

SibKit

A booklet for brothers and sisters of children who have pediatric Acquired Brain Injuries (ABI).



INTRODUCTION

Welcome to the SibKit!

What is the SibKit? The SibKit is a booklet filled with just-right, interactive tools and tips for brothers and sisters of kids who have pediatric acquired brain injuries (ABI).

Why is the SibKit helpful to me? A lot of changes happen when your sibling has an ABI. These tools and tips can support you to:

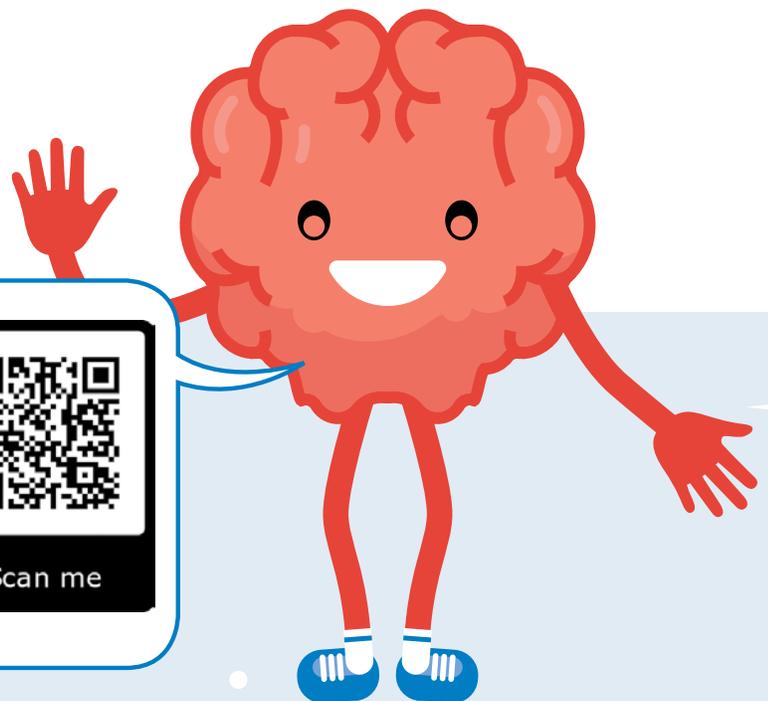
- Understand your sibling's ABI
- Feel more included in your sibling's rehabilitation
- Work through feelings you might experience

Who made the SibKit? The SibKit was made by people who have expert knowledge about ABI:

- Health professionals who work on the Brain Injury Rehab Team (BIRT) at Holland Bloorview Kids Rehabilitation Hospital in Toronto, Canada
- Siblings of kids with ABI
- Parents of kids with ABI
- Clients who have ABI

**Tell us what you think
about the SibKit by
completing this survey:**

www.surveymonkey.com/r/TTT863H



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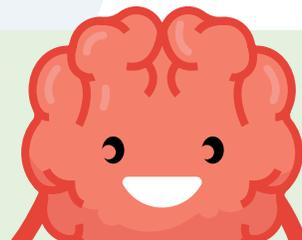
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ACTIVITIES LEGEND



Printable page



siblings **under 7**



ages 13+



ages 7-12



parents and caregivers

SOME IMPORTANT WORDS

There are some important words that we use many times in this book. Just to make sure we're all on the same page, here's what we mean:

Sibling

A sibling is any young person that lives in your home or spends lots of time with a child who has a pediatric ABI. This includes brothers, sisters, cousins and friends.

Parent

A parent in the SibKit is meant to refer to someone who cares for you and your siblings. This can include moms, dads, grandparents, aunts, uncles, step parents and foster parents.

Therapist

This includes someone who has special knowledge or training about how to help you, your sibling or your family after your sibling's pediatric ABI.

Pediatric Acquired Brain Injury (ABI)

Pediatric ABI means an injury to the brain that happens after birth. There are two kinds of pediatric ABI: traumatic and non-traumatic. This is what these kinds of pediatric ABI mean:

- *Traumatic pediatric ABI* happens when the brain gets hurt because of a force outside the head. This can include falling off of a bicycle, being in a car accident, or getting hurt while playing a sport.
- *Non-traumatic pediatric ABI* can take place when the brain is hurt or damaged without an outside force. The brain could be hurt by an infection, by a stroke which causes the brain to not get enough oxygen, or because of something growing in the brain, called a tumor.

<7 siblings under 7

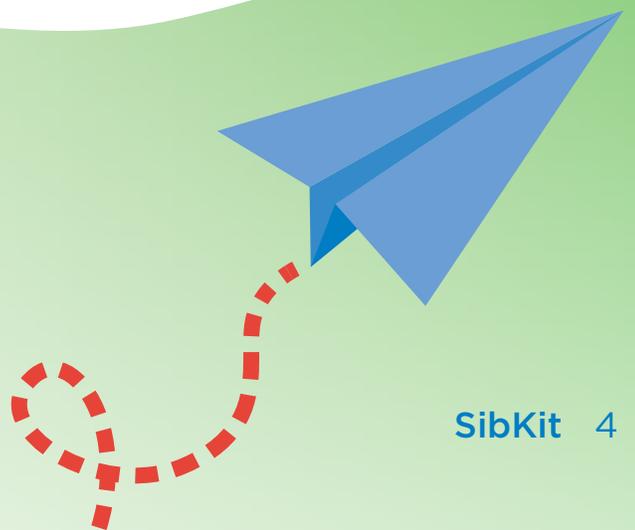
Go through this book with an adult who you trust.

7-12 ages 7-12

Go through this book with an adult who you trust. You take the lead on what pages you would like to read together.

13+ ages 13+

Go through this book on your own. Check in with an adult who you trust with any questions that come up.





TIPS FOR SIBLINGS

Here are some tips on how you can use the SibKit.

Remember that this kit is just for you! You decide how and when you would like to use the SibKit. You can decide to use the pages you think are interesting or helpful. 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 tips that might help with some of those feelings:

- As you go through the SibKit, you may be surprised by your own feelings. Remember that this is okay.
- 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 using the tools in this kit.
- 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, even after you have written them down one way.
- 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 Parents:

This may be a challenging time for your family. Tell your parents how they can help you use the SibKit. This can mean:

- If you're looking through the SibKit with a parent, let them know when you've reviewed enough. Some brothers and sisters just want to learn a little bit at

a time. Others want to hear as much information as they can all at once. Some siblings are somewhere in between. Whatever approach that is right for you is fine.

- Ask for more time if you need it to talk about your thoughts and feelings. Talk about your thoughts and feelings for as long as you need.
- You may want to talk about your thoughts and feelings for a short time after your sibling's brain injury, or you may want to keep talking about them for months and years after the injury. Either way is fine.
- Ask your parents your questions, because there are no bad questions.
- It's okay to ask the same questions more than one time. It can take time to understand.

Remember this is your SibKit, made just to support you. You can visit the SibKit over and over again, for months and years to come.



TIPS FOR PARENTS

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

As you go through this kit with your child, here are a few tips to support the conversations you have:

- *Be open and honest.* It's ok to share age-appropriate information that is accurate. Children may "fill in the blanks" with incorrect information if they are not told what is happening.
- *You are the expert on your child.* Follow your instincts.
- *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 the pediatric ABI occurred. They may need to ask the same question multiple times. This is fine and part of the processing and adjustment process.

- *Ask your child questions* to see if they understand. This is a good opportunity to discuss any misunderstandings.
- *Give your child age-appropriate updates* on their sibling's progress, no matter how small. Reassure them that their brother or sister is receiving very good care.

For Additional Tips on how to support the sibling of your child with pediatric ABI, please refer to the 'Parent Tipsheet: Supporting Siblings', or the 'Sibling Tipsheet: Tips for Inpatient Siblings'. You may access this by emailing: resourcecentre@hollandbloorview.ca, or visiting the Resource Centre in person or online.

Note that each section of the SibKit contains suggestions offered by therapists who have expertise on each topic. If you would like additional support with any sections of the SibKit, please reach out to your child's clinical team.

If you'd like to connect with other parents of children with brain injuries for additional support, please speak to your child's brain injury team and/or your local Brain Injury Association.



TIPS FOR PROFESSIONALS

The SibKit is a tool to engage and inform the siblings of children with acquired brain injuries. Here are some tips on how you might use the SibKit in your own clinical practice.

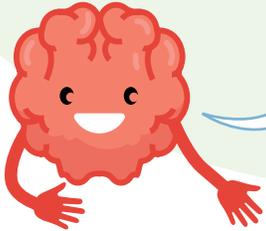
- *Follow the client and family's lead.* Families and siblings may approach you with the SibKit, asking for your support to complete some of the activities in the kit. This is an opportunity for you to engage and inform the sibling about the client's care. Check in with siblings about what questions 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 brain injury/illness. Remember that you can pick and choose the pieces of the kit that would be most beneficial to the siblings you meet. You don't need to work through the whole kit.
- *Follow the sibling's lead.* If you decide to actively engage a sibling with the SibKit, follow the 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 the event cause the brain injury. They may need to ask the same question multiple times. This is all normal.
- *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 Brain Injury team. If the child does not have a social support team in place, you can encourage them to reach out to their local Brain Injury Association for additional support.
- *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 with brain injury.

All about me

This SibKit is yours - so it's time to get started personalizing it! This page might be something you share when you tell your story about your sibling's brain injury.

 **To get started, draw or print a picture of yourself in the middle circle. Then fill in your name and age.**



Around the circle, write down or draw what makes you wonderful.

What's wonderful about me?

What makes me unique and great?

MY NAME

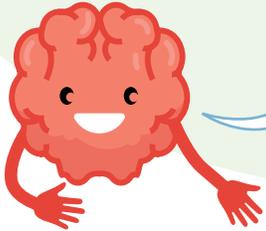
MY AGE

When you experience big changes in your life, it can be helpful to take some time to think about your strengths. Here are some ideas to get you started:

- smart
- kind
- curious
- athletic
- thoughtful
- good listener
- honest
- playful
- fair
- courageous
- polite
- hardworking
- optimistic
- organized
- funny
- creative
- forgiving



People I trust



Keep in mind: You may have different people you trust when you feel lonely or need help.

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 puzzle pieces, 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.

Who am I comfortable talking with when I feel lonely?

IN MY FAMILY

Who am I comfortable asking for help?

IN MY FAMILY

AT SCHOOL

AT SCHOOL

IN THE COMMUNITY

IN THE COMMUNITY



Holland Bloorview

Kids Rehabilitation Hospital

Some children and teens come to Holland Bloorview Kids Rehabilitation Hospital in Toronto after they experience a pediatric Acquired Brain Injury (ABI). 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. Your brother or sister who has a pediatric Acquired Brain Injury (ABI) will be supported by the Brain Injury Rehab Team (BIRT).

After experiencing a pediatric ABI, your sibling may now need help to eat, talk, remember, solve problems, walk or do activities like brushing their teeth. Rehabilitation or rehab is the word we use to describe activities that let your sibling practice things that might now 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 BROTHER OR SISTER NEED TO STAY AT HOLLAND BLOORVIEW?

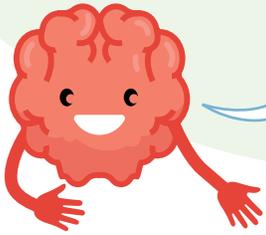
Your brother or sister receives help from many different kinds of therapists to have the best recovery after a brain injury. Each therapist they will see from the BIRT Team is an expert in one of the things your sibling now needs help with. Holland Bloorview is famous for having some of the best therapists in the world to help kids get as much better as possible.

By staying at Holland Bloorview, your sibling can do rehab with lots of different therapists every week. There is a school inside the hospital to help your sibling to not fall behind on their learning.

? HOW LONG WILL MY SIBLING STAY AT HOLLAND BLOORVIEW?

Usually, kids stay at Holland Bloorview for 4 to 8 weeks. Some kids might stay longer, if they need more therapy. Other kids might stay for a shorter time, if they need less therapy. Most of the time, your brother or sister will go home to see you on the weekends.

Therapist scavenger hunt



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 puzzle pieces below, write the names of each therapist that your sibling works with. You can also write one fun or interesting fact about each therapist. For help filling this out you can:

- 👉 Visit your sibling at Holland Bloorview. Participate in their therapies and fill out each puzzle piece like a scavenger hunt.

 Transition Coordinator _____ Fun Fact: _____ _____	 Nurse's Name _____ Fun Fact: _____ _____	 Child Life Specialist's Name _____ Fun Fact: _____ _____	 Psychologist's Name _____ Fun Fact: _____ _____
 Speech Language Pathologist's Name _____ Fun Fact: _____ _____	 Occupational Therapist's Name _____ Fun Fact: _____ _____	 Doctor's Name _____ Fun Fact: _____ _____	 Child & Youth Worker's Name _____ Fun Fact: _____ _____
 Physiotherapist's Name _____ Fun Fact: _____ _____	 Therapeutic Recreationist's Name _____ Fun Fact: _____ _____	 Social Worker's Name _____ Fun Fact: _____ _____	 Therapeutic Clown's Name _____ Fun Fact: _____ _____



Here are some of the therapists that may help your brother or sister after they have experienced pediatric Acquired Brain Injury (ABI).



**TRANSITION
COORDINATOR**

Supports bringing your brother or sister into the hospital and the BIRT program. Can find professionals in your community to help your sibling and your family after discharge, which is when your sibling is ready to go home.



NURSE

A medical expert who will support your sibling's healthcare needs such as assisting with day to day care, and giving any needed medications.



**CHILD LIFE
SPECIALIST**

Helps kids cope with their feelings while they are in the hospital. This therapist can teach you and your sibling tips to deal with big, sometimes upsetting feelings.



PSYCHOLOGIST

May test your sibling who has pediatric ABI to find out how they now think, feel and behave. They can make good suggestions to your family and to your sibling's school to support best coping and managing.



**CHILD AND
YOUTH WORKER**

Helps families and kids to better cope and manage behaviour.



DOCTOR

Your sibling's doctor on the BIRT Team, who has special training to help kids with pediatric ABI. They supervise the best recovery of your sibling, talks with other doctors involved and can prescribe needed medications.



**OCCUPATIONAL
THERAPIST**

Helps your sibling practice daily activities like getting dressed and printing.

Also helps with balance so your brother or sister does not fall down. Supports your sibling to remember things, pay attention and be safe at home and in the community.



**SPEECH
LANGUAGE
PATHOLOGIST**

Helps sibling's talking, understanding, thinking and swallowing.

Also works with the Occupational Therapist to decide what food is safe for your sibling to eat.



7-12

13+



PHYSIOTHERAPIST

Help your sibling with muscle strength, movement and balance.



THERAPEUTIC RECREATIONIST

Plans fun recreational activities to help your sibling practice their rehabilitation goals.



SOCIAL WORKER

Provides the orientation tour to you and your family before your sibling comes to Holland Bloorview for neuro rehabilitation. Supports your family to get needed supports and services during admission, and towards discharge. Supports you and your family to cope and manage emotions related to your sibling's Acquired Brain Injury.



THERAPEUTIC CLOWN

Has special training to work in a hospital. They are experts in making kids laugh, play and feel better.



7-12

13+

A week at HBKRH



All of these activities help your sibling have the best recovery from pediatric ABI.

Many siblings wonder about what their brother or sister's days are like at the hospital.

With the help of your sibling, parent or caregiver, you can fill out a schedule of what your sibling's day looks like.

You can write down information such as:

-  **When your sibling's therapies are scheduled**
-  **When your sibling goes to school**
-  **What other activities your sibling participates in during the day or in the evening**

Sunday	Monday	Tuesday	Wednesday	Thursday	Friday	Saturday
						
						
						



Meet the Brain

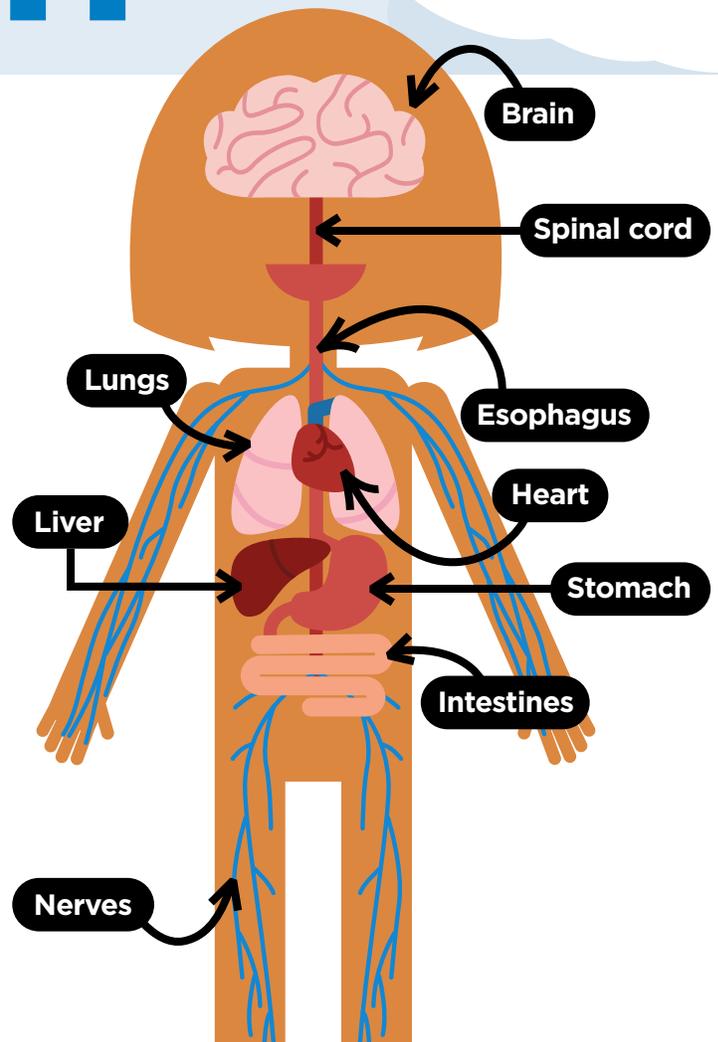
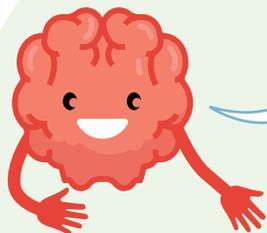
The brain is a very important organ in your body. **An organ is a group of tissues in your body that has its own job.** Your heart is another example of an organ, and its job is to pump blood through your body. Your stomach is also an organ which helps your body break down the food you eat so that you can use it for energy.

The brain is a very busy organ in the body. It controls everything that your body does. There are about 100 billion, tiny cells in our brains called neurons. Neurons are cells that send messages from the brain to all the different parts of your body, telling them what to do.

A team of neurons that send their signals together are called nerves. Nerves look like wires all over your body. They carry the messages from your brain to the different parts of your body.

The left side of your brain tells the right side of your body what to do, and the right side of your brain tells your left side what to do.

The brain stores all sorts of memories you have including facts and figures, as well as smells, tastes and things that you have seen, heard or touched.



DID YOU KNOW?

The front of the human brain is larger than any other animal's - even a dinosaurs!

The neurons in our body send more messages than all the phones in the entire world.

The nerves in your body send the information back to your brain at more than 240 kilometers per hour. That's two times as fast as a cheetah!

Our brains are three times bigger than that of a chimpanzee! Do you think that means we're necessarily smarter?

Lobes of the brain

The brain is very soft and squishy. A child's brain feels like tapioca pudding, and an adult's brain feels like Jell-O. So a child's brain is much softer and more at risk for injury than an adult brain.

Each part of the brain has its own job. When one part of a child's brain gets hurt

it becomes harder for the child to do the jobs which that part of their brain did.

The skull keeps the soft and squishy brain safe. The skull is a hard shell around the brain. It's like your brain's home. The skull is about 3-5 stacked nickels high in thickness.

Frontal Lobe

The "Boss" of the brain, it helps with "thinking skills", such as:

- organization
- attention
- planning
- getting started
- how you act with others

 [More on page 16](#)

Temporal Lobe

Helps with:

- understanding language
- sharing our ideas with words
- writing
- remembering language
- feeling emotions

 [More on page 17](#)

Parietal Lobe

Helps us get and understand various senses, such as:

- touch
- temperature
- pain
- where our body is when we move

 [More on page 21](#)

Occipital Lobe

Helps you see and to make sense of complicated images

 [More on page 20](#)

Cerebellum

It gets information from the parts of the brain that manage sensations, and then helps with motor movements such as:

- body posture
- coordination
- balance
- smooth movements

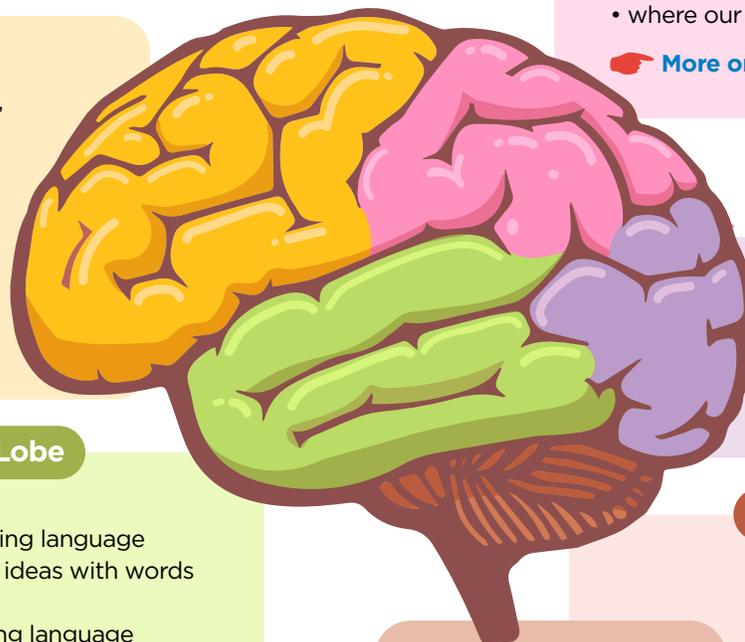
 [More on page 19](#)

Brain Stem

Controls all of the body functions that we do not think about, such as:

- breathing
- digesting food
- swallowing
- body temperature
- heart rate
- sleep/awake

 [More on page 18](#)



TIP for your parents



If your child is under age 7, it might be hard for them to learn the names of all the different parts of the brain.

Instead, show and tell your child about the front part of the brain or the side part of the brain etc.

My questions about my sibling's brain injury

My questions

about my sibling's brain injury

Many siblings find it difficult to understand what happened to their brother or sister.

These next few pages will help you put together some of the pieces of the story of your sibling's brain injury.

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

You may need to talk to an adult you trust to help figure some of this out. You could also ask your sibling's doctor or therapists to help you understand what happened.

 **What do you want to know about how your sibling injured their brain?**

 **Write or draw your questions below.**

ALERT
for your parents



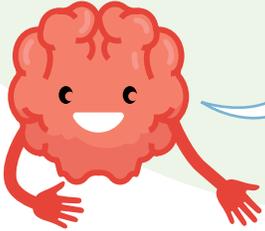
The answers to some of these questions might be difficult to talk about.

It is important for your parent to look at these questions and make sure they feel comfortable answering them. If they need extra help answering these questions, they can talk to your siblings therapy team. When your parent is ready, you can plan to spend some time together to answer these questions.



Changes

I have noticed in my sibling

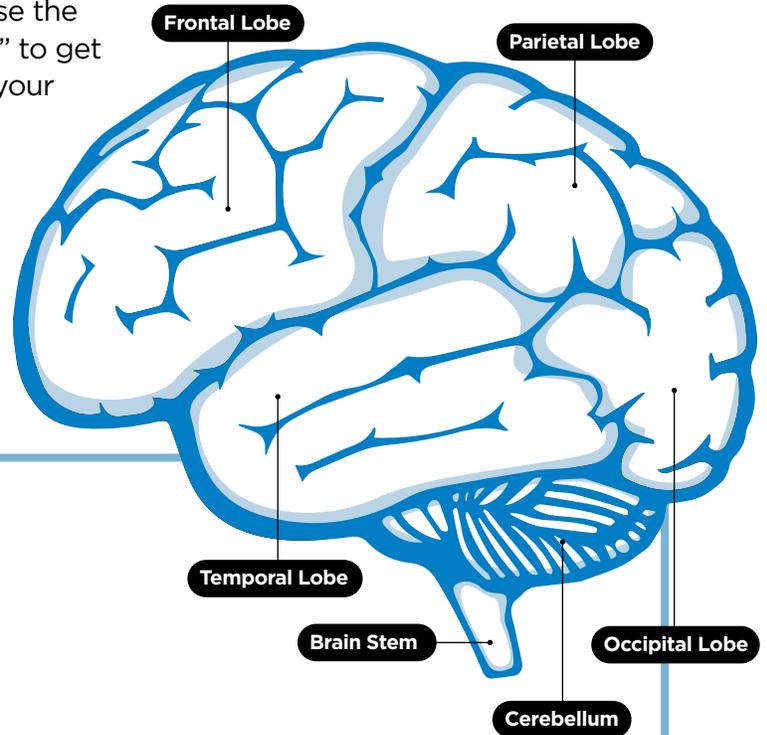


Remember... all the parts of the brain work together. That means, you might see changes in one part of the brain even though your sibling got injured in another part of their brain.

A brain injury may cause changes in how your sibling looks, acts and feels. Use this page to write and/or draw the changes you see in your sibling since their brain injury.

If you need some help getting started, you can use the pages with the title "The Brain and How It Works" to get some ideas about the changes you might see in your brother or sister.

- ➡ **Colour in the part of the brain that is injured in your sibling.**
- ➡ **Think about what's different about your sibling after their brain injury. Write these changes in the box below.**



ALERT for your parents



The answers to some of these questions might be difficult to talk about.

It is important for your parent to look at these questions and make sure they feel comfortable answering them. If they need extra help answering these questions, they can talk to your siblings therapy team. When your parent is ready, you can plan to spend some time together to answer these questions.



7-12

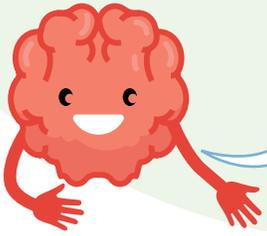
13+

UNDERSTANDING MY SIBLING AND THEIR BRAIN INJURY

Chart: What's the same? What has changed?

Chart:

What's the same? / What has changed?



Use this page to collect information about your sibling's brain injury.

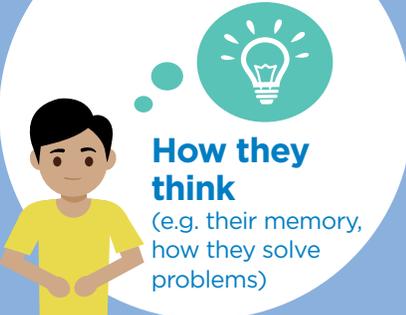
You may need to talk to an adult you trust to help figure some of this out.

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

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

What's the same about my sibling?

What's different about my sibling?

 <p>How they think (e.g. their memory, how they solve problems)</p>		
 <p>How they feel and how they express their feelings</p>		
 <p>How they talk</p>		



7-12

13+

UNDERSTANDING MY SIBLING AND THEIR BRAIN INJURY

Chart: What's the same? What has changed?

What's the same about my sibling?

What's different about my sibling?

 <p>How they react to things and how they behave</p>		
 <p>How they move</p>		
 <p>How they eat</p>		
 <p>Equipment (e.g. assistive devices, protective gear)</p>		



7-12

13+

UNDERSTANDING MY SIBLING AND THEIR BRAIN INJURY

Chart: Before/Now/After

Me and my sibling

before • now • after

Now it's time to think about **you and your sibling**.

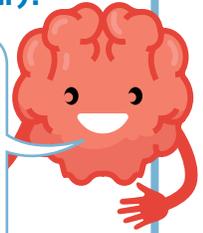
 Draw or write your ideas in the boxes below.

What was it like to spend time with your sibling before their brain injury/illness?

What is it like to spend time with your sibling now?

What do you think it will be like to spend time with your sibling in the future (e.g. next year)?

Remember that your sibling might have a brand new set of strengths and weaknesses after their brain injury.



TIP for your siblings and parents

These pictures you make are a great way to start a safe, healthy, open conversation with your parents. It's a good idea to share these pictures with your parents when you have a good amount of time to talk and ask questions. You can ask your parents questions about what things might change in your sibling and what things might stay the same. Remind your parents that it's okay if they don't know all the answers. If you and your parents aren't sure about how things will change, you can talk to your sibling's therapy team.



UNDERSTANDING MY SIBLING AND THEIR BRAIN INJURY

Chart: Before/Now/After

Me and my parents

before • now • after

Now it's time to think about **you and your parents**.

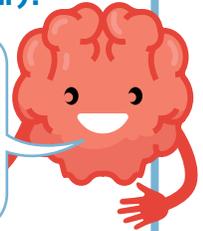
 Draw or write your ideas in the boxes below.

What was it like to spend time with your parents before your sibling's brain injury?

What is it like to spend time with your parents now?

What do you think it will be like to spend time with your parents in the future (e.g. next year)?

Talk to an adult you trust about your hopes for the future.



TIP for your siblings and parents

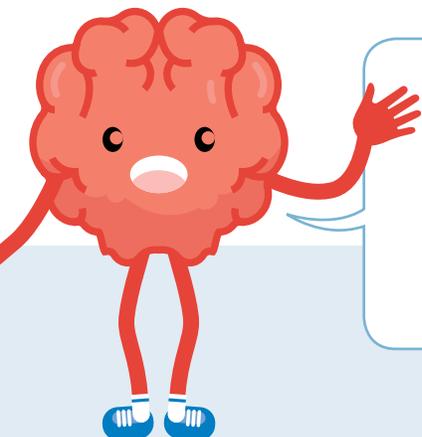
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Sharing My Version of the Story

An important part of coping with your sibling's brain injury 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 brain injury.

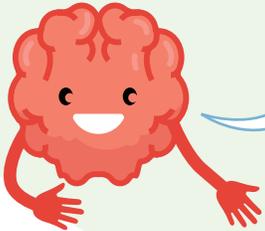
- 1** Tell your version of the story.
- 2** Check your story.
- 3** Practice your story.
- 4** Decide who to tell.
- 5** Talk when you are ready.



Remember that your story is YOURS.

- 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.

1 Tell your version of the story.



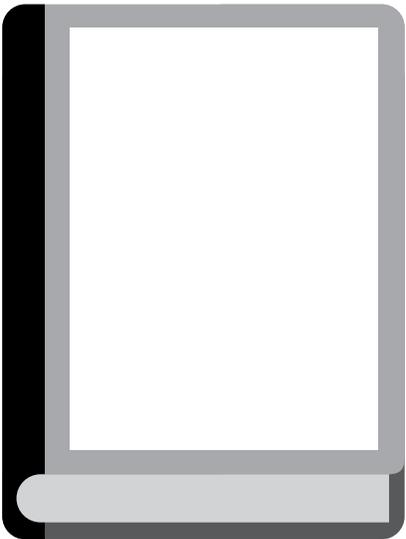
Only fill in the parts that you feel comfortable with. Be sure to add any other details that you think are important.

Now that you have collected lots of information about your siblings brain injury, you can use this page to put it all together.

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

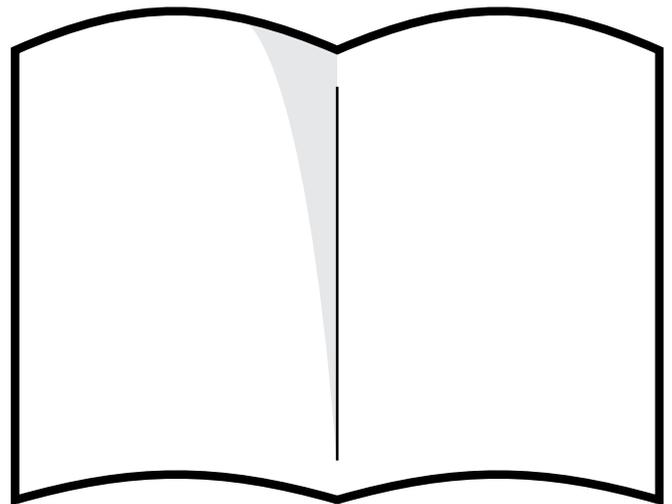
- Using the questions in the boxes below to write or draw the different parts of your story.
- As you fill in the boxes, you can think about how you might explain to others what happened.

My Sibling
(who is the story about?)



When Did it Happen?

Where Did it Happen?

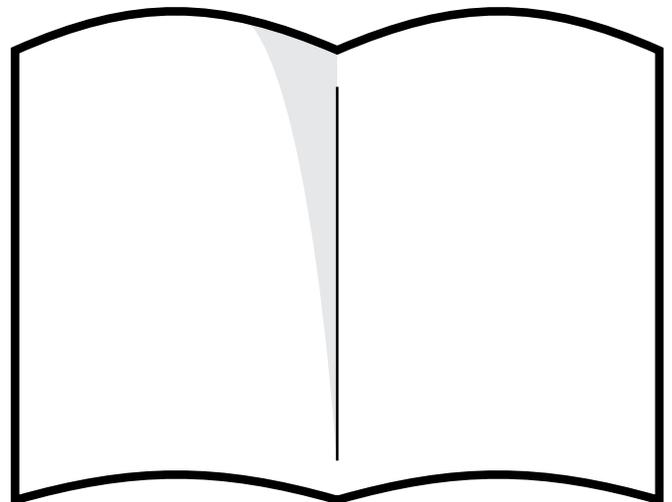
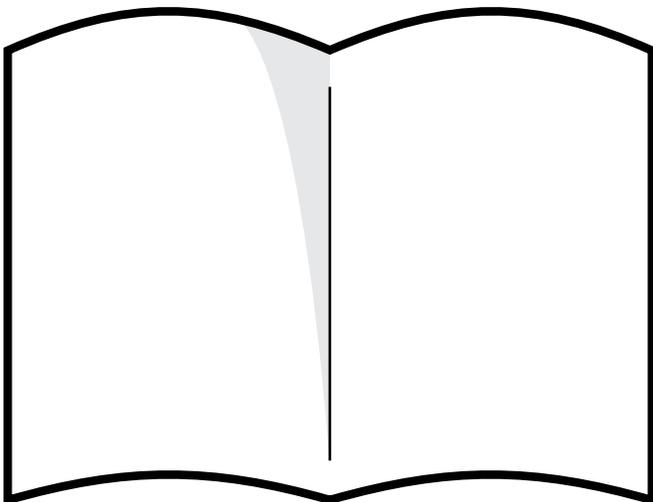


Other Important Details

What Happened to Them?

How Do You Feel About it?

Where Are They Now?



2 Check your story.

Before you share your experience of your sibling's brain injury, make sure you check with your parents and your sibling with the brain injury. 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 of what happened, if it's okay with them.



3 Practice your story.

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

You can practice your version of the story with your family, friends, sibling and your sibling's therapy team. That way, you will be ready when people ask and you are ready to share.

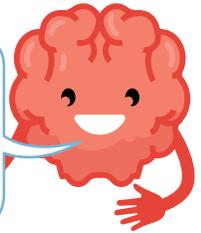
4 Decide who to tell.



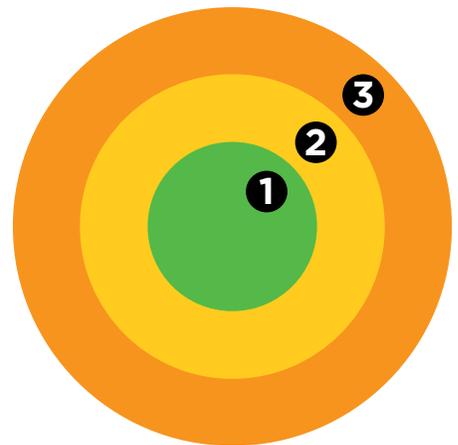
All of us have different groups of people we trust. In this activity, people in the inside circle should be those who we trust the most. These are the people that we can say anything to. People in the most outside circle are those that we know and trust less. We might not share very personal information with these people.

- 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 brain injury/illness.
- The people in the middle of the circle might be the ones you tell some parts of your story about your sibling's brain injury/illness.
- 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 brain injury.
- 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.

People in the inside circle (1) should be those we trust the most.



Circle of Trust



 With the help of an adult you trust, think of 1 or 2 examples of each of these types of people:

1 Trusted Family & Close Friends

These are people I really trust. I feel safe with them. I can tell my whole story, if I want to.

Person 1:

Person 2:

2 Other Friends & People

These are people I can tell parts of my story, if I want to.

Person 1:

Person 2:

3 Everyone Else

I don't need to tell these people my story, but I can if I want to.

Person 1:

Person 2:



Share this page with anyone who cares about your sibling but may not understand how to help them. These pages could help teachers, and other grown ups who care, understand how to help. We all need help with different things at different times.



? WHAT IS AN INVISIBLE DISABILITY?

When people say the word “disability” they might imagine someone whose body works differently. For example, if someone’s legs get tired quickly, they might need a wheelchair to play tag. Sometimes, these kids need a little extra help to do the things that kids like to do. Usually, we can use our eyes to see what part of the body is affected and what the kid needs help with.

Sometimes, kids might need extra help and we can’t see why. Their disability may be invisible. The changes that happen to a kid after a brain injury can be invisible. They may think, act and talk differently even though they look like most kids. Because of these changes, they may need extra help to learn and play. This is called an invisible disability.

Signs of an Invisible Disability

Think about your sibling after their injury or illness. Do you notice any of these changes?

Check off the ones you notice.

These are examples of signs that your sibling might have an invisible disability.

Signs in The Body

- getting tired more quickly
- headaches
- trouble falling asleep
- dizziness

How they feel & act

- getting frustrated
- feeling bored
- feeling restless
- feeling impatient
- feeling sad or blue
- feeling lonely
- complaining
- hard to start new activities
- get upset quickly

Signs in their thinking

- feeling confused
- misplacing things
- forgetting what they were about to say
- thinking slowly
- finding it hard to make a choice
- hard to concentrate
- forgetting what they did
- forgetting what they read
- forgetting names
- getting distracted easily

Signs in how they talk

- having a hard time thinking of the right word
- arguing
- making spelling mistakes
- only thinking about themselves
- feeling uncomfortable around other people
- writing slowly
- trouble understanding what people are saying
- trouble talking to others
- writing that is messy or hard to read

ADAPTED FROM: BIFI-A, v.4, Gan & Kreutzer 2017.



Share this page with anyone who cares about your sibling but may not understand how to help them. These pages could help teachers, and other grown ups who care, understand how to help.

Because we can't see where they got hurt, we may forget that our sibling had a brain injury and that they can't do things the way they used to.

People can help your sibling by:

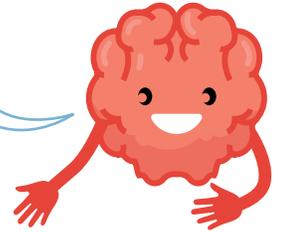
Trying your best to stay positive

- Don't take things personally. Your sibling may get upset more quickly because of their invisible disability. It's not your fault and it's not their fault.
- Take a break. Come back to the situation when you and your sibling feel calm.
- Focus on the things your sibling can do. Use the "My Family and Me" pages to get some ideas on activities you can enjoy together.

Making Things Clear

- When you start a new activity together, show them how to do it.
- 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. Don't share too much information too quickly.
- Double check your sibling understands you by asking short, simple or yes/no questions.

ALWAYS REMEMBER to ask if you can help first. Sometimes, people with challenges don't need your help and they feel proud to do things by themselves.



Reducing Distractions

- Minimize background noise.
- Have one person talking at a time.
- Be patient and give your sibling time to say their idea.

Helping your sibling save their energy

- Ask your sibling if they're tired or if they need a break.
- Ask your sibling if they would like some paper to write down or draw anything that is important for them to remember. That way they don't need to hold all that information in their head.



Thoughts and feelings

about my sibling's brain injury



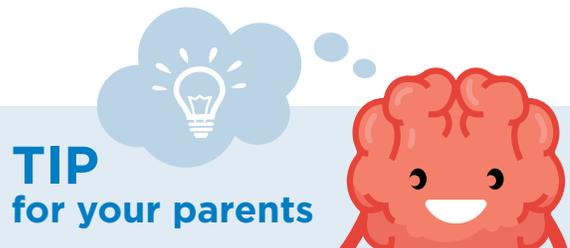
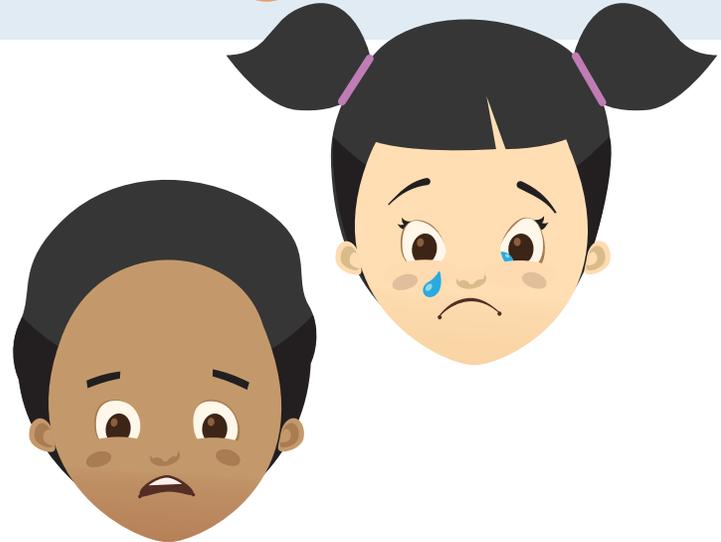
A brain injury affects the whole family – including you! As a sibling of someone with a brain injury, you can feel lots of different feelings.

These next few pages have examples of feelings that other brothers and sisters felt after their sibling's brain injury. 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. Or perhaps, you might not want to eat or you might want to eat all the time.

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 feel, and to feel fully. Try to focus on healthy ways to release each emotion. We have included some suggestions to get you started.



TIP for your parents

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
- talking to your sibling's therapists, if they need help with these feelings

the rainbow

of thoughts and feelings

The feelings on these pages are organized according to how people feel when big changes happen to someone that is very important to them. All the feelings on the board can be grouped together under these umbrella feelings.

Some feelings could fall under more than one umbrella. As well, sometimes you might feel lots of different feelings, from different umbrellas, 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 feel 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.



THOUGHTS AND FEELINGS ABOUT MY SIBLING'S BRAIN INJURY

The Rainbow of Thoughts and Feelings

	Examples of this Feeling	What this feeling might look like	What I can do about this feeling
 <p>Anger</p>	<ul style="list-style-type: none"> • Angry • Frustrated 	<ul style="list-style-type: none"> • It can be hard to understand • 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 brain injury or illness happened to your family. 	<ul style="list-style-type: none"> • Talk to someone you trust. They can help you understand why your sibling might need some extra help. • Try and learn more about your sibling’s brain injury. You can write down or draw everything you learn in the “Understanding Brain Injury” section of this kit.
 <p>Shock</p>	<ul style="list-style-type: none"> • Shocked • Surprised • Scared • Worried 	<ul style="list-style-type: none"> • It can be hard to believe that this brain injury or illness has happened to you and your family. • It’s normal to be shocked when something out of the ordinary happens. • It can happen that you worry about your sibling a lot now. 	<ul style="list-style-type: none"> • Talk to someone you trust about how you are feeling. You might find out that they feel the same way as you. • If you feel comfortable, you can be honest and tell the people you trust about what happened to your sibling. You can use the page “Explaining My Sibling’s Brain Injury” pages to help you.
 <p>Confusion</p>	<ul style="list-style-type: none"> • Confused • Jealous • Embarrassed 	<ul style="list-style-type: none"> • It’s common for siblings to feel confused, hurt, envious or jealous of all the attention and special treatment their sibling is getting after their injury. 	<ul style="list-style-type: none"> • Talk to someone you trust. They can help you understand why your sibling might need some extra help. • Try and learn more about your sibling’s brain injury. You can write down or draw everything you learn in the “Understanding Brain Injury” section of this kit.



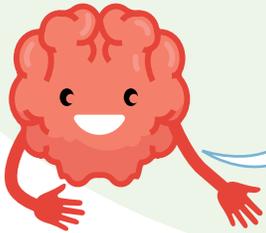
THOUGHTS AND FEELINGS ABOUT MY SIBLING'S BRAIN INJURY

The Rainbow of Thoughts and Feelings

	Examples of this Feeling	What this feeling might look like	What I can do about this feeling
 <p>Depression</p>	<ul style="list-style-type: none"> • Depressed • Sad • Alone • Tired 	<ul style="list-style-type: none"> • Siblings can feel like they are alone because their parents are taking care of their brother or sister who has a brain injury. You are not all alone. Your parents and sibling are thinking of you and they care about you. • Your sibling may be different after their brain injury. Because of this, many siblings feel like they “lost” the way their sibling used to be. They miss the way their sibling used to be. 	<ul style="list-style-type: none"> • Look at the list you made of the “people you trust” in the Introduction Section of this kit. • Ask your parents if you can talk to these people when your parents can’t be around. • Remember that it’s ok to feel sad about these changes in your sibling. • It is also really important to take care of yourself. Check out the Taking Care of Myself section of this kit for more ideas on how to take care of yourself and Reconnecting the Family pages to help.
 <p>Acceptance</p>	<ul style="list-style-type: none"> • Accepting • Happy • Loved • Protective • Proud • Strong • Confident • Relieved 	<ul style="list-style-type: none"> • Some siblings feel happy that their sibling is safe and getting better every day. • Some siblings feel really proud of their brother and sister. They see how hard they are working and how they are getting better every day. • Sometimes, when families go through hard times, they remember, all over again, how much they love each other. 	<ul style="list-style-type: none"> • It’s OK to feel happy. • Share your happy story or happy feelings with your family. It may cheer them up too! • Enjoy the feeling of being loved. • Make a photobook of your family and loved ones. You’ve been through a lot together. • Take a picture in your mind of this good moment. It’s really important to remember all of the good things. These memories or ‘pictures in our minds’ can help comfort us when things feel hard.



weekly planner



Taking care of yourself is as important as taking care of others.

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.

 Here are some ideas of what you can include in your weekly planner.



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, your sibling coming home for a visit, family plans or even plans with friends.



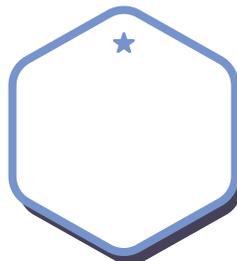
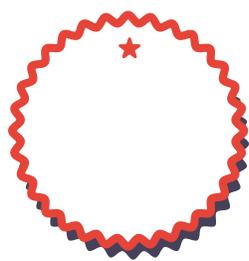
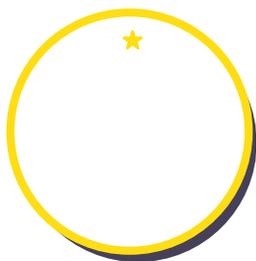
Put a check mark for days that you ate three good meals. Eating well is an important part of taking care of yourself. It can also affect your mood.



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. All of this is okay.



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.



7-12

13+

MONTH				Sunday	Monday	Tuesday	Wednesday	Thursday	Friday	Saturday

Print a copy of this sheet out for each new week.



7-12

13+

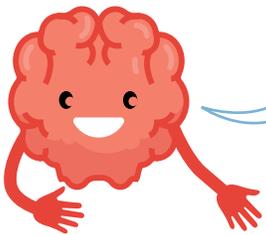
Me and my family

after brain injury

After spending time apart, it can be really important for families and siblings to spend time doing fun things together. Use this page to help plan some fun activities for you, your siblings and your family.

 Think about some of the things you and your sibling(s) like to do together. Write them here or draw a picture.

 Think about some of the things you and your family like to do together. Write them here or draw a picture.



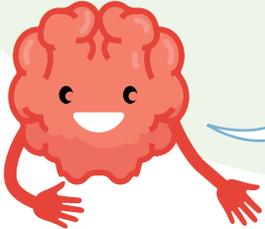
Here are some ideas to get you started.

- 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



Me and my family

after brain injury



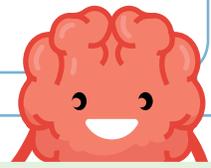
Here are two examples to get you started.

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

Activity: <i>Playing a board game</i>			
<p>For this activity, we need to:</p> <ul style="list-style-type: none"> - Roll the dice - Counting steps - Moving pieces 	<p>It might be hard for my sibling to...</p> <ul style="list-style-type: none"> - Move their hand to roll the dice 	<p>But my sibling would be really good at...</p> <ul style="list-style-type: none"> - Holding something bigger, like a cup 	<p>We can change the activity by...</p> <ul style="list-style-type: none"> - When it's my siblings turn, we can put the dice in a cup. My sibling can shake the cup to roll the dice.

Activity: <i>Playing Headbanz</i>			
<p>For this activity, we need to:</p> <ul style="list-style-type: none"> - Use words to ask questions - Understand questions - answer questions - Use the information shared and put it all together to guess the picture on your head 	<p>It might be hard for my sibling to...</p> <ul style="list-style-type: none"> - Get out their words to explain their ideas 	<p>But my sibling would be really good at...</p> <ul style="list-style-type: none"> - Drawing pictures - Acting things out with their hands and body 	<p>We can change the activity by...</p> <ul style="list-style-type: none"> - Give everyone a choice, when it's their turn to guess: Ask if they want their clues as words, pictures or acting out.

TIP:
Use your 'Understanding My Sibling's Brain Injury' page to help.



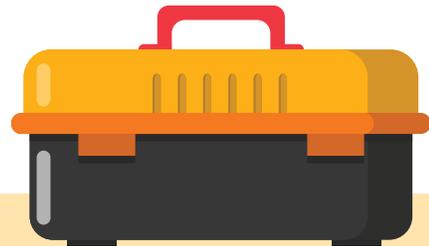
Understanding challenging behaviours in:

- ✓ **My Sibling Living with ABI (for Brothers and Sisters living with ABI)**
- ✓ **My Children (for Parents living with Pediatric ABI)**

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. Parents may see an increase in "bad behaviours" in your child with the brain injury and/or in their siblings. This can be a normal reaction to the many sudden changes that the children are experiencing in their relationships and routines following the brain injury.

To support a child to communicate/behaviour 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

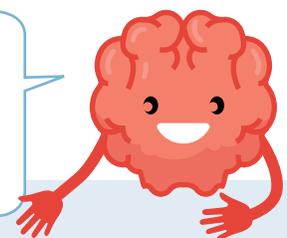
Children feel a sense of power and control in their lives when they are provided with choices. This can be especially important following a brain injury, when children may be feeling helpless. Limit choices so the child does not have a chance to say no and does not feel overwhelmed.

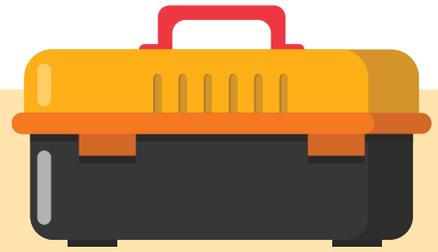
Control Environment

You can modify the environment to help decrease negative behaviours or increase positive behaviour by dimming lights, playing soothing music, and limiting the number of people who are around as examples.

More on page 45 ...

TIP:
This section may be especially helpful for parents.





BUILDING YOUR TOOLBOX TO HELP SET CHILDREN UP FOR SUCCESS

...Continued from page 44

Use Prompts

Prompts are like clues or reminders to help your child if you are a parent, or your brother or sister if you are a sibling, 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). You can work with your therapy team to figure out what kinds of prompts might be most helpful. That way the whole team can use the same prompts in the same way.

Give Praise

Verbally praising encourages the positive behaviours you want to see. It also helps to increase children’s confidence and self-esteem. This may seem small but positive praise can make a dramatic difference in children’s behaviour. Be generous and provide a lot of positive praise!

Set Limits

Often, setting limits means enforcing rules that existed before the brain injury. 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 following your child’s brain injury. Ensure that the limits are clear, simple, consistent, reasonable and enforceable.

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

	Examples of Behaviours	Shaping More Positive Behaviours
<p>1</p> <p>Need for Attention</p> <p>Some children would rather have “bad” attention than no attention at all.</p>	<ul style="list-style-type: none"> • Throwing a tantrum • Threatening “I’m going to run away” • Defiance “I’m going to do it anyway” 	<ul style="list-style-type: none"> • 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
<p>2</p> <p>Need for Item or Activity</p> <p>Some difficult behaviour might be a way to get a “reward” or activity they really like.</p>	<ul style="list-style-type: none"> • A child throws a tantrum and the parent bargains to buy the child a new toy if they stop the tantrum 	<ul style="list-style-type: none"> • 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 with item or activity • Don’t make a threat you can not follow through on



	Examples of Behaviours	Shaping More Positive Behaviours
<p>3</p> <p>Need for Escape</p> <p>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.</p>	<ul style="list-style-type: none"> • Hitting or misbehaving during a therapy session • Ignoring what you are telling them to do • Throwing a tantrum before leaving for the hospital 	<ul style="list-style-type: none"> • It is very important to always follow through with the requested task • By following through you are showing them these challenging behaviours can't be used to escape or avoid • Follow through also creates structure and predictability
<p>4</p> <p>Need for Sensory Stimulation</p> <p>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.</p>	<ul style="list-style-type: none"> • Rocking back and fourth • Flapping hands • Hitting knees • Banging head against the wall 	<ul style="list-style-type: none"> • Ask about the Snoezelen room at Holland Bloorview. This multi-sensory therapy room allows children to enjoy the feelings of touch, lights and sounds • Hugs for comfort • Massage for deep pressure • Light up toys • Ask about art and music therapy at Holland Bloorview

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.

-  Visit a park
-  Computer/video game
-  Homemade crafts
-  Go to the library
-  Watch a movie
-  Outside playtime
-  Spend time with friends
-  Game night
-  Finger painting
-  Attend a school activity
-  Dollar store treat
-  Dance party
-  Have a sleepover
-  Cooking or baking
-  Scavenger hunt



RESOURCES

Understanding The Brain 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

Websites

- “What I need others to realize about my life after traumatic brain injury” by themighty.com;
<https://themighty.com/2017/01/invisible-disability-life-after-traumatic-brain-injury/>
- “Invisibility Disability Project”;
<https://www.invisibledisabilityproject.org/>
- “The Invisible Disability: Coping with a Traumatic Brain Injury (TBI)” by Gillette Children’s Speciality Healthcare;
<https://www.gillettechildrens.org/khm/the-invisible-disability-coping-with-a-traumatic-brain-injury-tbi>

Siblings and Young Caregivers

Websites

- “Ontario’s Young Carers” by The Change Foundation;
<https://www.changefoundation.ca/ontarios-young-carers/>
- “Sibling Support Project”;
<https://www.siblingsupport.org/>
- “Helping Children Cope with Head Injury in the Family” by Audrey Daisley, Rachel Tams, and Udo Kischka;
<https://www.brainline.org/article/helping-children-cope-head-injury-family>

Behaviour Management

Book

- “Ain’t Misbehavin’: Tactics for Tantrums, Meltdowns, Bedtime Blues and Other Perfectly Normal Kid Behaviours” by Alyson Schafer

Taking Care of Me

Websites

- “80+ Self-Care Activities for teens” by kiddiematters.com;
<https://www.kiddiematters.com/80-self-care-activities-teens/>
- “Best Affordable Self-Care Ideas” by The Mighty;
<https://www.teenvogue.com/story/best-affordable-self-care-ideas>

Thoughts and Feelings

Books

- “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 entire “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
- “Peaceful Piggy Meditation” by Kerry Lee Maclean



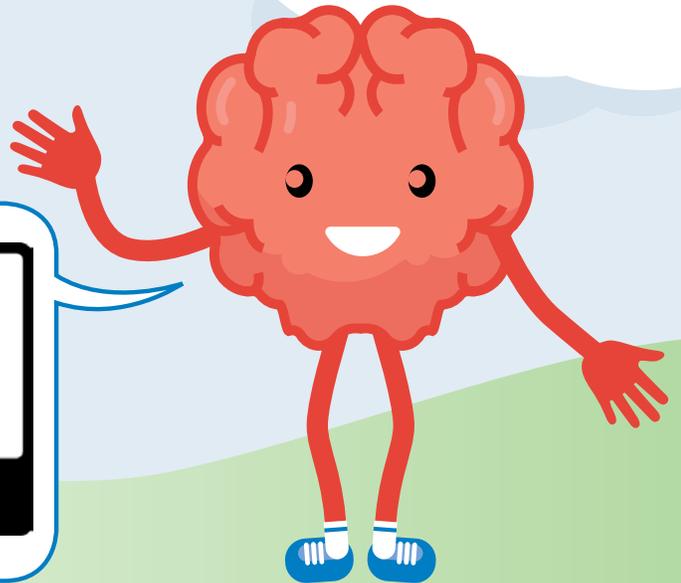
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**Tell us what you think
about the SibKit by
completing this survey:**

www.surveymonkey.com/r/TTT863H



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