Holland Blcorview

Kids Rehabilitation Hospital

Siokit

A booklet for brothers and sisters of children with disabilities, medical complexities or diagnoses



INTRODUCTION

Welcome to the SibKit!

What is the Sibkit? The SibKit is a booklet filled with interactive tools and tips for brothers and sisters of kids with disabilities, medical conditions or diagnoses.

Why is the SibKit helpful to me?

These tools and tips can support you to:

- Understand your sibling's diagnosis
- Feel more included in your sibling's journey
- Work through feelings you might experience
- Learn about who will help support your family

Who made the SibKit?

- Siblings
- Parents
- Clients who have disabilities, medical complexities or diagnoses
- Health professionals who work at Holland Bloorview Kids Rehabilitation Hospital in Toronto, Canada

Tell us what you think about the SibKit by emailing

resourcecentre@hollandbloorview.ca



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INTRODUCTION | Meet the sibs

This team of sibs knows a lot about what it's like to have a sibling who visits Holland Bloorview. They are here to guide you through this workbook, adding tips and hints along the way.



Hi my name is **Dimitri**, I'm 18 years old, I have a sibling with ASD and I'll be your guide to My Future.

> Hi my name is Aaliyah, I'm 11 years old, I have a sibling with ASD and I'll be your guide to Resources.



Hi my name is **Meghan**, I'm 7 years old, I have a sibling with CP and I'll be your guide to Care for Myself and Others.

Hi my name is **Aaron**, I'm 14 years old, I have a sibling with Medical Complexity and I'll be your guide to Thoughts and Feelings.



Hi my name is Liam, I'm 25 years old, I have a sibling with ASD and I'll be your guide to **My Story**.

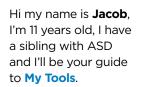


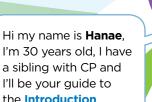


Hi my name is **Abby**. I'm 11 years old, I have a sibling with ASD and I'll be your guide to Circle of Care



Hi my name is **Tallula**. I'm 8.5 years old, I have a sibling with CP & Seizure disorder and I'll be your guide to What Makes Us Unique.













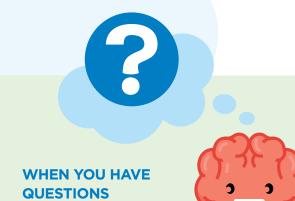


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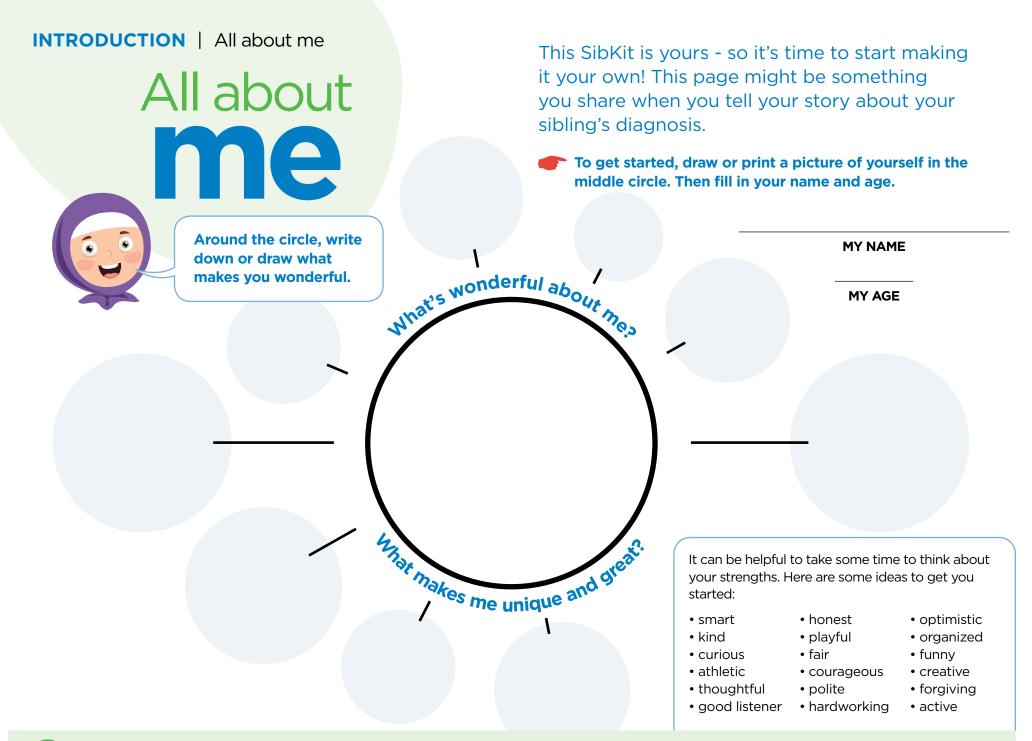


The SibKit is full of new ideas and information and we know you will have questions! At the end of each chapter, you will see a spot where you can write down any questions you still have.

When you're ready, take some time to go over these questions with an adult you trust.









TIPS FOR SIBLINGS

You can go through the SibKit on your own or with someone you trust. If you're reviewing with someone else, let them know when you've reviewed enough.

Remember that this kit is just for you! You decide how and when you would like to use the SibKit. Some of the pages might be more helpful now, while other pages might be more helpful later. You don't have to use all of the pages.

Going through the SibKit may bring up some big feelings. Here are some helpful tips:

- As you go through the SibKit, you may be surprised by your own feelings.
- Be honest about your thoughts and feelings.
 Holding back or ignoring your feelings just makes
 them grow bigger. You can write your feelings down
 or share them with an adult who you trust.
- Your feelings may change as you go through the SibKit. Your feelings may also change over time. It's okay if your thoughts and feelings change.
- As you go through the SibKit, some of your thoughts and feelings might be upsetting. It is okay to fully feel your emotions. It is also okay to take a break and come back to the SibKit at another time.





Getting Help From Trusted Adults:

- It is okay to choose who you want to talk to, and when you want to talk, when you're comfortable. Ask for more time if you need it to talk about your thoughts and feelings.
- There are no bad questions. It's okay to ask the same questions more than one time. It can take time to understand.

You can visit the SibKit over and over again, for months and years to come.

INTRODUCTION | Tips



TIPS FOR PARENTS/CAREGIVERS

Talking about your child's diagnosis may feel challenging. We suggest sharing thoughts and feelings as a family can help to understand and cope.

- Be honest. It's important to share information that is accurate. Children may "fill in blanks" with incorrect information if they are not told what is happening"
- Be open. The best way to encourage your children to share and talk about their feelings is to do that yourself. Make time to sit with your family and discuss these feelings. Build resilience and strengthen your family bond.
- Follow your child's lead. Some siblings may prefer just a little bit of information at a time. Others may feel the need to talk about these topics at length, for months or years after. This is fine and part of the processing and adjustment.

- Ask your child questions to see if they understand.
 This is a good opportunity to discuss any misunderstandings.
- *Give your child updates* on their sibling's progress, using words they understand, no matter how small. Reassure them that their brother or sister is receiving very good care.
- Check in with your child as they are completing this SibKit.

 It's important to validate and acknowledge any feelings and emotions that may come up for them as they work through desired sections.

For additional tips on how to support the sibling of your child with disabilities, medical conditions or diagnoses, please refer to the Resource section at the end of the Sibkit, or visiting the Resource Centre at Holland Bloorview in person or online.

If you'd like to connect with other parents for additional support, please speak to your child's paediatric team, doctor, or health care staff.



TIPS FOR PROFESSIONALS

- Follow the family's lead. Families and siblings may approach
 you with the SibKit, asking for your support to complete
 some of the activities in the kit. This is an opportunity for
 you to engage and inform the sibling about the client's care.
 Check in with siblings about what questions they have and
 answer them to the best of your ability.
- Identify siblings who may benefit from the SibKit and share it with them. Clinicians are encouraged to identify and share the Sibkit with siblings who could benefit from education and/or emotional support regarding their sibling's diagnosis.
- Reach out to your team. If you feel that the discussions that arise while working through the SibKit are beyond your

- scope of practice, you can encourage the family to reach out to their child's clinical team. If the child does not have a social support team in place, you can encourage them to reach out to a local association.
- Use resources to support your work. We have included a resource list at the end of this kit to support you as you care for the siblings of clients.



Holland Bloorview

Kids Rehabilitation Hospital

Some children and teens come to Holland Bloorview Kids Rehabilitation Hospital in Toronto to meet with a doctor or clinician. Here is some information about Holland Bloorview.



WHAT IS HOLLAND BLOORVIEW?

Holland Bloorview Kids Rehabilitation Hospital is a rehabilitation hospital in Toronto, Ontario that helps children and youth with disabilities and/or medical conditions.

Rehabilitation or rehab is the word we use to describe activities that let your sibling practice things that might be hard for them.

To learn about Holland Bloorview, you can check out our website at:

www.hollandbloorview.ca/

To see where your brother or sister is staying, click here for a virtual tour:

www.hollandbloorview.ca/Aboutus/VirtualTour



WHY DOES MY SIBLING NEED TO GO TO HOLLAND BLOORVIEW?

Your brother or sister may work with a therapist, clinician or doctor at the hospital. Each therapist they will see is an expert in one of the things your sibling needs help with. Holland Bloorview is famous for having some of the best therapists in the world who help kids reach their best potential!

By going to Holland Bloorview, your sibling can do rehab with lots of different therapists every week. There is a school, pool, art studio, cafeteria and gym inside the hospital, which your sibling might visit as well.



HOW OFTEN WILL MY SIBLING VISIT HOLLAND BLOORVIEW?

Depending on your needs, they will need to spend different amounts of time at Holland Bloorview. Some kids might visit more often if they need more therapy. Services your sibling might access at Holland Bloorview include; Dental, Occupational Therapy, Physiotherapy, Orthotics and Prosthetics, and many more!

The **Body**



Before we talk about the diagnoses, it's important for us to understand the job of each body part.

Eyes

Two organs that allow you to see what's around you. This information is sent to the brain which processes the information, so your brain knows what's going on around you.



https://kidshealth.org/en/kids/eyes.html

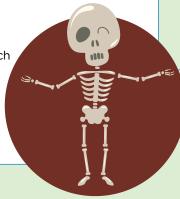
Nose

An organ that allows you to smell and is a main part of your respiratory system that allows you to breathe.

Bones

Bones give your body structure help hold you upright, allow you to move, protect your internal organs, and much more. All of your the bones in your body make up your skeleton.

https://kidshealth.org/en/kids/ssmovie.html?WT.ac=en-k-htbw-main-page-g



Ears

Two organs that allow you to hear sounds around you in your environment and help maintain your sense of balance.

Muscles

Muscles allow your body to move and they control organs in your body that are essential to its functioning. Some muscles are voluntary which means you control them (moving your arms) while others muscles are involuntary which means you can't control them (your stomach or heart).

https://kidshealth.org/en/kids/msmovie.html?WT.ac=en-k-htbw-main-page-a

DNA

The material that carries all the information about how a living thing will look and function. For example, it determines physical traits such as eye colour but also how different parts of the body work.

https://kids.britannica.com/kids/ article/DNA/390730





THE BODY | Organs

Lungs

Two bag-like organs that fill with air when you breathe in (inhale). and The oxygen from this air is then carried from your lungs to your blood. The lungs also help your body push out old oxygen called carbon dioxide when you breathe out (exhale).

Trachea: The trachea or windpipe is part of your airway, it allows air to enter your lungs. The trachea is lined with cilia (small hairs), which help keep fluids and foreign particles (dust) out of the airway so that they stay out of the lungs.

Kidneys

Two bean-shaped organs that filter waste from the blood and produce pee to get rid of it. If they didn't do this, toxins (something we don't want in our body) would quickly build up in the body and make the person sick. People usually have two kidneys but can live a healthy life with just one.

https://kidshealth. org/en/kids/pee. html **Nerves:** Something inside our body that looks like wires or cables that send signals to and from the brain. The brain uses nerves to communicate with everything in your body.

Central Nervous System

Consists of two parts that allow your body to send and receive signals.

Brain: controls your thoughts, memories, emotions, sense of touch, movement, vision, breathing, temperature, hunger and every process that controls our body.

Spinal Cord: a bundle of nerves that connect your brain to the rest of your body which allows your body to function. Your spinal cord is protected by your spinal column which is made of many bones.



Liver

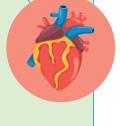
The largest solid organ in your body. It's three main jobs are:

- 1. cleaning your blood
- 2. producing an important digestive liquid called bile
- 3. storing energy in the form of sugar called glycogen
- https://kidshealth.org/en/kids/liver.html?ref=search



A strong muscle about the size of your fist. It pumps blood through blood vessels around the body and sits inside the chest, protected by the ribcage. The blood carries oxygen and other nutrients your body needs.

https://kidshealth.org/en/kids/csmovie. html?WT.ac=en-k-htbw-main-page-a



THE BODY | Organs

Pancreas

An organ in your abdomen that helps digest the in the digestion process of breaking down foods that you've eaten and it also helps regulate your blood sugar.

https://kidshealth.org/en/kids/ word-pancreas.html?ref=search

Esophagus: a long stretchy pipe that moves food from the back of your throat to your stomach. But also at the back of your throat is your windpipe, which allows air to come in and out of your body. When you swallow a small ball of mushed-up food or liquids, a special flap called the epiglottis (say: ep-ih-GLOT-iss) flops down over the opening of your windpipe to make sure the food enters the esophagus and not the windpipe.

Intestines

Part of your digestive system.

Small Intestine: helps break down the food mixture so your body can absorb all the vitamins, minerals, protein, carbohydrates and fats, which are nutrients found in the food you've eaten.

Large Intestine/Colon: absorbs water and salts from the material mixture that has not been digested. Anything leftover leaves the body as waste (poo). as food and get rid of any waste products left over.

https://kidshealth.org/en/teens/ digestive-system.html?ref=search



A stretchy sack shaped like the letter "J". Your stomach size depends on the size of your body and how much and how recently they have you've eaten.

- 1. Store the food you've eaten
- 2. Break down the food into a liquid mixture
- 3. Slowly empty that mixture into the small intestine
- https://kidshealth.org/en/kids/ digestive-system.html?ref=search



Bladder

A sac that holds pee until it's time to go to the bathroom.

https://kidshealth.org/en/kids/ pee.html?ref=search

Urethra: the tube that carries pee from the bladder out of the body.



Write your questions here!



DIAGNOSES

Everyone is different, which means that a diagnosis might look different for each person. The important thing to remember is that this is just a little bit of information, but you know your sibling best. Diagnoses don't change who your sibling is to you. If you have any questions about words or diagnoses you hear you can always ask an adult you trust.

Amputation

An operation to remove a body part (such as a foot or arm) that is sick or injured when the care team realizes it cannot be made better.

(Phoenix Children's Hospital, 2020)

Attention Deficit Hyperactivity Disorder

Often called ADHD, people who have ADHD tend to find it challenging to pay attention and are very active, which means they might have trouble sitting still.

https://kidshealth.org/en/kids/word-adhd.html?ref=search

Autism Spectrum Disorder

Autism Spectrum Disorder is a difference in the way someone's brain develops. Someone with Autism may understand the world differently. Someone with Autism might communicate using sounds, gestures, or technology, as well as talking. Some people may need support with making friends, fitting in, coping with changes in routine, handling loud noises, bright lights, or crowds. No one knows the exact cause for Autism but doctors and scientists agree that this is something that a person is born with.

https://kidshealth.org/en/kids/autism. html?ref=search

Brain Injury

Brain injuries come in many different forms, sometimes they are caused by illnesses and sometimes they are caused by injuries. Brain injuries can impact almost all areas of the body and how it works. People can have challenges with walking, talking, eating, thinking or controlling their emotions and behaviours after a brain injury.

Cancer

A

A group of cells in your body that are not supposed to be there. All cells have important jobs but cancer cells do not carry out an important job in the body so medical teams often choose to remove

these cells. There are three main ways to remove cancer cells through medicine, radiation or surgery. Cancer can come in many different forms and impact all different areas of the body. Sometimes the cells group together to form a tumour.

Cerebral Palsy

A condition that can make it hard to walk, talk, or eat. Cerebral palsy (or CP for short) affects how the brain communicates with muscles. People with CP may find it challenging to control how their muscles move, and some may need to use a wheelchair, walker or crutches.

https://kidshealth.org/en/kids/word-cerebral-palsy.html?ref=search

Chronic Pain

Chronic Pain is used to describe repeated or ongoing pain that lasts longer than 3 months. Pain can affect all parts of someone's life and can also impact their family. Chronic pain can happen for many different reasons.



Developmental Coordination Disorder

Occurs when there is a delay in the development of motor skills like running or difficulty coordinating movement like walking downstairs or catching a ball. When someone has a developmental coordination disorder it may require more effort performing common, everyday tasks.

https://canchild.ca/en/diagnoses/developmental-coordinationdisorder

Developmental Delay

Developmental Delay is a term used to describe someone who learns and grows at a different speed than others of the same age. Delays may affect physical abilities, speech and language, thinking, play and social skills. There are many things that can cause a developmental delay and many therapies that can help someone gain and learn new skills.

https://www.ssmhealth.com/cardinal-glennon/developmentalpediatrics/developmental-delay

Diabetes

When a person has diabetes their pancreas cannot create insulin, this is called Type 1 Diabetes. In Type 2 Diabetes a person can create insulin, but it doesn't do the job it should be doing.



https://kidshealth.org/en/kids/diabetes-basics/what?ref=search

Down Syndrome

Down syndrome happens when a baby is born with an extra chromosome. This extra genetic material changes the way the baby's body and brain develops. People with Down Syndrome may have added challenges when they are learning new things. It can also affect other parts of their health (e.g. heart or hearing).



Epilepsy

Epilepsy is a condition where the nerves in someone's brain has trouble communicating. When this happens it causes a seizure. There are many types of seizures and each one looks different. Sometimes people may fall asleep, shake, stare, or fall down. Doctors may prescribe medicine, change the person's diet or perform surgery to help a person with epilepsy.

Hearing Impairment

Something that happens when there is a concern with one or more parts of the ear or ears, the nerves coming from the ears, or the part of the brain that controls hearing. "Impairment" means something is not working the way that is expected. Someone who has hearing challenges might be able to hear some sounds or nothing at all.



https://kidshealth.org/en/kids/hearing-impairment. html?ref=search

Invisible Disability

When people say the word "disability" they might imagine someone whose body works differently. Sometimes, kids might need extra help and we can't see why. Their disability may be invisible. They may think, act and talk differently. Because of these changes, they may need extra help to learn and play. This is called an invisible disability.

Guillain-Barre Syndrome

Guillain-Barre Syndrome is a condition where the nerves outside the brain and spinal cord are attacked by the Immune system which leads to temporary weakness or difficulty moving your muscles.

https://kidshealth.org/en/parents/gbs.html?ref=search





Learning Disability

Learning challenges happen because of the way the brain takes in and understands information. When someone has a learning disability, it doesn't mean they can't learn. It means they might need to figure out different ideas or strategies that help them learn best.

https://kidshealth.org/en/kids/learning-disabilities. html?ref=search

Muscular Dystrophy

Muscular Dystrophy is an illness that slowly weakens the body's muscles. It's caused by incorrect or missing genetic information that stops the body from making everything it needs to build and maintain healthy muscles.

https://kidshealth.org/en/parents/muscular-dystrophy. html?ref=search

Rett's Syndrome

Rett's Syndrome is a disorder that affects the way the brain develops, causing a loss of motor skills (like walking or climbing) and speech.

https://www.mayoclinic.org/diseases-conditions/rett-syndrome/ symptoms-causes/syc-20377227

Scoliosis

Scoliosis is a condition where the spine is curved rather than being in a straight line. Sometimes people will need to wear a brace and/or have surgery to help change the shape of their spine.

Spinal Cord Injury

Spinal Cord Injury occurs when the bones protecting the spinal cord are damaged in some way.

There are two types of spinal cord injury:

- 1. Incomplete: The ability of the spinal cord to send messages to and/or from the brain is not completely lost. Some feeling and movement is possible below the level of injury.
- 2 Complete: A total loss of feeling and movement below the level of injury.

https://www.christopherreeve.org/living-with-paralysis/newlyparalyzed/how-is-an-sci-defined-and-what-is-a-complete-vsincomplete-injury

Stroke

Stroke is a condition that occurs when blood stops flowing to part of the brain.

(Phoenix Children's Hospital, 2020)

Vision Impairment

Vision impairments impact people differently and can range from not being able to see to not seeing colours the same way others do.

https://kidshealth.org/en/teens/visual-impairment. html#:~:text=Visual%20impairment%20is%20a%20 term, have %20 what's %20 called %20 legal %20 blindness.



Write your questions here!



EQUIPMENT

AFOs

AFO is the short way of saying an Ankle Foot Orthotic (brace) that supports a person's ankle or foot by keeping it straight so they can move more easily.

Cane

A long stick that a person can lean on to help them keep their balance so they can safely walk.

G-tube

A small tube that goes from the outside of the belly directly into the stomach to give food, drinks, or medicine.



Helmet

This piece of equipment is important for us to wear while we do many sports. It is also important for people who have frequent falls or need to protect their head as it heals from a brain injury.

KAFOs

KAFOs is the short way of saying a Knee Ankle Foot Orthotic (brace) which supports a person's whole leg and foot, to help the joints and muscles, move more easily.

NG tube

A long flexible tube that goes into the nose, down the throat and the esophagus (the muscular tube that connects your mouth and your stomach) and into the stomach. It allows a person to receive formula and/or medicine when they cannot swallow safely.



A brace that provides support and increases movement for people who are born with or develop problems in their muscles, bones and/or joints. They can also help correct or prevent problems, improve movement (like walking), reduce pain and support the spine and upper or lower body (arms, legs, etc.).

https://www.nemours.org/services/pediatric-orthotics.html

Prosthetics

A device that replaces and helps people regain function in a missing body part like an arm or leg.

https://www.nemours.org/services/prosthetics.html

Tracheostomy

A small opening made in someone's throat where a tube can be placed to help them breathe.

Walker

A four-legged frame with or without wheels that allows a person to lean on it for support, rest or balance so they can safely walk.

Wheelchair

A chair with wheels that supports people who cannot walk, or have difficulty walking, to move. Some people may use a wheelchair for a short-time (temporarily) or a long-time (permanently).



Circle of trust

This page was made to remind you that you are not alone by remembering the helpful people who are part of your life.

In the circles, write the names of the people who know and support you. This could be a family member, a teacher, a coach, a friend – anyone who you feel safe with.



Keep in mind: You may have different people you trust when you have questions or need help. AT SCHOOL

IN MY
FAMILY

IN THE
COMMUNITY

Who am I comfortable talking with?

Who am I comfortable asking for help?





THE CIRCLE OF CARE | Circle of care

Here are some of the people that may help your sibling.



A team member who plans fun recreational activities to help your sibling practice their goals.



SPEECH LANGUAGE PATHOLOGIST A team member who focuses on a person's talking, understanding, thinking and swallowing. They work closely with an Occupational Therapist to decide what food is safe for a person to eat.



SOCIAL WORKER

A team member who helps explore all different types of support not just for your sibling but for your whole family!



A team member who has special training to work in a hospital. They are experts in making kids laugh, play and feel better.



PERSONAL SUPPORT

A team member who helps to take care of people while making sure they can take part in many daily activities and fun experiences.



PSYCHOLOGIST

A team member who may give your sibling tests to find out more about how they think, learn and are feeling. They can give suggestions to your sibling's teacher or can spend time talking with your sibling about their feelings.



A team member who uses art as a way to help people express their feelings.



EDUCATIONAL ASSISTANT

A team member who works in schools, helping children to feel included in their class and making sure they are supported while completing their school work and activities.



NURSE

A team member who will help to take care of your sibling. You may see a nurse when you go to appointments or the nurse may come to your house.

THE CIRCLE OF CARE | Circle of care



MUSIC THERAPIST A team member who often works in the hospital to help people meet physical, emotional, social and learning goals with music. They might play, listen to or record music during music therapy sessions.



PHYSIO-THERAPIST A team member who helps your sibling with muscle strength, movement and balance.



OCCUPATIONAL THERAPIST

A team member who has many neat ideas to help people be as independent as they can be at home or school while making sure what they do is safe for them.



TRANSITION COORDINATOR

A team member who can find professionals in your community to help your sibling and your family.



CHILD LIFE SPECIALIST

A team member who helps patients and siblings cope with their feelings while they are in hospital.



RESPITE WORKER

A team member who might help to take care of your sibling while other caregivers can have a short break, do other tasks, or spend time with you.



DOCTOR

A team member who helps people when they are sick or hurt. Doctors can also help care for people by making sure they are growing and developing! Doctors focus on all different areas of the body so your sibling may have many doctors caring for them.



CHILD AND YOUTH WORKER

A team member who helps families and kids to better cope and manage behaviour.



Write your questions here!

THE CIRCLE OF CARE | Circle of care

Circle of care



Talk to your sibling about their team of therapists for help filling this out

Your sibling will be getting the help of lots of different therapists while they are at Holland Bloorview. Each therapist is an expert in one of the things that your sibling needs help with. You can use this page to help you remember them all.

In the circles below, write the names of each therapist that your sibling works with. For help filling this out you can:



Visit Holland Bloorview with your sibling. Participate in their therapies and fill out each circle like a scavenger hunt.





What makes us unique

my sibling and I



Draw yourself and your sibling or paste a picture of you two together.

Everybody is different and unique, here is a chance to show us what makes you and your sibling special.



WHAT MAKES US UNIQUE | Interests



Let's explore what makes you and your sibling different or the same when it comes to interests. What makes each of you unique? Work on this chart alone or with your sibling.

Fill out this page by writing, drawing, colouring or pasting in pictures.

	My Favourites	My Sibling's Favourites
Food		
Sports		
Books		



	My Favourites	My Sibling's Favourites
Games/ Activities		
Movies		
Music/ Singer or Band		



WHAT MAKES US UNIQUE | Understanding my sibling



Use this page to write down information about you and your sibling.

You may need to talk to an adult you trust to help figure some of this out.

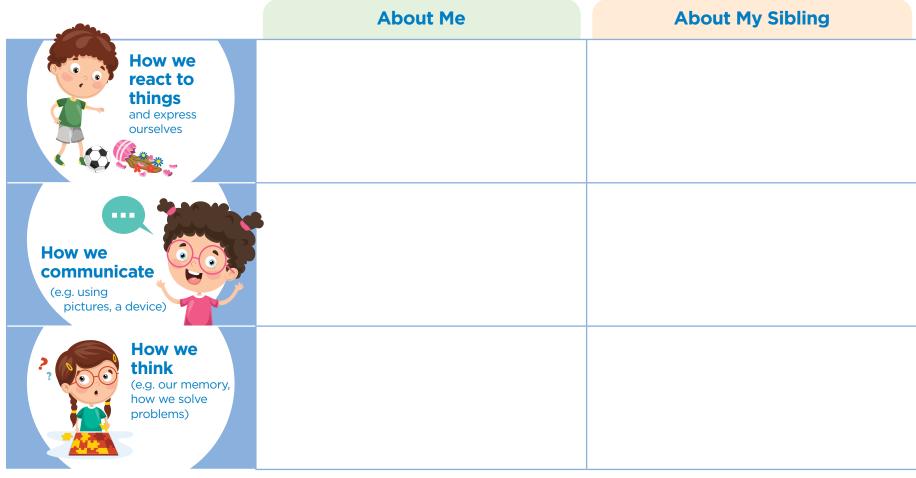
You could also ask your sibling, your sibling's doctor or therapists to help you understand.

You can fill out this page by writing, drawing, colouring whatever you like!

	About Me	About My Sibling
How we eat (e.g. with my hands, with utensils, via feeding tube)		
How we move (e.g. do they move on their own or using equipment?)		
Equipment* (e.g. assistive devices, protective gear, or medication)		



WHAT MAKES US UNIQUE | Understanding my sibling





Write your questions here!



24

Thoughts and feelings

about my sibling's diagnosis

A diagnosis affects the whole family – including you! As a sibling of someone with disabilities, medical complexities or diagnoses, you can feel lots of different feelings.

These next few pages have examples of feelings that other brothers and sisters felt about their sibling's diagnosis. Your feelings might be different than theirs. You can add to these pages by writing down or drawing any other feelings you feel.

It's important to know that your feelings might show up in different ways. For example, you may notice it's harder to fall asleep. You may not want to talk to your friends as much. You might find it hard to concentrate in school or to focus and finish your homework. These are a few examples of different ways your body and brain might show what they're feeling.

Always give yourself permission to notice and feel. Try to focus on healthy ways to release each emotion. We have included some suggestions to get you started.



TIP for your parents/caregivers



When talking to your parents about your thoughts and feelings, your parents can help by reminding you that it's okay to have these feelings. They can show you that your feelings are okay by:

- listening to you
- asking you questions to help them understand what you're thinking and feeling
- sharing their own feelings
- Finding the sibling a therapist or talking to their therapist if they need help processing those thoughts and feelings.





The feelings on these pages are organized according to how people feel when big changes happen.

Sometimes you might feel lots of different feelings, all at the same time. This is okay. Some of your feelings might be upsetting (closer to the red side) and other feelings might feel really good (closer to the purple side). Some feelings might feel comfortable, while others might feel uncomfortable. Some feelings might be new to you. Some feelings might take a long time to understand, work through and get used to. It's ok to have different kinds of feelings at the same time and all of these feelings are normal.





Examples of What this feeling might look like this feeling Angry • It can be hard to understand Frustrated • You may notice that your brother or sister is being treated differently than you. • You may not know why you get told not to do something your brother or sisters seem to "get away with". • You may also feel angry that this happened. **Anger** When I'm feeling angry or frustrated, I go for a walk to cool off What I can do when Things my sibling does that makes me feel angry or frustrated I'm feeling angry or frustrated



Examples of this feeling	What this feeling might look like
• Surprised	• It can be hard to believe that this has happened.
• Scared	You may worry more about your siblings and family members now.
• Worried	You may be scared about what's coming next or what the future looks like.
Irprise	When I'm feeling scared or worried, I find it helpful to ask questions



Examples of What this feeling might look like this feeling Confused • You might feel jealous or confused when your parents spend more time with your sibling. Jealous • You might feel embarrassed when others don't understand how Embarassed your sibling reacts. Confusion When I'm feeling jealous, I spend a day with my parents. When I'm feeling embarrassed, I talk to other people who know what it's like. Things my sibling does that makes me What I can do when I'm feeling feel confused, jealous, or embarassed confused, jealous, or embarassed



Examples of What this feeling might look like this feeling Sad • You might feel alone because your parents are taking care of your brother or sister. Alone • You might feel sad because your sibling is going through something Tired hard. • You might feel tired because you're helping out more at home. **Sadness** When I'm feeling When I'm sad or tired, I like to feeling sad or alone, watch my favourite I find it helpful to movie or read talk to somebody my favourite I trust. book. Things my sibling does that makes What I can do when I'm feeling me feel sad, alone, or tired sad, alone, or tired



Examples of What this feeling might look like this feeling Accepting • Proud • Some siblings feel really proud of their brother and sister. They see how hard they are working. Happy Strong • It's important to remember to celebrate each other's small Confident Loved victories, like getting a good grade or winning a game. Acceptance When I'm feeling confident, strong, and proud, I listen to happy music Things my sibling does that makes What I can do when I'm feeling me feel accepting, happy, loved, accepting, happy, loved, proud, protective, proud, strong, confident, strong, or confident or relieved



Understanding

challenging behaviours in my sibling:

TIP:
This section may be especially helpful for parents/caregivers.



Behaviour is the way a person acts in response to a particular situation to achieve a certain goal. Behaviour can be thought about as one way of communicating. Children may use their behaviour to say something about their environment (the world around them) or about what's going on inside their body (the world inside of them).

Often, we believe children's "bad behaviour" is because the child is just being difficult. The truth is that children may use negative behaviours to communicate when they don't have the abilities to say what they feel in a more positive way. This can be a normal reaction to the many sudden changes that the children are experiencing in their relationships and routines.

To support a child to communicate/behave in a more positive way, it's important to figure out what they might be trying to tell you. Whenever possible, approach a child's behaviour with curiosity. What are they trying to tell you?

BUILDING YOUR TOOLBOX TO HELP SET CHILDREN UP FOR SUCCESS

Provide Choices

Not everything is a choice but, children feel a sense of power and control in their lives when they are provided with choices. This can be especially important when children may be feeling a loss of control. Limit choices so the child does not feel overwhelmed.

Control Environment

Environment can make a big difference in how children feel. Think about if there are things that can be added or taken away to benefit the child. (Ex. Are the lights too bright? Too many distractions?)





BUILDING YOUR TOOLBOX TO HELP SET CHILDREN UP FOR SUCCESS

Use Prompts

Prompts are like clues or reminders to help your child with a specific behaviour. Prompts can be verbal (something you say), visual (a picture), gestural (pointing), or physical (gently moving your child's or sibling's body).

Give Praise

Verbally praising encourages the positive behaviours you want to see. It also helps to increase children's confidence and self-esteem.

Set Limits

Limits let a child know what is expected of them. They also create a sense of predictability and security while the family is going through significant changes. Ensure that the limits are clear, simple, consistent, and reasonable.

Consequences

If limits are not followed, there need to be fair consequences that are clear, reasonable and enforced in a timely manner. When there is no follow through on consequences, children will continue to test their limits.

Most behaviours are expressing a need that falls into one of the following categories:

Examples of Behaviours

1: Need for Attention

Some children would rather have "bad" attention than no attention at all.

• Throwing a tantrum

- Threatening "I'm going to run away"
- Defiance "I'm going to do it anyway"

Shaping More Positive Behaviours

- Planned ignoring—not giving any attention to the negative behaviour (if it is safe to do so)
- Over exaggerating praise for good behaviour
- Planning activities together

2: Need for Item or Activity

Some difficult behaviour might be a way to get a "reward" or activity they really like.

- A child throws a tantrum and the parent bargains to buy the child a new toy if they stop the tantrum
- Make sure you are not accidentally rewarding difficult behaviour with a rewarding item or activity.
- Try to find times when your child has positive behaviour and reward them then



MY THOUGHTS AND FEELINGS | Understanding Challenging Behaviours

3: Need for Escape

Challenging behaviours
can occur so that the child can get away
from the task at hand. The task itself
might be challenging or unpleasant for
the child.

Examples of Behaviours

- Hitting or misbehaving during a therapy session
- Ignoring what you are telling them to do
- Throwing a tantrum before leaving for the hospital

Shaping More Positive Behaviours

- It is very important to always follow through with the requested task, it creates structure and predictability
- Switch your environment to do the same task

4: Need for Sensory Stimulation

A child may behave in a way that is "self-stimulating". This behaviour provides the child with a feeling in their body that is pleasing to them OR is a response to something outside of them that is displeasing (e.g. pain). These behaviours should not be treated as avoiding or attention seeking.

- · Rocking back and fourth
- Flapping hands
- Hitting knees
- Banging head against the wall

- Look for multi-sensory rooms in your community. These spaces allow children to enjoy feelings of touch, light and sound.
- Hugs for comfort
- Massage for deep pressure
- Light up toys
- Ask about occupational, art or music therapy or work to create a sensory space at home

LOW TO NO COST REWARDS

Rewards for good behaviour do not need to be complicated or expensive. Here is a list of low to no cost rewards to help encourage positive behaviour in children.

- 쓝 Visit a park
- Go to the library
- Spend time with friends
- Attend a school activity
- Have a sleepover

- Computer/video game
- 🜟 Watch a movie
- Game night
- Mar Store treat
- Cooking or baking

- Homemade crafts
- **Outside** playtime
- Ringer painting
- 😭 Dance party
- Scavenger hunt



Write your questions here!



Sharing My Version of the Story



An important part of coping with your sibling's diagnosis is to understand what this all means for you. In this section, you will be able to tell **YOUR VERSION** of the story of your sibling's diagnosis.



- It's up to you to decide if, and when and how you want to share your story.
- You don't need to tell anyone your story just because they asked.
- You might decide that you only want to tell part of the story.
- You can pick and choose what parts of the story you want to share, it can be as long or as short as you'd like



Tell your version of the story.

Check your story.

Practice your story.

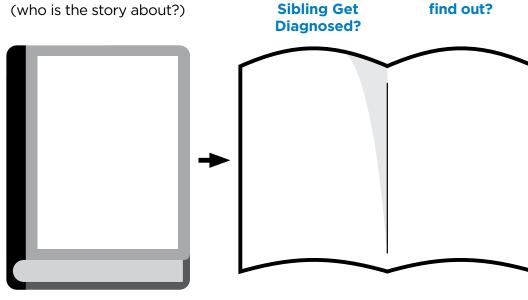
Decide who to tell.

Talk when you are ready.

Tell your version of the story.

This page will help you make your version of the story of your sibling's diagnosis.

- Using the questions in the boxes below to write or draw the different parts of your story.
- As you fill in the boxes, you can think about how you might explain to others.

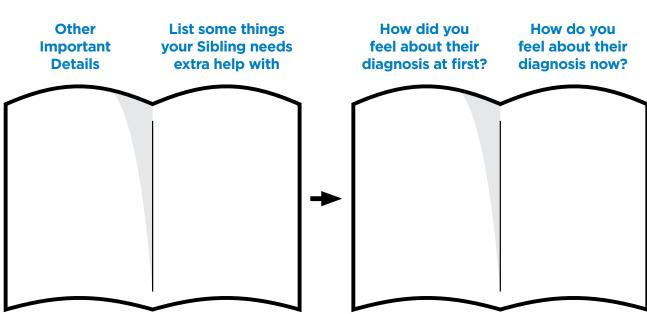


When Did Your

My Sibling



Only fill in the parts that you feel comfortable with. Be sure to add any other details that you think are important.





How did you

Check your story.

Before you share your experience of your sibling's diagnosis, make sure you check with your parents and your sibling. This is not just your story, this story belongs to everyone in your family. This means it's important to check with the people in the story, before you tell it.

- Do not share any information your sibling doesn't want you to share.
- Share your own version of this story. Each person has different levels of comfort about sharing.
- Your version of this story may change over time, and that's okay.
- When you are with your sibling, let them tell the story first, don't speak on their behalf. If your sibling can't tell the story or doesn't want to tell the story, then you can share your version if it's okay with them.





Practice your story.



It can be really tough to talk about your sibling's diagnosis.

You can practice your version of the story with your family, friends, or your sibling. That way, you will be ready to share when you want to.

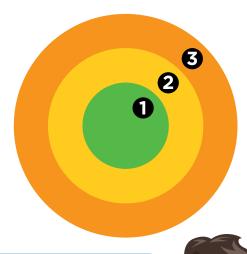


Decide who to tell.

All of us have different groups of people we trust. In this activity, you can list the different people in your life and decide where they fit best.

- The people on the inside of the circle are the ones we trust the most. They might be the ones you tell your entire story about your sibling's diagnosis.
- The people in the middle of the circle might be the ones you tell some parts of your story about your sibling's diagnosis.
- The people on the outside of the circle are the ones we trust the least. They may be the people that you decide not to tell your story about your sibling's diagnosis.

Circle of Trust



At times you might not feel like talking about this, even with the people you trust. It is good to talk to someone, but you can choose when you want to talk.



With the help of an adult you trust, think of 1 to 3 examples of each of these types of people:

1 People in my Family

2 People at School



Person 1:

Person 1: _____

Person 1:

Person 2:

Person 2:

Person 3: ______ Person 3: _____ Person 3: _____





Talk when you are ready.



People will ask you questions about your sibling that can be surprising and/or frustrating.

You do not have to answer these questions. Here are ideas of things you can say instead.

"Thank you, but I'd rather talk about this in private."

"I'm not comfortable sharing that right now."

"You're not asking in a nice way."

"This isn't the right time to talk about this."

"I don't appreciate the way you're asking."

"Why don't you ask my sibling instead?"

"That's none of your business."

"Let's do something else instead."

"There's nothing wrong with my sibling."



Here's some space to write in your own as well.

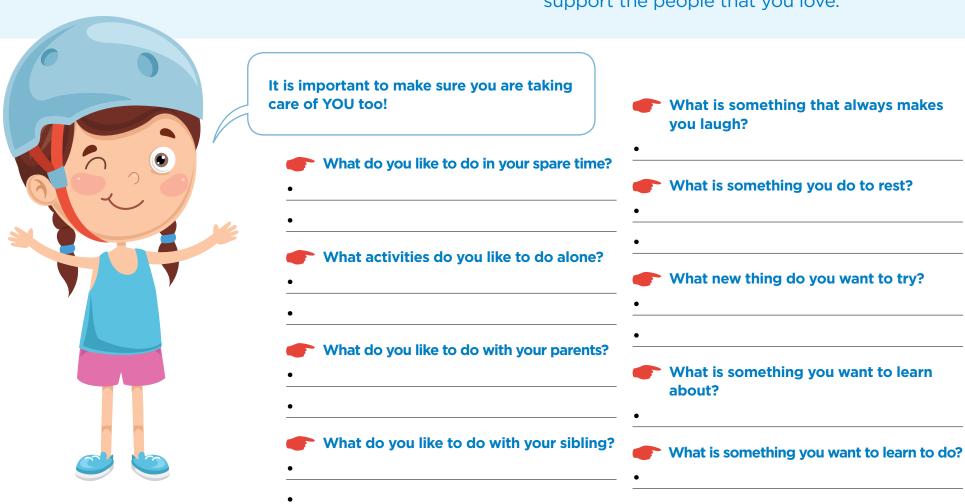


Write your questions here!



Care for myself and others

Use this next section to make a list of ways you can take time for yourself. This can include time on your own, with your sibling, and with your family. You can also make a list of ways to support the people that you love.





CARE FOR MYSELF AND OTHERS | Plans for the future

Use this page to draw or write down some fun activities for you, your siblings and your family.

Sports, Music or Arts and Crafts

Here are some ideas to get you started.

- Visit a park
- Go to the library
- Go to a school activity
- Spend time with friends
- Have a sleepover
- Play computer/video games
- Have a family movie night with popcorn
- Have a family game night

- Cook or bake something together
- Make a craft together
- Play outside
- Build a fort
- Have a dance party
- Have a beauty day with manicures and pedicures





CARE FOR MYSELF AND OTHERS | Activities Worksheet



Now pick some of your favourite activities, from the previous pages, and take some time to think about how you can include your sibling in this activity now.

F Here is an example to get you started.

Activity:	Playing a board game		
For this activity, we need to: - Roll the dice - Counting steps - Moving pieces	It might be hard for my sibling to - Move their hand to roll the dice	But my sibling would be really good at - Holding something bigger, like a cup	We can change the activity by - When it's my sibling's turn, we can put the dice in a cup. My sibling can shake the cup to roll the dice.

Activity:				
For this activity, we need to:	It might be hard for my sibling to	But my sibling would be really good at	We can change the activity by	



CARE FOR MYSELF AND OTHERS | Activities Worksheet

tivity:				
For this activity, we need to:	It might be hard for my sibling to	But my sibling would be really good at	We can change the activity by	

For this activity,	It might be hard	But my sibling would be	We can change
we need to:	for my sibling to	really good at	the activity by



CARE FOR MYSELF AND OTHERS | What I can help with

Some siblings like to be involved in their home life. You can help your parents or sibling with simple tasks. List some ideas below:

What is something that you do to help your SIBLING?



What is something that you want to learn how to help your sibling with?



What is something that you do to help your FAMILY?



What is something that you want to learn how to help your family with?





CARE FOR MYSELF AND OTHERS | How I can help my sibling



You can share these pages with anyone who wants to help your sibling, but may not know how.

Things about your sibling that other people might not know

Check off the ones you notice. These are examples of signs that your sibling might have an invisible disability.					
Their Body	How They Feel & Act	Their Thinking	Using an app or device to		
Getting tired more quickly	Getting frustrated	Taking longer to process	communicate		
Frequent falls and/or falls	Getting upset	information 	Arguing		
over more frequently	Finding it hard to	Finding it hard to make a	Only thinking about		
Getting headaches	understand how others feel	choice	themselves		
Having trouble falling asleep	Getting overwhelmed	Having a hard time concentrating	Feeling uncomfortable		
Getting dizzy	Being more sensitive to	_	around other people		
Moving differently or	noises and sounds	Getting distracted easily	Writing slowly or writing		
slower than others	Acting differently from	Needing choices	with help		
Needing equipment or	other kids their age	Other:	Finding it hard to understand		
help to move around	Having mood changes		what people are saying		
'Stimming' or making	Having meltdowns	How They Communicate	Finding it hard to talk to		
repetitive movements	Feeling lonely	Having a hard time	others		
Needing to hold items	Finding it hard to start	thinking of the right word	Writing that might be hard to read		
Other:	new activities and	Using a communication book	Other:		
	complete old ones		Ou ici .		
	Ohle au				



Things you might know about your sibling that other people might find helpful to know



Making Things Clear

- Ask them to bring their communication book or device along.
- Show them how to do a new activity.
- Share stories and information with your sibling a little bit at a time. Their brain may need a bit more time to take in all of the information.
- Double check your sibling understands you by asking short, simple questions or yes/no questions.

How to Include Your Sibling

- Play a game or do an activity that you both like.
- Watch your favourite tv show or movie.
- Introduce them to your friends or ask them to introduce you to theirs.
 - Learn something new at the same time.
 - Do something that is just for you and your sibling, like a special high five or handshake.
 - Ask them what they like to do with just you.

Always remember to ask if you can help first. Sometimes, people don't need and/or want your help and they feel proud to do things by themselves.



Helping Your Sibling Stay Calm When They're Upset



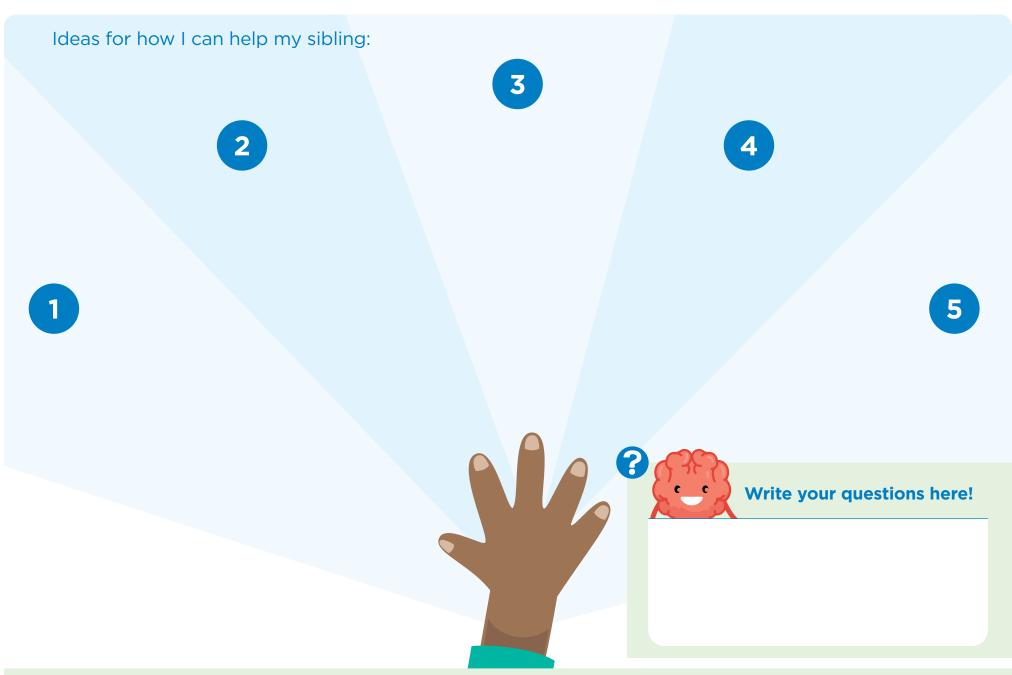
- · Ask them how you can help.
- Reassure them using calming words/ phrases like "It's okay" or "It's almost done".
- · Make them laugh.
- Watch funny videos with them.
- Take them to a quieter environment.
- Go to a place where there's no one else except you and your sibling.

Reducing Distractions

- Recognize what might be distracting to your sibling.
- Minimize background noise.
- Have one person talking at a time.
 Be patient and give your sibling time to share their idea.



CARE FOR MYSELF AND OTHERS | How I can help my sibling





My future



Some of you may be thinking about how your role as a sibling evolves as you get older. You're not alone, lots of other siblings have questions too. Here are some questions that siblings have asked. You might want to take a look and ask your family or friends about these questions too.





What are some questions you might have about the future?



How has your sibling changed your perspective?



How do you see the future and the role you will play in supporting your sibling? Who will they live with? Who will take care of them?



What do you wish for your sibling and your parents in the future?



MY TOOLS | The Weekly Planner





You're best able to help others after you help yourself.

With all of the things going on with your sibling, it can be very easy to forget to take care of ourselves.

Use this weekly planner to keep track of how you are feeling and what good things you do for yourself each day.



The 'My Tools' section is made to be printed and reused over and over again.

Here are some ideas of what you can include in your weekly planner. If you look back in your schedule, you might find patterns.



Write in the **month** and the **numbers** for all of the days.



Write down **how many hours you slept** that night. Getting a good night's rest is an important part of taking care of yourself. It can also affect your mood.



Write down any **special events** that are coming up in the month. This can include birthdays, family plans or even plans with friends.



Put a check mark for days that you ate three good meals. Eating well is an important part of taking care of yourself. It can also affect your mood.



In each square, write or draw in **how you feel today**. Use the Thoughts and Feelings pages to get some ideas. Remember your feelings will change each day, and you might have more than one feeling at a time.

MY TOOLS | The Weekly Planner



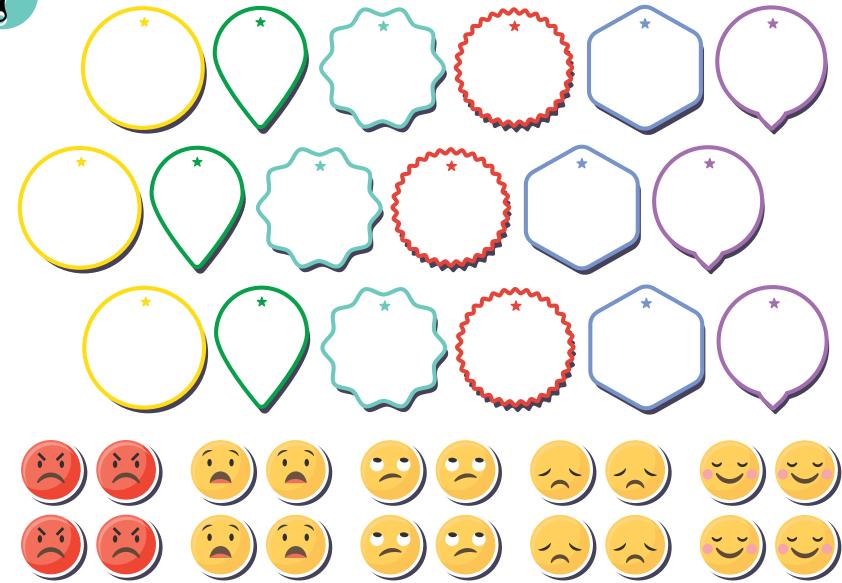
Cut out some of the badges below. Stick these on the days you did something extra special to take care of yourself. You can also make your own badges by filling in things you do that make you feel good.



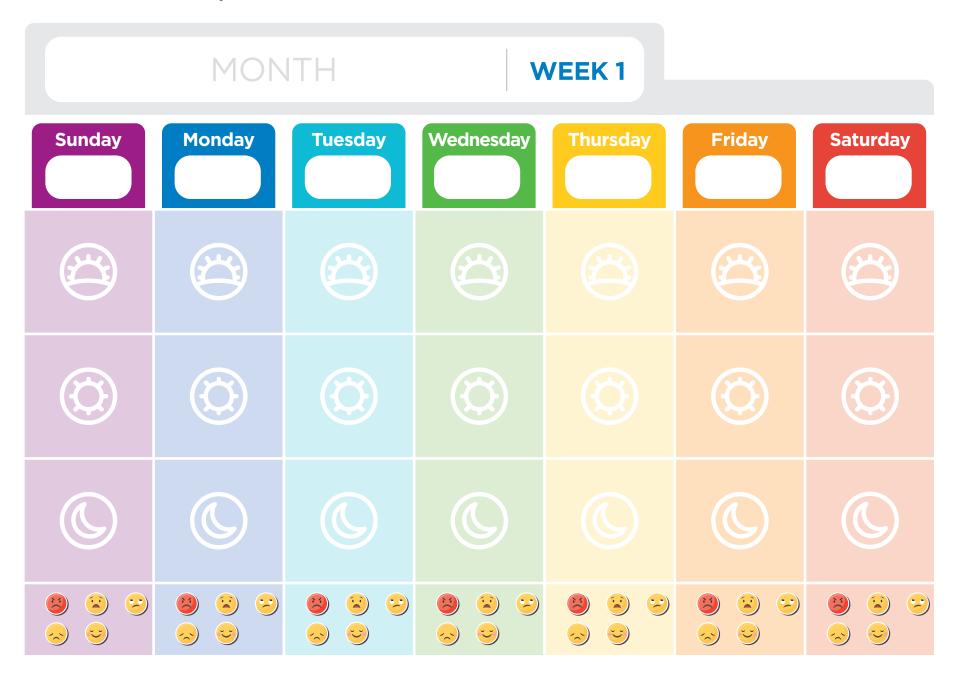




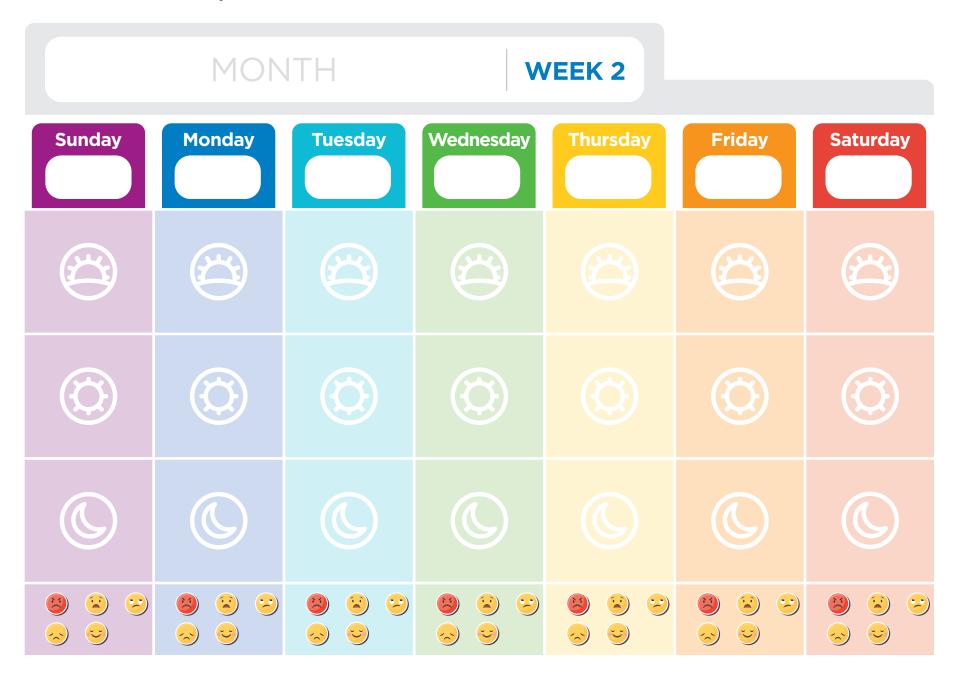
Here are some emotion icons and extra blank badges to fill in with your own activities.



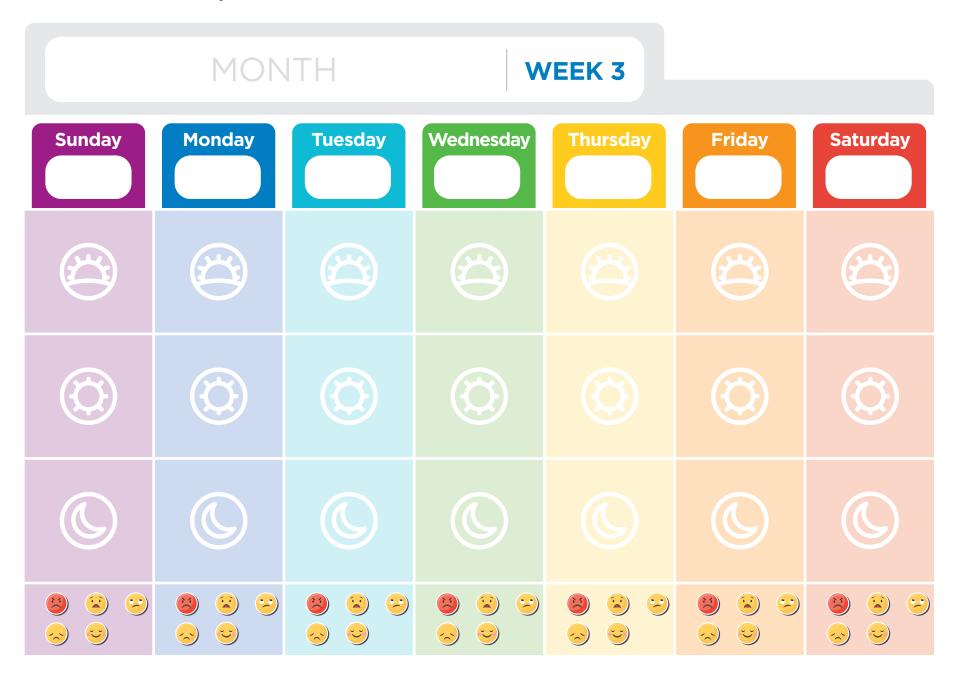




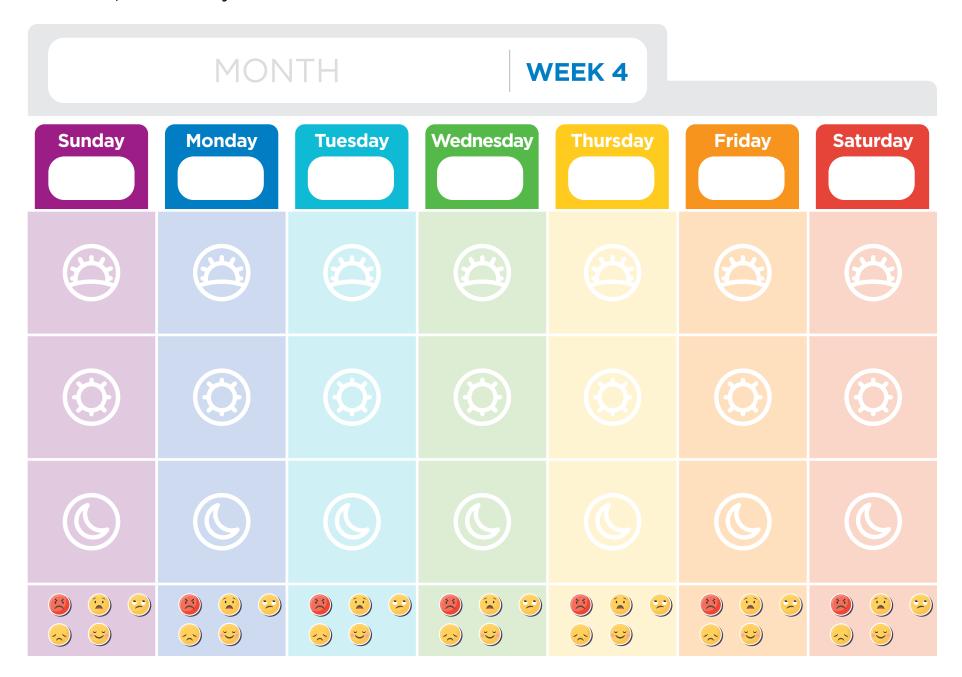




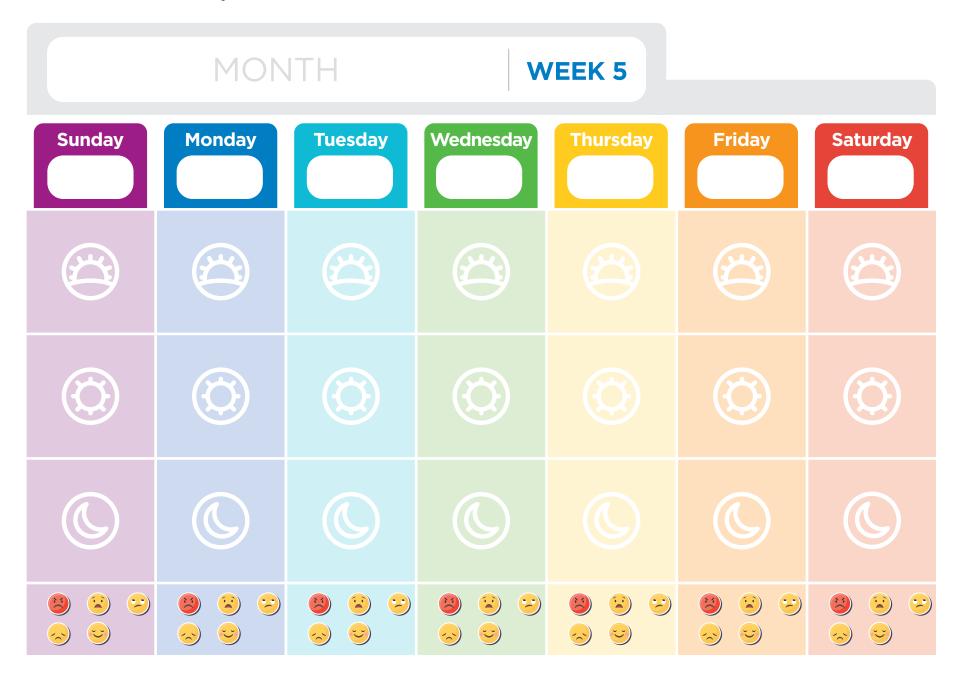
















If you ran out of space for your questions in another section, add them here!



Write your questions here!

Resources



This list can help you find information that you might need or want. You may see a small number beside some of these resources! If you are reading a printed version of this SibKit, you can match these numbers to the number of the QR code on page 61. Just scan the QR code that matches the resource number!

Behaviour Management

Books

- "Ain't Misbehavin': Tactics for Tantrums, Meltdowns, Bedtime Blues and Other Perfectly Normal Kid Behaviours" by Alyson Schafer
- "The ABC's of Anger: Stories and Activities to Help Children Understand Anger" By Ray Ali, illustrated by Eric Olsen
- "Angry Monster Workbook" By Hennie Shore
- "Stress Relief for Kids: Taming Your Dragons" By Martha Belknap
- "How to Take the Grrrr Out of Anger" By Elizabeth Verdick (also has some great books to help with kicking, biting, teaching manners, and toddlers)
- "I Was So Mad" By Mercer Mayer
- "What Are You So Grumpy About?" By Tom Lichtenheld

Websites

- Geneva Centre learning events¹
- <u>Triple P: Positive Parenting Program²</u>

Understanding The Body And How It Works

Books

- "Elvin the Elephant Who Forgets" By Heather Snyder
- "Jessica's X-Ray" By Pat Zonta "Young Genius: Brains" By Kate Lennard
- "A Terrible Thing Happened" By Margaret Holmes
- "Focused" By Alyson Gerber
- "What about me?: A book by and for an Autism Sibling"
 By Brennan & Mandy Farmer
- "Young Genius: Brains" By Kate Lennard
- The "<u>Little Senses</u>3" series By Samantha Cotterill
- Books by Autistic Authors⁴

Websites

- KidsHealth website (definitions)⁵
- Siblings in the hospital: Helping your children cope⁶
- What I need others to realize about my life after traumatic brain injury⁷
- Invisible Disability Project⁸
- The Invisible Disability: Coping with a Traumatic Brain Injury (TBI)⁹
- Sibkit Brain Injury¹⁰

Apps

• <u>Simply Sayin'</u>¹¹ (family friendly way of explaining medical definitions to kids)

Movies

Finding Nemo, How to Train Your Dragon, Dolphin Tale, Crip Camp, The Reason I Jump, Wreck-It Ralph

RESOURCES

Mental Health Services

Websites

- Skylark Mental Health Services for Siblings¹²
- Young Caregivers Connect¹³

Taking Care of Me

Websites

- 80+ Self-Care Activities for teens14
- Best Affordable Self-Care Ideas¹⁵

Activities

- Yoga for Kids¹⁶
- 9 Minute Home Exercise for Kids¹⁷
- Frozen: A Cosmic Kids Yoga Adventure¹⁸

Planning for the Future

Websites

- Extend-A-Family Adult Sibling Group¹⁹
- Partners for Planning: Planning Network²⁰
- Planned Lifetime Advocacy Network²¹
- The Ontario Caregiver Association²²
- <u>The Sibling Collaborative</u>²³

Siblings and Young Caregivers

Websites

- Ontario's Young Carers²⁴ by The Change Foundation
- Sibling Support Project²⁵
- Sibling stories on The Mighty²⁶

Activities

- Stay Home Kit²⁷
- Stay Home Kit: Part 2²⁸

Groups

- Holland Bloorview's Sibling Support Group²⁹
- Young Caregivers Association³⁰
- Young Carers Program Toronto³¹

Books

- "The Sister Book" and "The Brother Book" By Todd Parr
- ParentBooks Booklist: Siblings of Children with Special Needs³²
- SourceKids Booklist: For Siblings of Children with Disabilities³³

Tips and Ideas for Families

Supporting Siblings³⁴

Family Tipsheet: Family, Parent and Caregiver Groups in the Community³⁵

Sibling Tipsheet: Tips for Inpatient Siblings³⁶

RESOURCES

Thoughts and Feelings

Books about stress and worrying

- "Anxious Annie: the World's Greatest Thinker" By Jill Bobula & Katherine Bobula
- "Be the Boss of Stress" By Timothy Culbert & Rebecca Kajander
- "Is a Worry Worrying You?" By Ferida Wolff & Harriet May Savitz
- The "Scaredy Squirrel" series by Mélanie Watt
- "Be the Boss of Your Pain" By Timothy Culbert & Rebecca Kajander
- "The Relaxation & Stress Reduction Workbook for Kids: Help for Children to Cope with Stress, Anxiety & Transitions" By Lawrence Shapiro & Robin Sprague

Books on feeling relaxed and happy

- "Peaceful Piggy Meditation" By Kerry Lee Maclean
- "Mindful Monkey, Happy Panda" By Lauren Alderfer, illustrated by Kerry Lee MacLean
- "The ABCs of Yoga for Kids" By Teresa Power & Kathleen Rietz
- "Have You Filled a Bucket Today? A Guide to Daily Happiness for Kids" By Carol McCloud, illustrated by David Messing.

- "How Full is Your Bucket? For kids" By Tom Rath and Mary Reckmeyer
- "It's Okay to be Different" By Todd Parr

Books on grief, death and bereavement

- "The Fall of Freddie the Leaf" By Leo Buscaglia
- "When Dinosaurs Die" By Laurie Krasny Brown

Books that are disability-specific

- "The Survival Guide for Kids with Autism Spectrum Disorders (and Their Parents)" By Elizabeth Verdick and Elizabeth Reeve
- "It's OK to Be Me! Just Like You I Can Do Almost Anything!"
 By Jennifer Moore-Mallinos
- "Taking Cerebral Palsy to School" By Mary Elizabeth Anderson
- "Some Kids Use Wheelchairs" By Lola Schaefer
- "Zoom" By Robert Munsch
- "Since We're Friends: An Autism Picture Book" By Celeste Shally

Movies

Inside Out, Up, Soul, Coco



8		10		
	15	16		
				24
		28	29	
		34	35	36

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- Lorena Ubeda Chacon, Parent Leader & Content Expert
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- Vibhuti Bhatt, Research Assistant
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- Diane Dennis, Parent Leader
- Yael Diamond, Social Worker
- Caron Gan, Family Therapist & Research Assistant
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