcome! These activities will help you think about how your illness is affecting your life.

Start Here!

How you can use this book pg. i




#1 About Me pg. 1



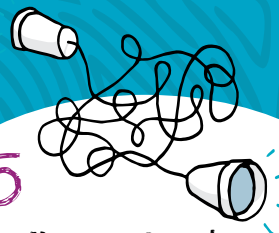
#2 Making Sense of Changes pg. 2



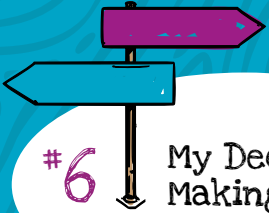
#3 My Body and Mind pg. 6




#4 My Feelings pg. 14




#5 Talking About Your Illness pg. 25



#6 My Decision-Making Toolkit pg. 31




#7 Common Questions About Having an Illness pg. 39



#8 What Happens When Someone Dies? pg. 44



#9 My Community & Me pg. 50



#10 Resources & Downloadable PDF pg. 60

Click on the topics to jump to that page

Adults – please read “Information
for adults” on pages 58-59

How you can use this book

Use this book any way you want to! Since we made this book for people with all different kinds of illnesses and situations, some parts may feel useful, and others may not feel like they are right for you. That is okay, you can do, change, or skip any parts you choose.

You can

- Work at your own speed
- Skip sections
- Come back to sections later
- Do the activities in your own way
- Stop anytime
- Save your answers
- Work on it with a parent or healthcare provider

You may have lots of different questions, feelings, and ideas as you go through this book. You may want to talk about or work on the activities in this book with a parent, healthcare provider, counsellor, or another adult who you trust, so they can try to help you with hard questions and 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 work on this part."
- "Can you stay with me while I work on this part, but without talking about my feelings?"



This site includes activities you can do - grab a sketchbook or some scrap paper and draw along!

You can go through the activities in order to make your own path.

Back to [Start Here](#) page



About Me

I am years old. I live in

I also have an illness. It is called

Here are some of the people who take care of me:

.....

.....

.....



Activity - People in my life

Use your sketchbook to make a collage or a picture book of the people in your life. You can draw or paint them, or you can print, cut out, and glue or tape photos!



Activity - If my illness was a character..

Imagine your illness as a comic book character. What would it look like? Can you draw or paint a picture of it? How would it act? What would it say or do? What would you want to do or say to it? Make up a story or draw a comic strip about it. You can keep your story, or you might want to cut or tear it into little pieces. You can do whatever you want!

Back to [Start Here](#) page



Making Sense of Changes

Some people are born with an illness, and some people get diagnosed with an illness when they are very young. For other people, an illness is something unexpected that happens later in life.

For me, my illness is:

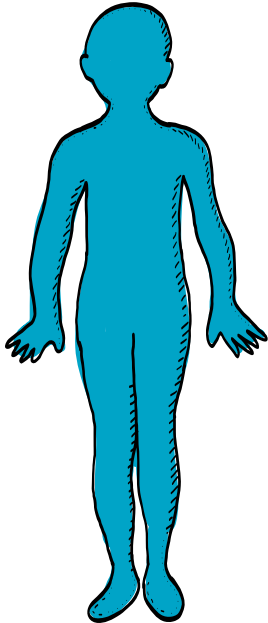
- **Very new:** This illness started a short time ago.
- **A little bit new:** This illness started a while ago, but it has started to get worse.
- **Not new:** I have lived with this illness for a long time, and it is getting worse.
- **I'm not sure**
- **Other:** _____

When you have a new illness, or when an illness starts to get worse, you may notice some changes. Your body may feel different. You may have thoughts and feelings that you've never had before. Some of your daily activities might also change.

Let's explore these changes and what they mean for you:

How your body feels.

You may feel pain, discomfort, or tired. How you move might change, or the way your body works might be different.



Have you felt any changes in your body?

What has changed?

When did you start to feel these changes?

What is that like for you?

What you think and how you think

It might be harder to focus or think clearly, to talk, or to tell your body to do what you want it to do. You may have questions or worries about the illness.



Has anything changed about how you think, focus, talk, or learn?

What has changed?

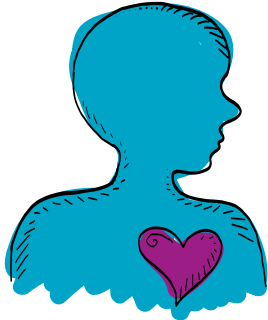
When did you start to feel these changes?

What is that like for you?

Feelings, emotions or moods

You may have new, stronger, or different feelings, emotions, or moods than you are used to having.

Have you felt different or stronger feelings?



What has changed?

When did you start to feel these changes?

What is that like for you?

Friends and family

You might not get to see some friends or family as often. Some people may treat you differently than they used to. You might find it hard to do some things, or to talk about some things the way that you used to.

Have any of these things changed for you?



What has changed?

When did you start to feel these changes?

What is that like for you?

Everyday life

You might feel like your "normal life" has changed a lot. You might do things differently than you used to do. You might miss doing regular, everyday activities like colouring or climbing. You might miss things like playing sports, taking music lessons, or going to clubs.

Have your daily activities changed?



Do you have less time to do things you used to do?

Do you spend more time doing new things?

What is that like for you?



Activity - Knowing what to expect

When big changes are happening, it can seem like everything is different and unfamiliar. Creating your own calendar can help you to know what to expect and to feel more prepared. Print out a calendar (<https://print-a-calendar.com>), use one you have already, or make one out of craft paper and supplies! Use it to write down what you'll be doing, where you'll be, and who will be with you! It can include:

- activities or special dates
- visits to your doctor or other healthcare providers
- decorate your calendar, and hang it somewhere you can see so that you know what to expect in the days ahead.

Back to [Start Here](#) page



My Body and Mind

Serious illness can affect different people in different ways. Being aware of what is happening in your body is important. Knowing how to express your feelings can help you talk to your doctors, find support, and sometimes find ways to feel a bit better.

There are many ways to show or tell what we are feeling in our bodies or minds, like pictures, words, or using numbers to rate how strong a feeling is. In this section, you can try different ways and see what works for you.

About My Body

Here are some of the ways your body might be feeling because of your illness. Have you felt any of these? Circle or point to anything you have felt, or that you have a question about.



Headache



Stomachache



Vomiting (or feeling like you are going to vomit)



Sharp pain



Dull aches



Feeling hot



Feeling cold



Tingling



Numbness



Dizzy



Itchy



Prickly



Hungry more or less often?



Tired more?



Weak muscles



Trouble sleeping



Can't sit still



Hearing changes



Vision changes

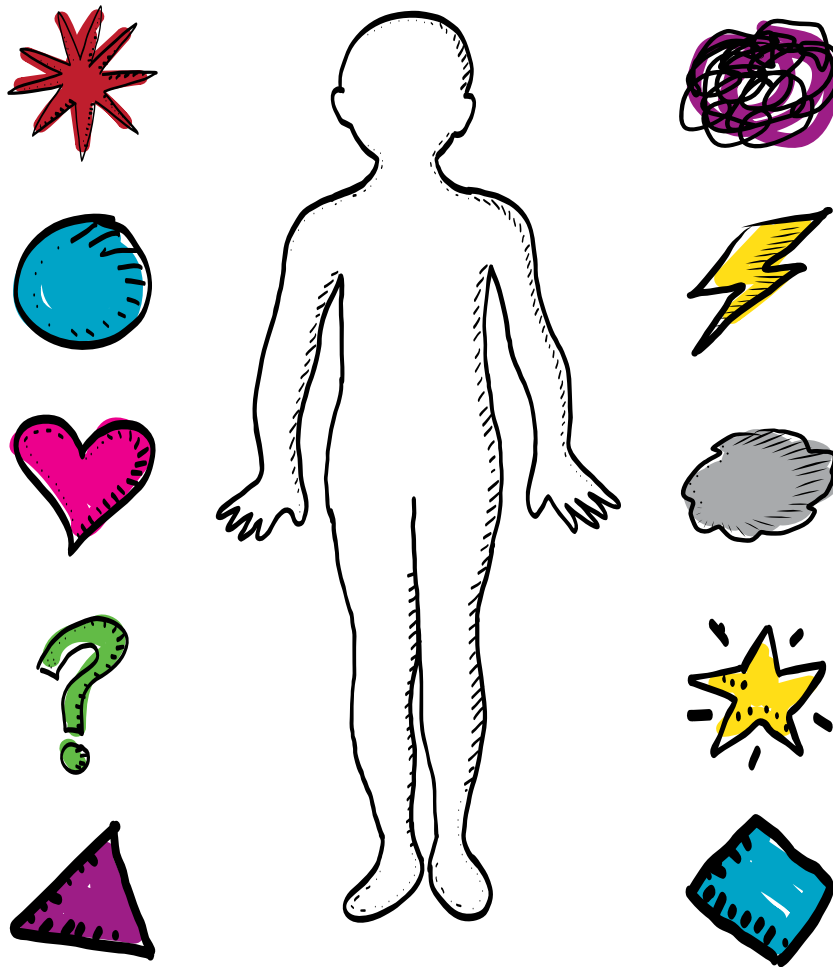


Changes in smell or taste

Have you felt things in your body that are not on this list? What are they? Write or draw anything you've felt that isn't on this list.

Think about the different feelings you have, and where you feel them in your body.

1. **What hurts or is uncomfortable?** Pick a shape that matches the feeling and draw it, or point to show where you feel it on the body pictured here. For example, you could draw a triangle or zigzag for sharp pain, or dots for tingling.
2. **What feels okay?** Point or use your favourite colour to colour in the parts of your body that feel okay.



Sometimes your body might feel different at different times of day, or because of medicine, sleep, eating, exercise, or other reasons. This is natural. Knowing how your body feels at different times can help you feel prepared.

In the morning my body feels...



0
No Hurt



1-2
Hurts
Little Bit



3-4
Hurts
Little More



5-6
Hurts
Even More



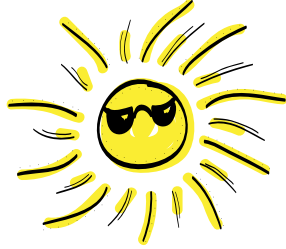
7-8
Hurts
Whole Lot



9-10
Hurts
Worst

If it is changing, explain how: _____

In the afternoon



my body feels...



0
No Hurt



1-2
Hurts
Little Bit



3-4
Hurts
Little More



5-6
Hurts
Even More



7-8
Hurts
Whole Lot



9-10
Hurts
Worst

If it is changing, explain how: _____

In the evening my body feels...



0
No Hurt



1-2
Hurts
Little Bit



3-4
Hurts
Little More



5-6
Hurts
Even More



7-8
Hurts
Whole Lot



9-10
Hurts
Worst

If it is changing, explain how: _____

Overnight...



my body feels...



0
No Hurt



1-2
Hurts
Little Bit



3-4
Hurts
Little More



5-6
Hurts
Even More



7-8
Hurts
Whole Lot



9-10
Hurts
Worst

If better or worse, explain how: _____

Let's learn more about your mind, and then we'll work together to "Make a Plan" for more ways to feel better.



About My Mind

Having an illness can change what you think about. It might also change how your brain works.

Can my illness affect what I think about?

Yes, this is very common! When you start to learn about your illness and treatments, you have to make sense of a lot of new information. It might feel like you are always thinking about these things, even when you're not trying to. It's okay if you have lots of questions or worries about what is happening now, or about what might happen in the future.



Can an illness make it harder for me to think or focus?

Some illnesses and medicines can make it hard to stay focused on something. You might feel like your thoughts are "foggy," or you might get confused or forget things more easily.

Exploring my mind

Decorate your brain with pictures, symbols, words, or colours to show what you think about and how you think.

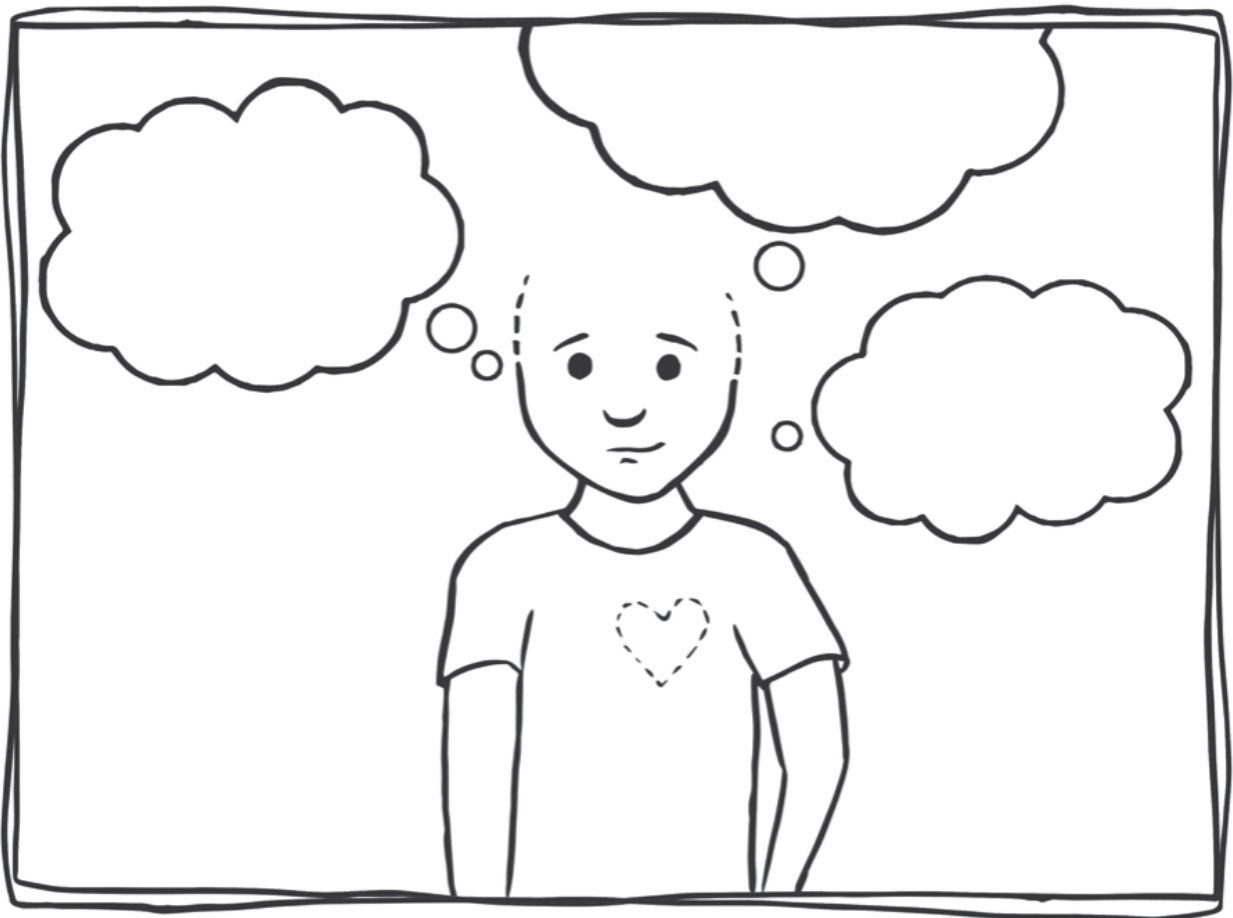
You can choose and circle things you like, things you don't like, and anything you wonder or worry about. If you sometimes get headaches or feel "foggy," you could show that in your drawing, too. There is no "right" or "wrong" way to do this. Be as creative as you want!





Activity - Use your sketchbook and draw!

Print and fill in this page with pictures, symbols, words, or colours to show what you think about. You can include anything you wonder, worry, hope, remember, imagine, or even dream. Be as creative as you want!



Make a Plan

Lots of things might help your body and mind feel better. Let's talk about what you have tried, and what could help in the future. Everyone is different - there's no "right" or "wrong" choice. This is all about you!

Draw a line from each image to the circle that shows:
I have tried this; I want to try this, I don't want to try this,
or I don't know if I want to try this.



Medicine



Warm bath



Rest



Deep breathing



Art



Focusing on something like a movie



Massage



Ice packs



Stretching



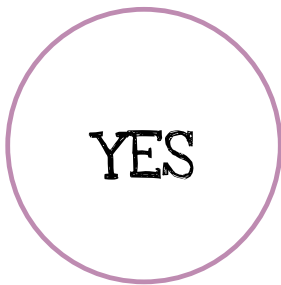
Listening to music



Writing in a journal



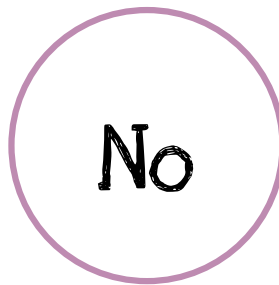
Moving around or changing positions



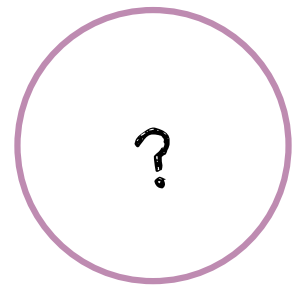
I have tried this



I want to try this



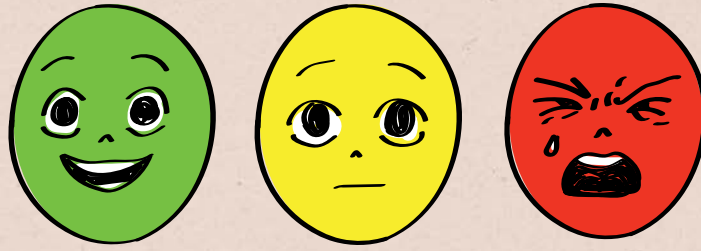
I don't want to try this



I don't know if I want to try this?

Is there anything else you might like to try? Write your answers here:

Back to [Start Here](#) page



My Feelings

Having an illness can be a very **emotional** experience. When you are seriously ill, you will have lots of changes in your life. These changes can be very hard, and you might have many feelings and emotions, like being sad, angry, confused, hopeful, scared, shy, and many more.

Even though having an illness can cause many hard feelings, there can be happy times, too. Some people wonder if it is okay to feel happy when they are ill. It is natural and okay to feel all different feelings, including happy. This mix of feelings is part of grief - grief is a natural reaction when something really hard happens, like having a serious illness.

Did you ever:


- Feel one way for a long time?
- Bounce quickly between different feelings?
- Feel different (even opposite!) feelings at the same time?
- Feel numb, or feel nothing at all for a while?
- Feel all of the things listed above?
- Something else


Emotions are natural. There is no "wrong" way to feel. Strong emotions can be hard to cope with. Here are some things to try that might help:


- Learn the names of your emotions
- Think about which of your emotions are harder
- Know what it feels like when you have hard emotions
- Think about what helps you when you have those emotions
- Share your emotions with someone else


Naming My Feelings


Here is a list of 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 some are hard. Explore each emotion. Think about which ones you feel most often and why.


 **SHY** - when meeting many new people who help you and your family


 **COMFORTABLE** - when symptoms are well managed, being with people you like, or doing something you like


 **ANNOYED** - having to do things you don't want to do, or when things don't go the way you expected


 **CURIOUS** - thinking about what is going to happen next


 **BORED** - when it feels like there isn't anything fun or interesting to do


 **HOPEFUL** - about going home from the hospital, feeling a bit better, or getting to do something you want to do


 **SNEAKY** - about not following rules or not taking medicines


 **SCARED** - about treatments or changes in your body, your life, or your family


 **SUSPICIOUS** - if you think that something is going on without knowing for sure


 **ANGRY** - about things changing or not working the way you want them to, or not being able to control or change something


 **HAPPY** - when you're having a good time, doing something you enjoy or with people you care about


 **SURPRISED** - about something you weren't expecting, either in a good way or a bad way.


 **ANXIOUS** - when something is going to happen or might happen, but you do not want it to, or you don't think it will go well

 **CONFUSED** - about medical information that is unclear or hard to understand, or when you don't know how to feel or what to do about something

 **EXHAUSTED** - when your body is so tired because of the illness or treatments, or you feel tired of feeling hard feelings and thinking about hard things

 **SHOCKED** - about something you weren't expecting, either in a good way or a bad way.

 **EXCITED** - about doing something or seeing someone

 **FRUSTRATED** - about things changing or not working the way you want them to, not being able to control or change something, or needing help with something you want to do by yourself



EMBARRASSED

- about having people see you or talk about you in a way that does not feel comfortable



PROUD

- when you do something hard or something you've been trying to do for a while, or when someone notices something special about you



SAD

- about things changing or not working the way you want them to, not being able to control or change something, or needing help with something you want to do by yourself



DISGUSTED

- when something smells, tastes or looks awful. Some medicines can make your senses more sensitive so some things may smell, taste or look even worse than they used to



DEPRESSED

- a deep and lasting sadness about things that have happened, or that you think will happen



LONELY

- when you miss people you care about, or when you feel like you're the only person feeling the way you feel even if you're surrounded by people who care



GUILTY

- feeling bad about something you said or did, maybe about things that have happened or changed because of your illness



CAUTIOUS

- if you need to be careful to avoid germs, or if you are afraid to get your hopes up



OVERWHELMED

- when your feelings, thoughts or worries feel too big or too hard to deal with



JEALOUS

- when someone can do or have something that you can't, because of the illness or for another reason. Some people worry that being jealous of someone who is healthy is the same as wishing for that person to be sick - it is not the same. It is okay to feel jealous about being healthy



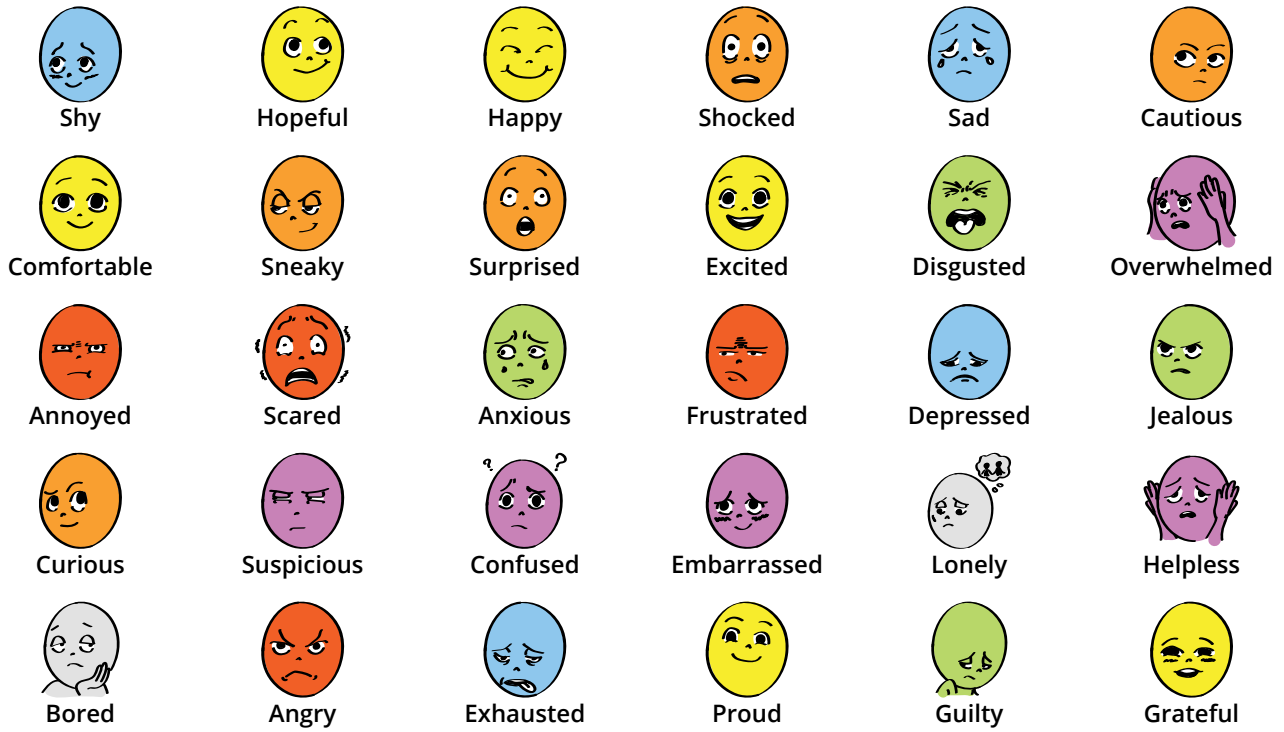
HELPLESS

- when you can't do anything to change something that really matters to you



GRATEFUL

- when you feel thankful for something someone did or said, or for something you were able to do



Circle or point to the faces or write your answers to the questions below.

1. How are you feeling today?

2. Some feelings are harder to deal with. What are the hardest emotions for you?

There might be times that are harder to manage than others.

Here is a list of times that feel harder for some people. Write or draw how you feel at any of the times listed here. If there are other times that are hard, write or draw them in the blank space, below.



at night

when they are alone

in the hospital



before a
medical appointment

when they can't
do something
they want to do

when they have to
do something they
don't want to do





Activity - Make your own "How I feel today" poster!

1. Print the blank emotions face sheet below.
2. Colour the emotions and decorate them to add your own style.
3. Cut out the emotions you feel most often and glue them to a colourful piece of paper OR keep all the faces together on the paper you coloured.
4. Cut out some arrow shapes from sticky-notes. Use these to point at the feelings you're having.
5. Put the poster on the fridge, your bedroom door, or wherever you want so that you and your family can see how you're feeling.



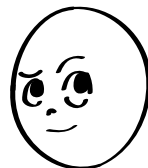
Shy



Comfortable



Annoyed



Curious



Bored



Hopeful



Sneaky



Scared



Suspicious



Angry



Happy



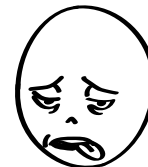
Surprised



Anxious



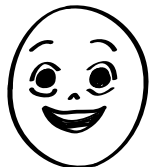
Confused



Exhausted



Shocked



Excited



Frustrated



Embarrassed



Proud



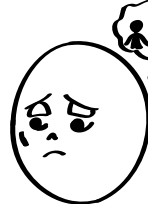
Sad



Disgusted



Depressed



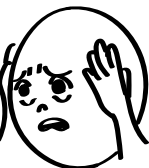
Lonely



Guilty



Cautious



Overwhelmed



Jealous



Helpless



Grateful

Make a Plan

Working through hard emotions

What do you do when you have hard emotions? Here are some ideas that might help:

Point or draw a line from each image to the circle that shows if you want to try it, or not, or if you have tried it before."



Talk with someone



Go somewhere else



Take a bath



Listen to music



Play a game



Read



Try to sleep



Cry



Practice deep breathing



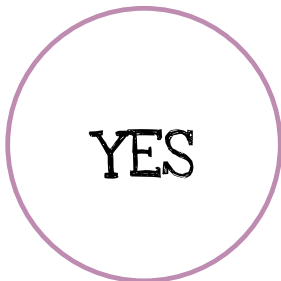
Colour



Eat something



Watch tv or a movie



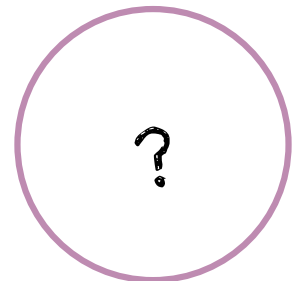
I have tried this



I want to try this



I don't want to try this



I don't know if I want to try this?

Other things I like to do:



Activity 1

SPONGEBALLS! You will need washable markers, tracing paper or other smooth craft paper, 2-6 sponges, string, duct tape, a bucket or large bowl with water.

- Use the markers to write or draw feelings that are hard to have, the things that cause those feelings, nightmares, or anything else that upsets you. The more colourful, the better.
- Make "sponge balls" by cutting sponges into strips and tying them together with string. (1-2 sponges for each sponge ball) When you pull the string tight, the sponge strips will look like a chunky pom-pom.
- Use duct tape to stick your drawing to a wall outside, or to the inside of your shower.
- Soak the spongeballs in the water and throw them at the pictures. Do this again and again until the spongeballs have washed away the pictures.



Activity 2

WRECKING THE HARD STUFF! Write down or draw any feelings that are hard to have, or the things that cause those feelings. Then tear or use scissors to cut the paper into little pieces.

Sharing your hard feelings

Share what you know about your feelings with others. Make a chart or list, or draw a picture. You can use this to help remind you, your family, and your healthcare team about some of the things that are hard for you and some of the things that help you feel better. Here's an example:

I feel...

When...

It helps to...

Anxious

I have to have a test

Know all about what's going to happen

Jealous

My classmates play a game that I can't play

Be the scorekeeper

Sharing your favourite feelings

Make a chart or list, or draw a picture about your favourite feelings. You can use this to remind you, your family, and your healthcare team about some of the things that help you feel better. Here's an example:

I feel...

When

Safe

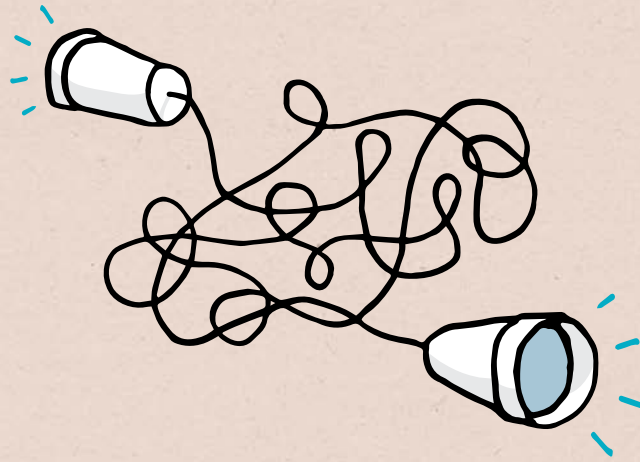
I hold hands with my mom when I get a needle

Excited

My friend sets up a video call with me

Talking about your feelings with your family and healthcare team lets them know more about how to help you.

Back to [Start Here](#) page



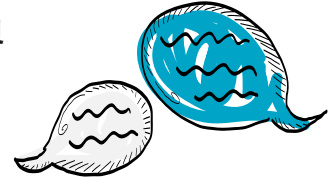
Talking About Your Illness

When you have lots of questions or worries about your illness and treatments, learning more about what is happening to you can help. You might know a lot about your illness, or you might only know a little. You might want to know "everything" about it, or you might only want to know some things.



Why Asking Questions Can Be Hard

Some questions may feel a little bit hard to ask and others may feel **too** hard to talk about at all. There are many different reasons why something might feel hard to talk about.



Finding the words

Explaining what you mean or what you want to know can be hard.

Can you think of a time you did not ask a question because you did not know how to explain what you were wondering?

Try starting by saying something like, "I have a question but I'm not really sure how to explain what I want to know." Next, you could say what you know already, and what you want to know more about. For example, "I know where my illness is in my body, but I don't really understand how it got there."

TIP:

- When you have a lot of questions, they can feel overwhelming. Try writing them down. After you ask a question, check it off your list. Then your mind might feel calmer. Use the next "Make a Plan" activity to think about your questions and make a list.

Feeling unsure or overwhelmed

Maybe you're not sure that you really want to know the answer to your question. Or maybe saying something out loud makes it feel more "real." It is natural to feel this way, but saying something out loud can't make it happen.

Is there something you are scared to ask about because you don't know if you want to know the answer? Are there topics you are not comfortable talking about?

TIP:

- Write down your questions, thoughts, or feelings so that you don't have to say them out loud. Then say what would be helpful, for example, "I need a hug, but I don't want to talk," or "I'd like to talk about this, but I don't know how to start."
- Start with an easier question and see how that goes. Next, you could try asking a question that is a little bit harder. Try this again until you feel more comfortable asking harder questions.

Finding the right person to ask

You may think that no one knows the answer to your question. They might not. But you might feel better if you share your questions and feelings with someone else.

Have you ever not asked a question because you weren't sure if anyone would know the answer?



TIP:

- Think about a time when you talked to someone about your illness or your feelings. How did it go? If it went well (or even "okay"), could you talk to that person again? If it didn't go so well, is there someone else you could talk with? Some people talk with a parent or another family member. Others talk with a healthcare team member, a teacher, a coach, or someone else in their community.
- Say something like, "I need to talk about something, but do you think you could just sit with me without trying to find an answer to my question?"

Not wanting to upset others

Maybe you're worried that your question or thoughts would upset someone. Most parents want to know what their children are thinking and worrying about so that they can try to help. If your parents cry when you say something, it's not **you** that is making them upset - it's the situation that you're in. You both might feel better after you talk about these things because it means you can deal with them together.



Sad



Surprised

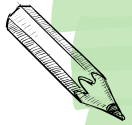


Hopeful

Have you ever not asked a question because you were afraid of making someone upset?

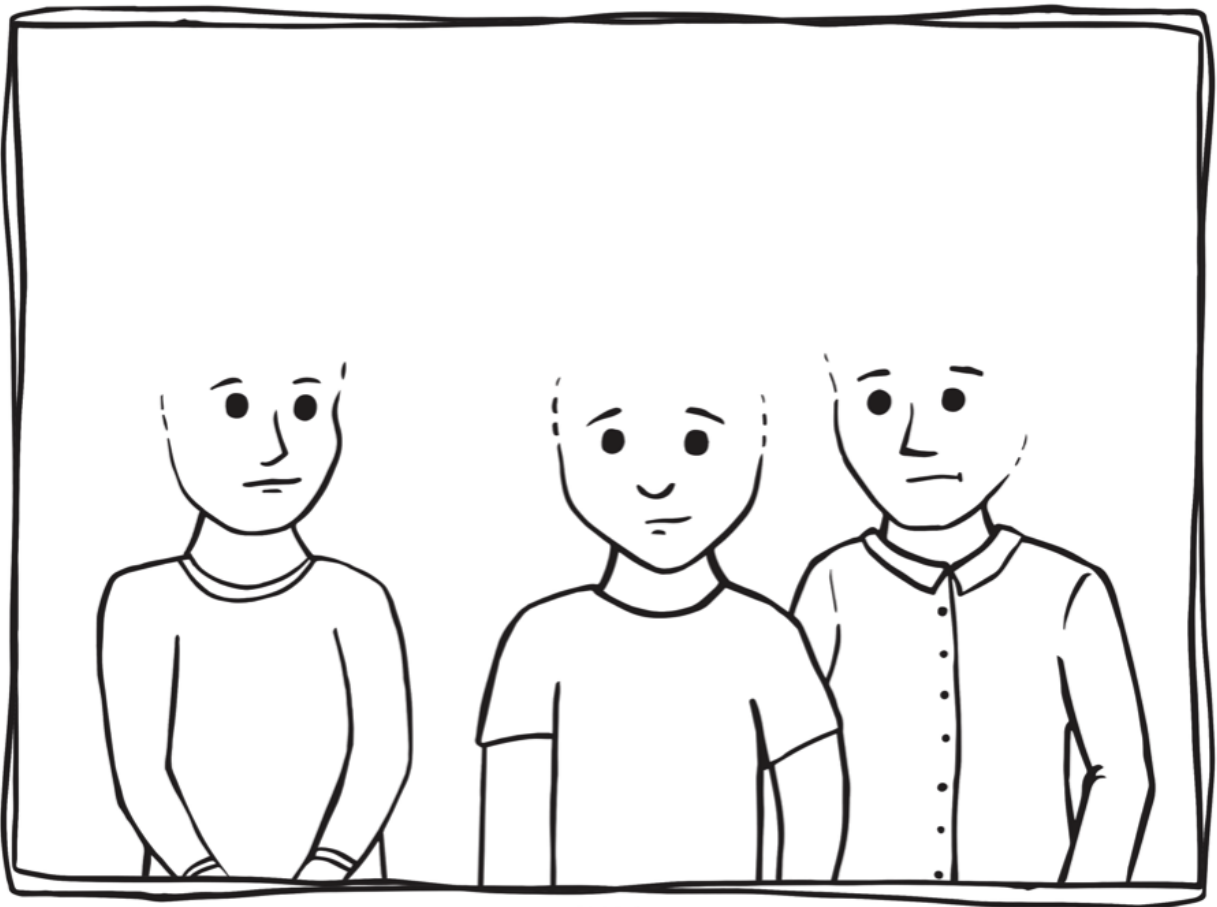
TIP:

- Say something like, "I need to talk about something, but I'm afraid you might get upset. Do you think you could listen without answering right away?"



Activity - Use your sketchbook and draw!

Print and fill in this page with pictures, symbols, or words to show the questions you think about. You can also write or draw what the people in your life might be wondering about, or how you think they might answer your questions. Be as creative as you want!



Make a Plan

In this activity, you will build your own **question and answer sheet** that you can share with your healthcare team. Your parents can help you print or email the sheet to your healthcare team so they can give you the answers you need. If you have more questions, you can always come back to this page and build another sheet.



Build your sheet:

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

- What is the illness called?
- Where is it in my body?
- What does it do, or how does it work?
- What medicines or treatments have I had?
- What did those medicines or treatments do, or how did they work?

2. Add your own questions here:

.....

.....

.....

.....

.....

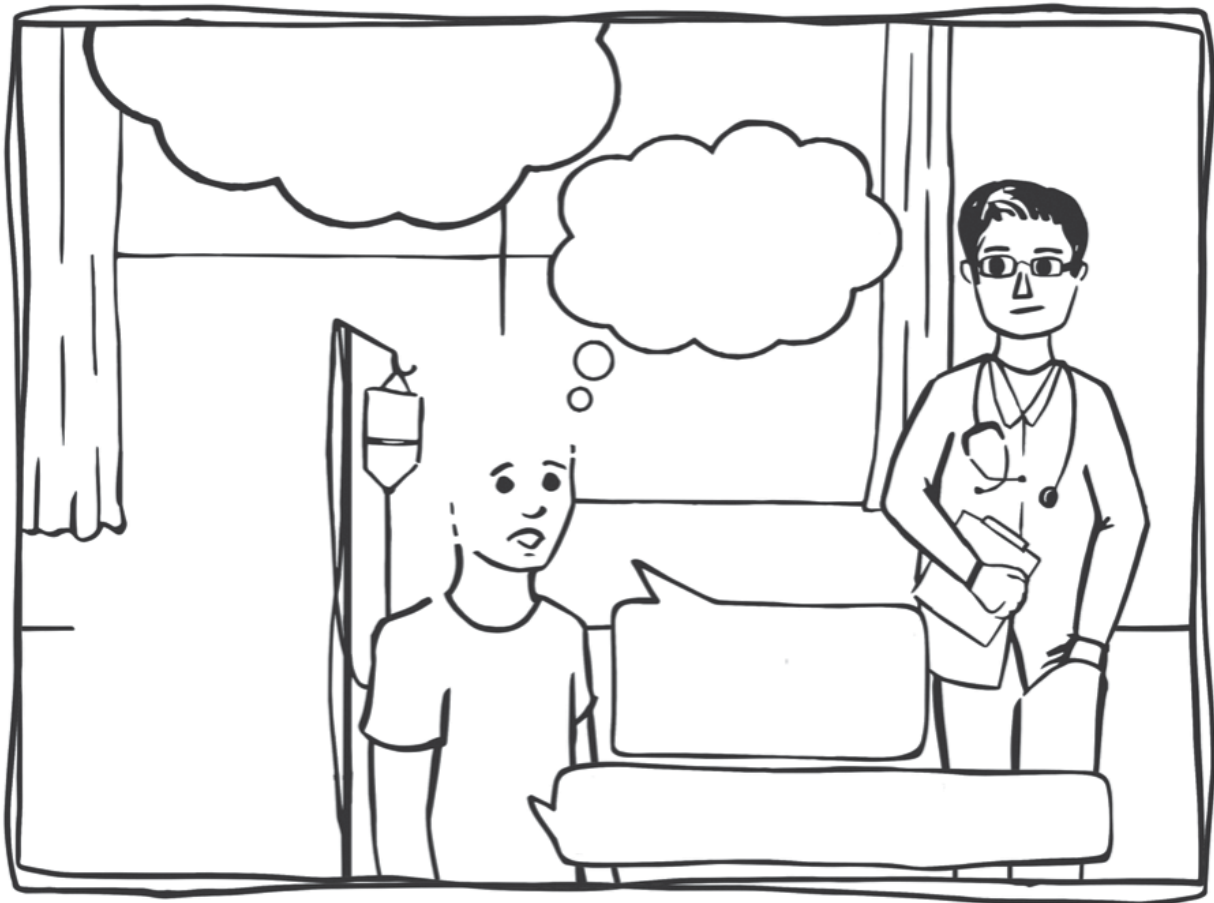
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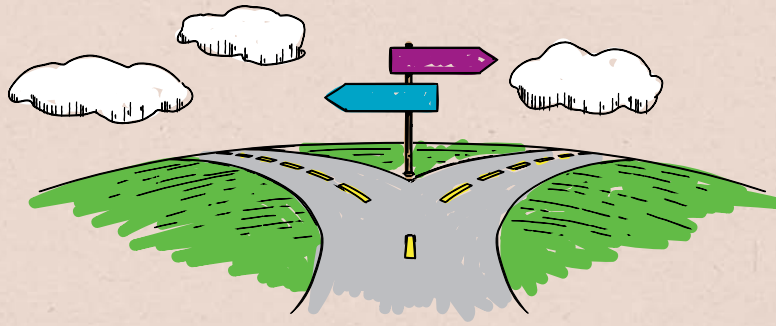


Activity - Use your sketchbook and draw!

Print and fill in this page with pictures, symbols, or words to show the questions you would like a health care provider to answer, in the talking bubbles. Use the thought-bubbles to show questions that feel too hard to ask, or how you feel about asking those questions. Be as creative as you want!



Back to [Start Here](#) page



My Decision-Making Toolkit

Sometimes, you ask questions because you want to know the answers for yourself. Other times, you may want information to help make a decision. When you are making a decision, you will want to consider all of the things we have discussed in this activity book: your emotions, how your body feels, what you care about, and the information you have about the situation.

You may have to make small and big choices in your life:

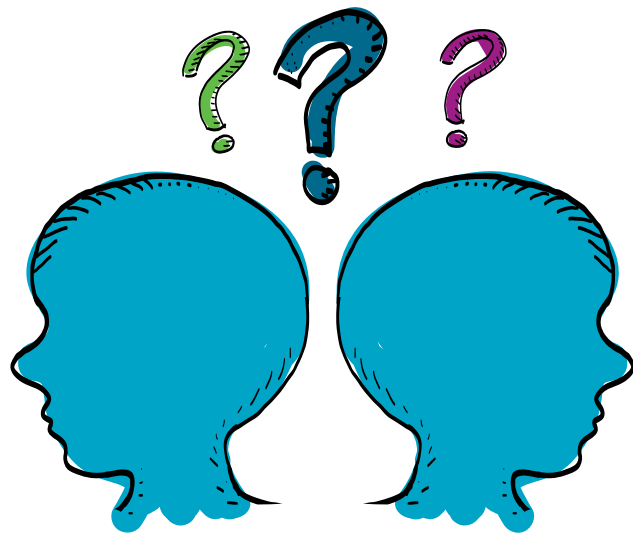
- **"Small"** choices are decisions about things like, what to wear, what movie to watch, and whether or not to go to school or visit someone.
- **"Big"** choices are decisions about things like trying new medical treatments. Depending on your age, you will usually make these decisions about your care with your parents or caregivers. But you can ask questions and say what you would like no matter how old you are.

Big decisions and choices can be hard to make. Talk with your parents and your healthcare team about what's important to you. Then they can do their best to make choices that feel good for you.

When you have a new choice or decision to make, here are some things to think about:

- what you already know about your illness and treatment
- Questions to ask your healthcare team; write a list or ask a parent to write a list
- what you want the team to know about you and how you feel; write a list or ask a parent to tell the team
- what you do or don't want to know about your treatment, for example, do you want to know ahead of time if something will hurt?
- what you do or don't want to know about how you are doing, for example, do you want to know how long the team thinks you might live?
- what's most important to you; what do you most want the treatment to do for you right now?

You might ask some or all of these questions yourself, or you can make a list and ask your parent or guardian to find out the answers for you.



Use this toolkit to think about and make decisions about some parts of your treatment and illness

Print as many copies of this page as you want so that you have one for each medication that you want to know about.



Questions about medications and my body:

What is this medication called?

.....

How will this medication affect my body?.....

.....

How will this medication affect my mood, my thinking or my energy?

.....

What does this medication do and how would it help me?

.....

Is there anything I can do to help this medication work better?

.....

Is there anything I cannot/should not do while I am taking this medication?

.....

How I feel about medications:



Continuing to take this medication makes me feel...
(tired, better, calmer, grumpy, etc.) _____







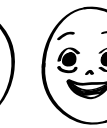


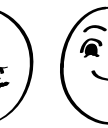




















The idea of taking this medication makes me feel...
(excited, hopeful, scared, confused, etc.) _____

The most important thing to me is...

(being comfortable, having energy, feeling like myself, feeling better, etc.) _____

I trust the decisions that [person/people] make about my medication _____

Point or circle the feelings that you have about medications and treatments:

									
Shy	Comfortable	Annoyed	Curious	Bored	Shocked	Excited	Frustrated	Embarrassed	Proud
									
Hopeful	Sneaky	Scared	Suspicious	Angry	Sad	Disgusted	Depressed	Lonely	Guilty
									
Happy	Surprised	Anxious	Confused	Exhausted	Cautious	Overwhelmed	Jealous	Helpless	Grateful

Finding out about changes in my body, treatments, or medication:

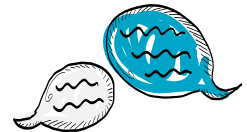
When there is new information about my body, treatments or medications, I would like _____ to tell me this information.

I would like _____ to be there with me.



I would like the person telling me about these changes to: (choose as many as you want)

Talk to me instead of someone else



Talk with _____ first before / instead of talking with me

Give me time to think before asking me to answer



Write down the information so I can read it again later



Ask if I have questions and give me time to think about it



Explain medical terms



Check in with me a little while later to see if I have questions



Other: _____

If I have questions that are hard to ask or to answer, I would like _____ to try to help me

Thinking about the future.



What is important for me to do when I am feeling well?

.....

What is important for me to do if my illness gets worse?

.....

Is there something that I do NOT want to do?

.....

What will the healthcare team do to help me if my illness gets worse?

.....

What else should my healthcare team know about me and what matters most to me, in order to care for me as well as they can?

.....

How to help me:

When I'm having a hard time, I would like the people around me to:



Give me some time/
space to myself



Hold my hand



Give me a hug



Sit quietly with me



Help distract me

Other:

When I feel overwhelmed, it might help to

What is important to me?

Write some of the things that are most important to you. These could be people, activities, beliefs, or dreams. Show this page to your parents and healthcare team so they can better understand what matters the most to you.



.....

.....

.....

.....

.....

.....

.....



Activity - Use your sketchbook and draw!

Write and draw some of the things that are most important to you, or create a collage using pictures from old magazines. These could be people, activities, beliefs, or dreams. Show this page to your parents and healthcare team so they can better understand what matters the most to you.

Back to [Start Here](#) page



Common Questions About Having an Illness

People who have an illness often share some common concerns. Your family might have the same questions! Take the quiz below to see what you know about illnesses already, and to get answers to some common questions.

Questions

1:
Most serious illnesses are not contagious, which means your friends and family can't "catch" the illness from playing, touching, or spending time with you.



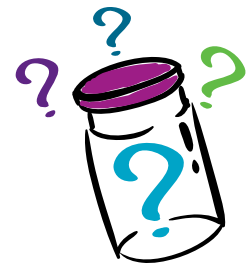
----- True ----- False

2:
Serious illnesses like cancer and genetic disorders cannot be caused by something you did or did not do.



----- True ----- False

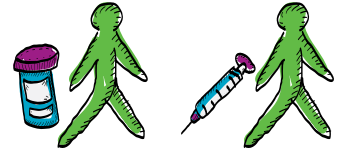
3:
Medical professionals always know what causes a disease.



----- True ----- False

4:

When someone has a disease, they are given the same treatments as everyone else with that disease.



----- True

----- False

5:

Some treatments can help cure a disease, while others are designed to make you more comfortable.

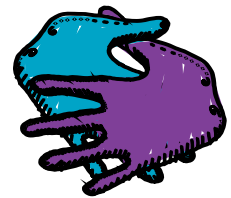


----- True

----- False

6:

You don't have to face your illness alone.



----- True

----- False

Answers

1:

Most serious illnesses are not contagious, which means your friends and family can't "catch" the illness from playing, touching, or spending time with you.

TRUE! Some illnesses, like a cold, flu, or COVID-19, are contagious, and you can "catch" them from another person. But you can't catch or spread most serious illnesses, even if you kiss, use the same pillow, or share or drink with someone else. Illnesses like cancer or genetic disorders are not contagious. That means you can't spread them from one person to another.



Some diseases can spread in the body of a person who is already sick. For example, cancer cells live inside a person's body and may spread to another part of the same person's body, but you can't "give" your illness to someone else. If you have questions about your illness, talk to your parent, doctor, nurse or other healthcare team member.

2:

Serious illnesses like cancer and genetic disorders cannot be caused by something you did or did not do.

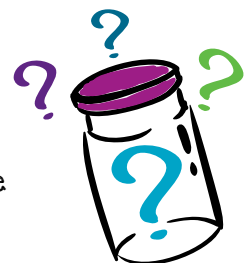
TRUE! You might wonder if your illness is caused by something that you did or didn't do. Doctors are still learning about why some people get serious illnesses and others do not. However, there is nothing that a child or teenager could personally do to cause cancer, genetic disorders, or other serious illnesses.



3:

Medical professionals always know what causes a disease.

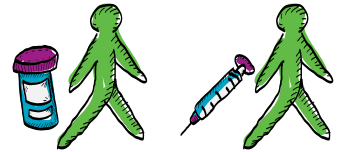
FALSE! It can be very frustrating not to know what caused a disease and it's natural to want answers. It can be very hard to believe that things happen that no one can control, no matter how hard you try or how careful you are. You may also think that you are causing stress for your family. It's not you - the illness is causing all the stress and changes.



4:

When someone has a disease, they are given the same treatments as everyone else with that disease.

FALSE! If a treatment has cured some people with an illness, you might wonder why it doesn't work for everyone who has that illness. That's because every person's body is a bit different, and the same illness affects different bodies in different ways. It's not because some people try harder or deserve to get better more than others.



5:

Some treatments can help cure a disease, while others are designed to make you more comfortable.

TRUE! People all over the world are trying to find ways to cure different illnesses. Some illnesses have treatments that can cure many people who have it. Some treatments cure some of the people who have an illness. Some illnesses have no cure at all.

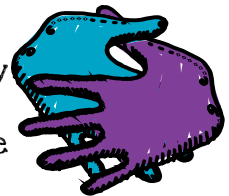


Even if there is no medicine to cure your illness, there may be medicines that can help you feel more comfortable. These medicines work differently than medicines that try to cure an illness. They focus on the specific "symptoms" - the ways that you feel because of the illness. Your doctor, nurse or another healthcare team member can answer any questions you have about medicines and cures.

6:

You don't have to face your illness alone.

TRUE! Whether you are receiving treatment to cure your illness or medicines to make you feel better, you have your family and healthcare team to face your illness with you. You and your family can talk with them about which team members will take care of you, where and how they will do that. You can also talk with your family about who will be with you, wherever you are, so that you will have company and care when you need it.



Even if you know your illness can be cured, you might still worry about lots of things. You might wonder, "What would happen if things got worse? Could I die?" These worries can lead to many other questions. Click on the questions below to see short answers.

Back to [Start Here](#) page



What Happens When Someone Dies?

Sometimes people die from illnesses and sometimes they don't. It is natural for people of all ages to wonder about dying and death, even when they are feeling well. When you or someone in your life has an illness, it's natural to think or wonder about it even more.

Dying can be hard to think or talk about, and it may be even harder when you or someone in your life has an illness. Sometimes people worry that thinking or talking about death could make it happen, but death does not work that way. Many people say that talking about their questions and worries helps them to feel better. Some questions have answers - talking about them can help us find answers or figure out who to ask. Other questions may not have answers, but it helps to wonder about them together and know that we're not alone with our feelings and worries. Either way, it will be important to talk with someone who knows you and can talk and wonder with you.

You might have some of these same questions yourself, or you can make a list and ask a parent or guardian to find out the answers for you, or to wonder together about them.

See "Note for Adults", next page

A NOTE FOR ADULTS:

Children naturally have many different questions about illness, dying, and what happens when and after someone dies. Some questions have answers and others may be mysteries. How you talk together about these things depends on many different things, including how a person died or might die, and religious, spiritual, or personal beliefs.

Try to answer in a clear and honest way using words that the child can understand. It is okay not to have all the answers and to say, "I don't know." For more information and guidance about exploring these questions, visit: <https://kidsgrief.ca/mod/lesson/view.php?id=211> and <<link to "Talking with your child" on caringtogether.life>>



What does it mean when someone dies?

When someone dies, it means that their body has stopped working and it cannot start working ever again. Their heart stops beating, and their lungs stop breathing. Their brain cannot think, and their body cannot move, feel pain, cold, hungry, or tired anymore. Doctors (and other people) can check by looking, listening, and touching a person's body after they have died.



What does dying feel like?


You might worry that dying is painful. The way a person's body stops working depends on their illness and where it is in the body. Many illnesses cause the body to slow down gradually until it stops. Other illnesses make the body stop more quickly. Usually, the stopping does not seem to be painful, but some people feel pain from their illness even when they are dying. Doctors and nurses do their best to help people feel as comfortable as they can. Every illness and every person is a little bit different.

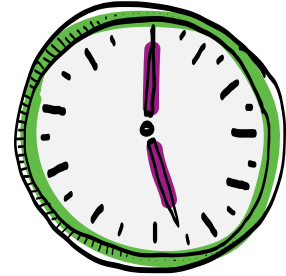


Talk with your doctor, nurse, or another healthcare team member about these questions and let them know what you're thinking and feeling so that they can help you.

Do people know when death is getting close? Can it happen suddenly?


You might worry that a person could feel pretty good one day and then die suddenly. Most illnesses work more slowly than this. Usually, the person who is dying feels more and more unwell, and more weak and tired. Every illness and every person is a little bit different.

 Talk with your doctor, nurse, or another healthcare team member about these questions if you have more concerns.



Will a person's family be okay without them?

When someone dies it is very, very hard for their family. Every family member misses, remembers, and struggles with different things. A family does not just "go back to normal" but most families can find ways to help each other. Over time they find new ways to feel "okay" and be a family even though they still love and miss the person who died.

 What are some of the ways that people in your family help to take care of each other? What is important to your family? What brings them strength or hope? Write or draw your ideas in your sketchbook.



Will their family remember them?

This is a common worry, but people who have had a family member die say that they could never, ever forget them. Some people talk with their families about how they would like to be remembered if they die. Here are some ideas that other children and young people have shared:



Keep pictures of them up around the house



Celebrate their birthdays with favourite foods and activities



Write to them in a journal that they keep in a special place



Choose a special symbol (like a rainbow, a dragonfly, or a cat), and think of them anytime they see one



Do something that was important to them, like learning guitar, cooking, or travelling



Include music, activities, or clothes in a funeral or celebration of life



Start a fundraiser for their favourite charity or to research the illness they died from



Take care of their special belongings (like toys, or jewellery) that they have given in a "will"



Plant a special garden or tree



Keep some of their clothes to wear or use as a blanket



Share stories and memories of them with others



If you were to die, how would you like people to remember or celebrate you? Write or draw your ideas in your sketchbook.

Many children and young people say that they were nervous or didn't know what to expect before they talked about these things with their families, but once they did, they felt relieved and comforted to know what their families would do if they died.

Back to [Start Here](#) page

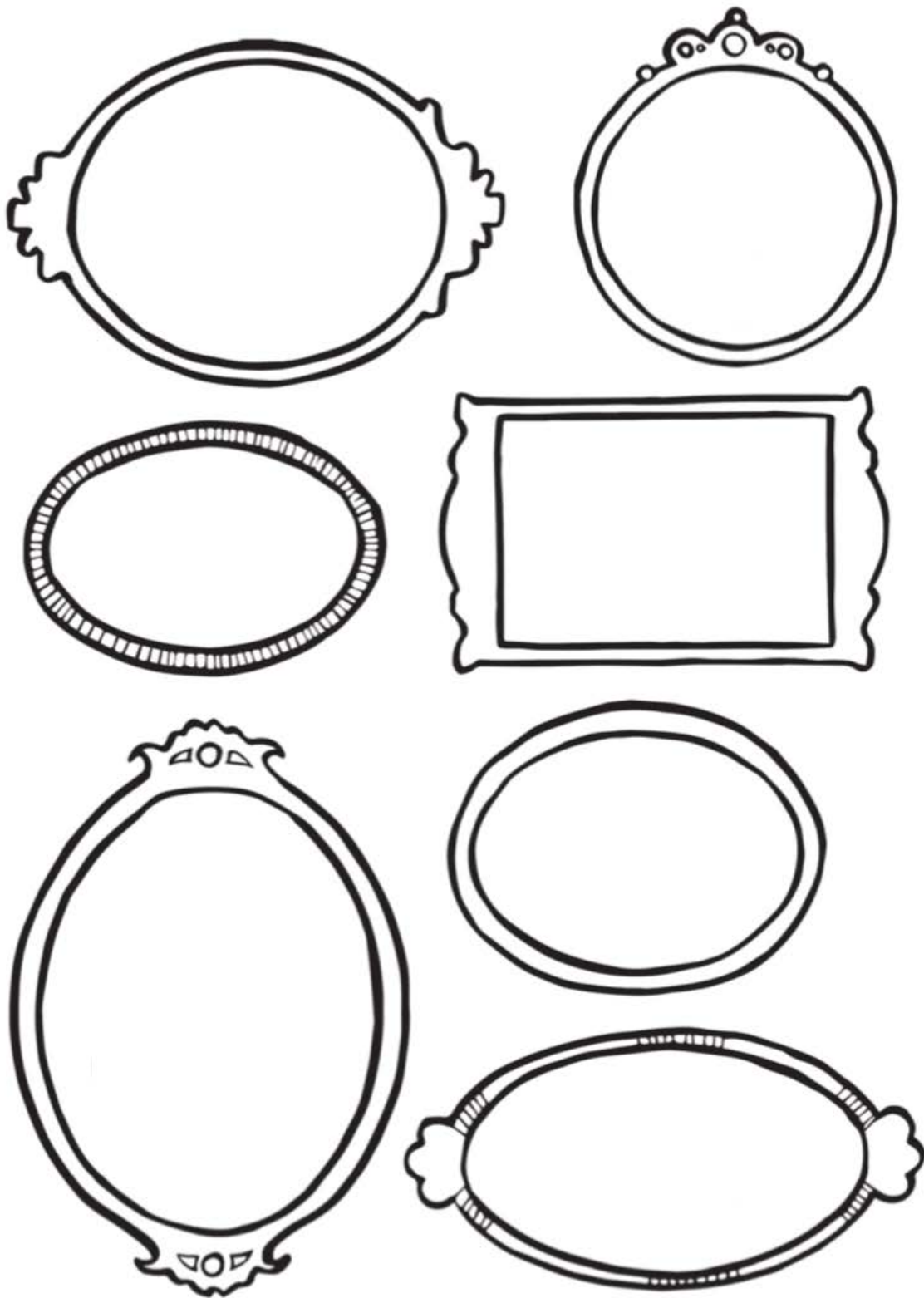


My Community & Me

Who IS in My Community?

Your community is all the people in your life who care about you and whom you might like to spend time with. When you have a serious illness, you may not get to see some people as often as you like. You might have to spend time at the hospital, or you might need to stay away from people or places that might have germs. It can be very hard not to see these people as often as you used to.

Draw or write the names of the people you miss spending time with below. Then make a plan for how to reach out to those people and connect with them, even in this new situation.



Why Relationships Feel Different

Relationships with some people may feel different because you are spending more or less time together, or dealing with new things.

Even if you do get to spend time with people who are important to you, you may feel like things have changed, especially if you can't do the same things together that you used to do. Here are some changes you might notice:

Being treated differently.

You might find that other people treat you differently than they used to. They may treat you differently than they treat other people, just because you are sick. Even if people are being extra nice to you, you might want to be treated the same way as before, or to be treated the same as everyone else.



Feeling lonely.

You might feel lonely even when you are with other people. It might seem like no one knows exactly how you feel. If that happens to you, try talking about how you're feeling. Sometimes other people have a lot of the same feelings even if they are going through something different.

Spending more time together.

This can be a good thing sometimes. You might feel like you are even closer than you used to be with some people in your family. On the other hand, spending a lot of time together might give you more chances to get on each other's nerves.

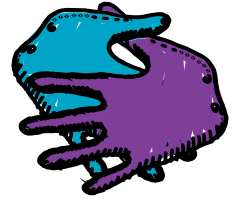


Going through a hard time together.

Sometimes this can be a good thing. You might feel closer than you were before, or you might realize that your family is stronger together than you thought. On the other hand, it can be hard to see other people in your family feeling sad or worried, or having other hard feelings. Some of you might try to hide your own feelings or keep your worries to yourselves. You might want to try to protect each other, but this can make you and your family members feel even more alone and more worried about each other. Try talking about your feelings together, even if it is hard to do at first.

Needing more help.

AS you get older, it's natural for you to do more and more by yourself, and not need as much help from your parents or other people in your family. But when you are sick, it's common to need more help again. That can be hard to deal with. You may feel frustrated that you don't have as much privacy, independence, or time to yourself. If you feel this way, it may be helpful to think of all the things that you can do on your own, or with only a little bit of help. Try to do those things whenever you can.



Feeling left out

Relationships with friends, classmates or other people in your life may feel different if you don't see them as often as you used to. You may miss your friends and activities, or you may feel left out. Here are some of the things that might happen and some ideas about what you could try.

If someone seems to be avoiding you, or if they don't know what to say or do around you, you could:

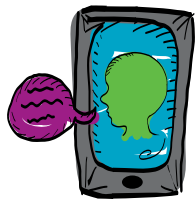
- Say something like, "I'm still the same person, and we can still do some of the same stuff we used to"
- Start talking about something you used to talk about together
- Write them a note or tell them what you do and don't feel comfortable talking about
- Suggest doing something that you used to do together.

If someone says something hurtful without meaning to, you could try saying something like, "I don't know if you meant it this way but when you say _____, it makes me think/feel/_____."

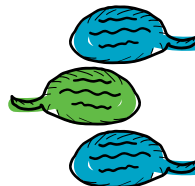
If someone says or does something hurtful, either on purpose or without meaning to, talk with an adult you trust who can help you figure out what to say or do to take care of yourself.

Make a Plan: Relationships

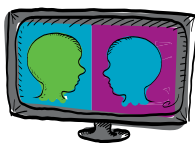
If your friends and family cannot visit often, try:



Talking on the phone



Writing email or text messages



Video chatting



Writing letters or send artwork



Doing an activity while you video chat, like baking, dancing, playing a game, or making a craft

When you see friends and family, you could:

Try to do "regular stuff" together.

Change the way you used to do things. For example, if you used to play hockey together, watch a game together instead. If you used to cook together, eat a favourite meal together.

Make a list of the people you would like to connect with, and some of the ways you might be able to reach out to them.

Person	Activity we can do together
-----	-----
-----	-----
-----	-----
-----	-----
-----	-----
-----	-----

Make a Plan: Activities

You may also miss activities while you are dealing with your illness. When you can't do something the way you used to, you might still enjoy doing it a bit differently. For example, if you miss going to school, you might be happy to work with a teacher at the hospital because doing schoolwork feels "normal." Or maybe doing schoolwork at the hospital will make you miss your school even more. Think about ways you might keep things feeling as "normal" as possible, and things you could try to find a "new normal."

What activities would you like to do? What are some ways you can do them with your illness?



Talk to friends



Listen to music



Play games



Tell jokes



Be with your family



Read



Eat favourite foods



Watch TV or movies

Other: _____



Activity - Use your sketchbook and draw!

What is the hardest thing about having this illness?

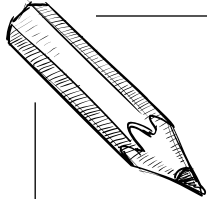
Is there anything good about having this illness?

These might be hard questions to answer. It's okay to have big feelings about it.

Use this space to write and draw what you think or feel about these questions.

Use this space to write or draw whatever you are feeling or thinking.

Has anything surprised you as you've worked on these activities? Have you learned or realized anything new about yourself or your life? You are an incredible, important, and unique person! We hope you will keep sharing your thoughts and feelings with other people.



A large, empty rectangular box with a thin black border, intended for writing or drawing.

Back to [Start Here](#) page

Information for adults

Who is it for?

This activity book has been designed for young people who are living with a serious or life-threatening illness. 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.

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 this book?

Families often say that there are things that feel important to talk about, but they worry about, or don't know how to talk about these things. This book was written to help guide parents, caregivers or health care providers explore some of these topics together with children who have a serious illness.

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

This book is a tool to help start, or guide a conversation. It should not be used instead of a conversation.

How can I prepare to use this book?

Review the whole activity book 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.

Will they complete it on their own or with help?

Most children and teenagers will find it helpful to have an adult work on this book 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 this book 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 content be “right” for this child?

Each child and situation is unique, so this book 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 to a child’s situation, needs, and interests. Here are some ideas for adapting this book 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 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

This activity book includes 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 awhile 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.

Content about dying and death

This book focuses on illness, feelings, and plans, and includes one section with questions about dying and death. This section is not focused on the child. It explores common questions people have even if they are feeling well.

More support

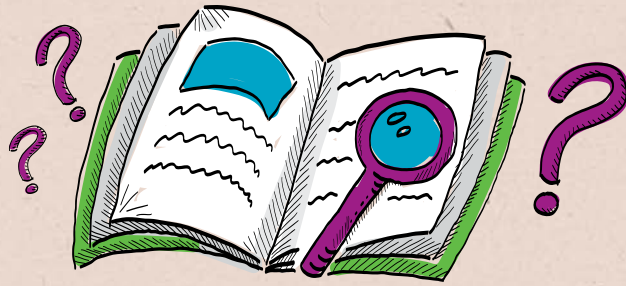
If you have questions about this workbook, you can contact us at info@virtualhospice.ca.

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

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



www.virtualhospice.ca



Resources & Downloadable PDF

Tools for relaxation and comfort:

HeadSpace (app - <https://www.headspace.com/meditation/kids>)

PeaceOut (podcasts - <https://app.kidslisten.org/pod/Peace-Out>)

CosmicKids Yoga (youtube videos including yoga with ASL translation, meditations, etc. - https://www.youtube.com/channel/UC5uIZ2KOZZeQDQo_GSi_qbQ)

Recorded guided imagery from pediatricians at CHOC (children's hospital): www.choc.org/programs-services/integrative-health/guided-imagery/

<https://kids.aboutkidshealth.ca/> - health games and videos for kids about how bodies and illnesses work, ways to help

<https://kidshelpphone.ca/> - call, text or chat to get help



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