Staying Connected:

a Guide for Families When a Sick Child has Trouble Communicating

Ceilidh Eaton Russell

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When a Sick Child has Trouble Communicating

This book was inspired by children with brain tumours and their families, and is based on their experiences and wisdom. We are deeply grateful to them for sharing their stories. This book was made possible by the generous financial support provided by BrainChild.

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Introduction

Introduction

Supporting a child or teenager who has a brain tumour is an incredibly important and difficult job. Trying to help them to understand and live with their changing abilities can be overwhelming, especially when caregivers naturally struggle with these changes themselves. It can also be a challenge because while physical abilities may change, cognitive abilities often stay intact. If a child or teenager has trouble communicating because of a brain tumour, the task of supporting them becomes even more complex.

Our team has worked with family members and caregivers in this situation. People have often told us about times when they did not know what to do or where to start and they often felt helpless and frustrated. But in the end they did it. With time, patience, creativity and support, families found ways of communicating with their children and teenagers even though these young patients had trouble speaking.

In this handbook we have put together what we learned from talking with fourteen families about their experiences, as well as from our own experiences working with families. The parents we spoke with generously shared the creative strategies and tools that they developed, the most important conversations they had and the lessons they learned. When we began to talk with these parents, our goal was to develop a new communication tool. In the end, they taught us that although tools are helpful, direct communication was most valued and helpful. Families encouraged us to create this resource to share with other families like yours, so that you would have some ideas about where to start and what to try, and so that you would know that you are not alone.

Of course every family and every child is unique, each with their own values, philosophies, experiences and backgrounds. Some of your family's experiences may be very different from those of the families we interviewed for this book. However, some of the situations they faced or the strategies they tried may be similar or helpful to you. We encourage you to think about the ideas outlined in this book, and to use or modify them so that they work for your family and are well suited to your child's age and developmental stage.

How to use this book

At the beginning of each section of this book we have included a list of "Quick Tips" that will be discussed in detail in that section, and the page number where you can find that topic. With these "Quick Tips" we've tried to capture the most important issues from each section so that you can read the short-version quickly, and know how to find more details about these issues when you have a chance to read and process that information in more depth.

Throughout this book you'll see a lot of quotes in bold font. These are comments that parents shared with us during their interviews. We wanted them to stand out to make them easy for you to find.

The families we spoke with and the members of our team sincerely hope that the information in this book will help you and your family feel, at the very least, a little more prepared and supported.

The opportunity to interview families and the creation of this handbook was made possible by generous support from B.r.a.i.n.Child.

A New Approach to Communication

Quick Tips:

- Remember that although this can be an incredibly difficult task, YOU CAN DO IT. Be patient with yourself, your child and the process (see pg. 7 & 12).
- Learn and practise ways to communicate without speech before they are needed (see pg. 8).
- Practise more than one way of communicating without words (see pg. 8).
- A couple of helpful ways to ask questions (see pg. 9):
    - Offer two clear choices
    - Ask questions that can be answered with “yes” or “no.”
- About “yes” or “no” questions (see pg. 10):
    - Practise more than one signal for “yes.”
    - Any part of the body that a young person can control can be used as a signal for “yes.”
    - Remind your child what the “yes” signal is before asking each question.
    - Instead of making a second signal for “no,” assume that if the child doesn’t say “yes,” they mean “no.”
- When there are fewer clues about what a child wants or needs, start by asking broad questions and then ask more and more specific questions based on the child’s responses (see pg. 11).
- Use simple sentences to get to the main point (see pg. 9).
    - Instead of “Do you want something for dinner?,” ask “Are you hungry?”
    - If your child has a hard time responding, repeat the question or simplify it. For example, simplify by saying, “Hungry?”
    - Remember the “KIS” principle: Keep It Simple
- Wait longer than usual for the child to respond (see pg. 10).
- To make sure that your child’s message is understood correctly, repeat what you think they said. For example, “Okay, you are hungry. Is that right?” or “So you’re not hungry. Is that right?” This gives your child a chance to confirm that his message was interpreted correctly (see pg. 9).
- Although interactions may feel different when a child has trouble speaking, he or she is still the same person as before (see pg. 12).

Communication

If you feel daunted, frustrated or overwhelmed, try to remember that although helping your child communicate may be an incredibly difficult task, YOU CAN DO IT. In fact, you have probably done it already, before your child first learned how to speak. Although your child has developed intellectually since that time and now has more complex ideas to express, remember that with your help, your child was able to learn and use a different way of communicating once before. At times when communication didn’t seem to be going well, some caregivers worried that it was because they were missing something or that they should have been doing more. Know that this is not the case; you’re doing the best job you can. Try to be patient with yourself, keeping in mind that the difficulties you’re facing are caused by this enormously challenging situation. If you need to, take breaks to manage your own stress. Young people can sense your anxiety, stress or frustration so allow yourself the time to re-focus and know that this can be a challenging process for anyone, no matter how experienced.

Preparing for the unexpected

It can be hard to prepare for something when we do not know what to expect. Brain tumours affect children's and teenagers' abilities in different ways at different times, but some changes are more common than others. Many of the caregivers we spoke to described their children as having trouble articulating words clearly, either because of weakness or because the muscles in the face and jaw were hard to control. In these situations, their speech sounded slurred and could be difficult to understand. Some children also felt weak or got tired easily, making it hard for them to use their arms and hands to write, draw or point.

No matter what kind of difficulties these young people faced, caregivers identified two things that were extremely important in order to prepare and help their children communicate as much as possible and for as long as possible. First, it was crucial that children **learned and practised ways to communicate without speech before they needed to use them.** This was not always easy, as children were sometimes reluctant to use communication strategies before they absolutely had to. Parents and children often do not want to think about a time when these strategies will be necessary. This is natural and understandable. However, by the time these strategies are needed, because children are not able to communicate in the ways that they used to, their abilities to learn a new skill requiring patience and concentration are not as strong as they may need to be.

One mother expressed, **"If communication is starting to be a challenge you wouldn't necessarily know if they completely understand how [a new communication strategy] functions without them being able to answer you."**

Most parents told us that although they hadn't wanted to think about the chance that their child could have trouble speaking, it was more important to be prepared **"sooner than later"** just in case she did. One father explained that their family had practised using hand signals in case their child lost the ability to speak, even though they hoped they would not need to use that new technique. He said, **"I mean it might not happen but at least we are prepared for that. And in our case it did happen and so when we said, 'Remember we practised the hands [for] 'yes' or 'no'?' and she nodded and she used that to communicate." This father also shared this important advice: "Try to have a plan. It is tough but if you don't have a plan it will be even tougher. It will be much tougher."**

The second thing that parents said was critical was to **practise more than one way of communicating without words.** That way, if any of the child's abilities changed in an unexpected way, she would still be able to use another means to communicate.

For a few of the families we spoke with, the child's abilities changed very suddenly. Because they had not been able to anticipate these changes, they were unable to practise new communication strategies ahead of time. In these situations it is still possible to learn to use new strategies. One mother explained, **"Kids will show you how they're able to communicate,"** emphasizing the importance of watching their eyes and facial cues for signs of understanding or confusion, agreement or disagreement, frustration or relief, and the importance of trusting your instincts.

In this book you will find a lot of different tools and techniques that you can try in order to find a few that fit for your child and your family. On page 15, you will find a list of tools and techniques with descriptions of how to use them.

Different ways to ask questions

When children and teenagers are not able to speak, caregivers can help them express themselves by asking questions that are very clear and carefully worded. Two helpful techniques that families used were:

- Offering two clear choices
- Asking questions that can be answered with "yes" or "no"

Learning to ask questions in these ways takes careful thought and practise, but families felt that by using these techniques, they could help their children express a wide range of messages.

Offering two choices

When children are able to move a finger, an arm, a hand, a foot or even their head, or if they can use their eyes to look in different directions, they should be able to choose between two things. It is important to clearly tell children what the two choices are and then ask them to show you which one they want.

One father explained to us that, **"Instead of asking them what you want to drink, you turn it around and you say 'Chocolate milk or juice?' Every question needs to have a choice and that choice has to be very, very obvious because if that choice is not obvious they are going to get so confused."** Using this example, a parent could hold chocolate milk in one hand and juice in the other. After showing them to the child and saying what was in each hand, the parent would ask the child which one she'd like, reminding her to show him by pointing or looking at the drink that she wanted. Once a child has made a choice, it's helpful to double-check by asking, "Do you mean that you want the juice?" and waiting for her to show you that she means, "Yes."

When the child is choosing between two things that you cannot show her, try asking a series of questions to find out what she wants, like this:

1. "I wonder if you would rather go for a walk or take a bath?."
2. "I'll ask you about one thing at a time and then I'll wait after each one in case you want to say 'Yes'."
3. "So, want to go for a walk?" After asking this question, pause for at least 10 seconds.
4. If the child does not respond, then say, "Okay. Want to take a bath?."

It may take the child longer than usual to make a choice, so remember to wait for her response. If she does not respond, here are a few things to try:

- o **Ask if she needs you to remind her what the signal is for "yes."**
- o Ask if she needs you to remind her what the options were, and wait for her to respond. If she says "yes," repeat the series of questions above and wait for her response.
- o Ask if she does not want either of the choices that were offered to her, and wait for her to respond. If she says "yes," try to think of what other options she may prefer.

Offering kids choices helps them feel like they have some control. Although this method can take a long time to find out what your child wants, it is usually worth the extra effort for the child.

Using "yes" or "no" questions

Even when children and teenagers are not able to point or to choose between two things, caregivers can help them express themselves by asking questions that can be answered with a "yes" or a "no." This was the most common technique that families used to communicate with their children and it worked well with a wide range of other communication tools and techniques.

Young people can show that they mean "yes" in a range of ways, like:

- Nodding their heads
- Giving a "thumbs up" or waving a finger up and down
- Raising their eyebrows
- Looking up (like nodding with their eyes)
- Wrinkling their nose
- Wiggling their toes or moving a foot

Any part of the body that a young person can control can be used as a signal for "yes." Instead of making a second signal for "no," it is easier to assume that if the child doesn't say "yes," they mean "no." That way there is less confusion about which signal to use for which word. Again, it is helpful for children to practise more than one signal for "yes" in case their abilities change, making it difficult to use a particular signal. Once a child has chosen a couple of signals, ask him five "yes" or "no" questions that you know the answers to and make sure your answers match his signals.

Since some questions may have more than one meaning, it is very important to ask in a way that is clear and direct. For example, asking a child, "How are you feeling?" can be confusing since it might refer to physical or emotional "feelings." A parent explained, **"We had to try to channel our questions more specifically; for example, asking 'Are you sad?' or 'Does your body feel okay?' instead of 'How are you feeling?'"**

When there are fewer clues about what a child wants or needs, parents started by asking broad questions and then asking more and more specific questions based on the child's responses. For example, if a child seems upset you could start by asking, "Is something bothering you?" If the answer were "yes," you could ask more specific questions, one at a time, until the child says "yes" again:

- "Is it something in your body that's bothering you?"
  - o If they say "yes," ask: "Is it your head?" "Is it your stomach?" continuing to ask about different body parts until they say "yes." Remember to pause after each question to wait for a response.
- Once a child has said "yes" about a particular body part, ask, "Is it sore?" "Is it itchy?" or "Is it hot?" etc.
- If they do not say "yes" to any part of their body, say "Okay, maybe it's not something in your body that's bothering you. Are you feeling upset about something?"
  - o If they say, "yes," ask questions about specific feelings, like, "Are you sad?" "Are you feeling frustrated?" until they say "yes" to something. See page 27 for some ideas that parents gave us about how to talk about different feelings.

If they do not say "yes," try asking, "Is it something you're thinking about?" or "Are you worried about something?"

(The tools on pages 15 can be used to help you talk with your child about a range of topics).

This example illustrates that it is often easier to know what to ask when the topic is concrete, like physical sensations, or finding out what a child wants to do. Talking about more abstract things like emotions and ideas can be much more complicated because there are so many more possible questions. Because of this, you will need to ask a lot more questions when you discuss these topics.

Parents told us that it sometimes felt like they asked a million questions and they still did not know what the child wanted. This was very frustrating for the parents and the child. If this happens, tell your child:

- o "I know that you know what you want to say. This is really hard for both of us but I want to try to help."
- o Then ask, "Should I keep trying to figure out what you're thinking or should we take a break? I'm going to ask you that again and wait for you to show me 'yes' after the one that you want me to do."
- o Then repeat these two options, pausing in between for the child's response.

It is especially important to be patient with the process and with yourself during these conversations. As much as you can, trust your instincts about your child's wants and needs, even though you won't always be able to easily identify what they're trying to say.

Figuring out what to ask

The parents we spoke with told us about different clues they used to help them figure out what questions to ask, or what the child might be thinking or feeling. One of the most helpful things was to consider past experiences with the child, including his or her typical behaviours, preferences and needs. Although interactions may feel different when a child has trouble speaking, he is still the same person as before, so your past experiences will tell you a lot about what he wants and needs. As one parent said, **"I would just kind of say things that I knew were something that he might say."** Another parent explained, **"Most communication can be improved by the amount of time you spend with your child. The more time you are able to spend together, the better you understand the eyes and facial expressions."**

Facial expressions and body language

One parent explained that facial expressions **"don't change for children; that's always the same whether they can communicate or not."** When you recognize a familiar facial expression, it probably means the same thing that it used to mean. For example, **"Being bored is a very big part of being a kid. I mean boredom is boring no matter what position you're in, sick or not."**

In addition to telling us a lot about their feelings and moods, a child's face or body can show that he is comfortable, with a relaxed body, or uncomfortable, which might be shown by a tense body or face. One mother told us about her daughter's facial cues, saying, **"Whenever she is in pain she squeezes her forehead and whenever she is at peace and comfortable, she just smiles."**

For some children, the tumour may affect muscles in their face causing facial expressions to look different than they used to. However, parents said that even with these changes they could often recognize what the child was expressing, and that especially the children's eyes continued to express a lot of emotions.

Routines and preferences

The time of day and/or familiar routines can offer clues about whether a child might be tired, hungry, want to bathe, go outside, or play. Although children might have to do these things in a different way than they used to, if they are losing some of their abilities it is still helpful for them to participate in familiar activities as much as they can. Thinking about the situation - where you are, who's around and what you are doing - will also help narrow down the questions or the needs that the child might have.

Even with all of these clues, there will be times when it is very hard to know what the child is thinking about. **One parent described it as "a guessing game… I just kept asking her, 'Do you want this? Want this? Want this?' And then I just thought 'Oh, okay, she's wanting this one'."**

One technique you can try is to ask your child, **"Am I getting closer?" (or "Am I getting warmer?"** if your child is familiar with that guessing game) to let you know if your questions are headed in the right direction. This can be useful with all different kinds of questions; for example, asking about different feelings or about things that you can point to, like toys on a shelf or a certain kind of food in the cupboard.

One of the lessons that parents said they learned was that often, **"It would be the simplest thing that he wanted."** This is an important and difficult thing to remember, especially when it feels like there are so many things the child could be thinking about. These parents advised to start with basic things like asking whether the child wants to sit up or change positions, or if they have a communication tool, check to see if that's what they're asking for. Many parents told us that with time and practise, **"You get to know the signs of what the child needs."**

"How" to communicate

One mother reflected, **"The manner in which you communicate is important,"** emphasizing that it is not only what is said that matters, but *how* it is said. A lot of emotional messages can be conveyed through hugs, touch or being close together. One father told us that another reason to be close to your child when you're communicating is that **"You get so much of your information out of what the person does facially… looking her in the eyes was a great way to figure out what was going on and what she was thinking about."** Being close and making eye contact also helps children feel more connected and comforted.

Communication Strategies

Quick Tips:

- Include the child in creating communication tools as much as possible (see pg. 17).
- Consider the child's unique voice: recording the child's voice, including jokes, common phrases in communication tools helps a child's personality shine through (see pg. 17).
- Learn and practise a range of communication strategies (see pg. 20).
- Adapt familiar communication tools to meet a child's changing needs rather than introducing brand new tools (see pg. 19).
- If a child does not want to use a certain tool, do not force him but explain that you want him to know how it works anyway, so that it is familiar if it is needed later (see pg. 19-20).
- Communication tips (see pg. 19):
    - o Even if the child can't talk, keep talking and including him in family interactions.
    - o Teach siblings how to communicate using the new tools or techniques.
    - o Use communication strategies to play games with your child.
    - o Try to be patient with yourself, your child and the process.

a. Practise calming techniques together on a regular basis (for example, deep breathing, blowing bubbles, soothing touch). Staying calm will help you communicate more effectively in difficult situations (see pg. 20).

b. Remember that the most meaningful part of communication is the connection between people, rather than the content of the message (see pg. 21).

Communication Strategies

Families communicated in a wide variety of different ways. In this section we have organized these creative communication strategies into two categories: **tools,** meaning that there was an actual "thing" that was used to help the child express himself, and **techniques,** referring to a special way of communicating but without using a physical tool. First, we will describe each of the tools and techniques, and then, on page 58, we have included some sample tools that you can try. Please note: this may be an overwhelming list of possibilities. We've included these to assist you in finding what will work best in your situation.

Tools

- **A bell or buzzer:** these could be used to get someone's attention if the child were in a different room, or as a way to say "yes." One child who wasn't able to ring a bell, learned to make a popping sound to get her mother's attention.
- **Paper & pencil / markers:** for kids who had learned to print or write, this was a very familiar way to express their thoughts. When one child had trouble hearing, her parents wrote down what they were saying and she wrote her answers back.
- **Magnadoodle:** (a magnetic drawing toy) kids could write messages, draw pictures, or draw an arrow to point the Magnadoodle at what they wanted. They really liked using Magnadoodles, partly because they were familiar and felt like using a toy rather than a "special device," but also because they were easy to use.

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- **Laptop / tablet:** some kids who knew how to type liked using tablets or laptops because they allowed them to send emails and even to type messages for someone to read at the same time. They also liked that they could watch movies on the same device. On the other hand, some people found that laptops were too heavy. Perhaps one of the lighter and smaller tablets or laptops might work well.
- **Keyboard:** a few children used regular keyboards that were not connected to computers. They would press a series of letters to spell what they wanted to say while someone else watched and figured out what they were typing. Special keyboards that have the letters in alphabetical order were also used this way. These tools allowed children to express a broad range of messages. Some people found that this could take a long time and sometimes a child might forget what letters they had already typed.
    - Many families created their own "keyboard" by clearly writing the alphabet in large letters on a piece of paper or cardboard.
- **Picture books or boards:** these could be like scrapbooks or a piece of cardboard with pictures and words, made by family and friends. They were portable and familiar, especially when photos were used. Some children may prefer to use this kind of "arts and crafts" tool rather than something that is less familiar or that they associate with the hospital. In addition, while technology is always changing and some tools may be either unfamiliar because they are new, or on the other hand, may feel out of date, arts and crafts-based-tools are timeless. Children would point to the picture or word, or parents would scroll through, pointing to one message at a time waiting for the child to say "yes" when they were pointing at the right message. Some people found it frustrating to search for the right message, especially when the child wanted to say something that was not included in the book or board.
- **"Menus":** a couple of families had lists of things that the child might want, sorted into categories so it looked like a menu. They used it the same way as a picture book or board.
- **Feelings faces:** a chart showing a variety of faces including happy, sad, angry, frustrated, lonely, bored, excited, hopeful, etc., helped children to express themselves by pointing (or to have their parents point) to the feeling they had. The number of different faces to include depends on a child's age and abilities. Some children may benefit from a wide variety of feeling faces to choose from while others may feel overwhelmed by too many options. It can be helpful to include the child in choosing which faces to include. More faces can be added or taken away later as a child's needs change. See page 62 for some examples.
- **High-tech communication devices:** these usually have buttons for children to press, with each button causing a different message to be spoken, allowing kids to express a range of messages. While some children liked using these, others did not. Some families found that certain devices were complicated, seemed unfamiliar, and were sometimes hard to use or felt impersonal.

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Tips about tools:

- For kids who are able to read, **include words as well as pictures or symbols** in communication books or boards. Children will associate the words with the symbols so that if it becomes difficult to read the words, they are still familiar with the meaning of the symbols or pictures.
- **Include the child in creating communication tools** (books, boards, high-tech devices) as much as possible. By choosing which images will represent different words, feelings, activities, etc., they maintain some control and will feel more connected and involved in the process. It also promotes familiarity and makes children feel more invested in using the tool. One mother talked about the value of having her daughter choose different images to represent different moods in her communication book. By giving children these choices, this mother explained, **"You're giving them that independence, that control over their life as they're lying in bed and they can't do anything and yet they can still express themselves."**
- As much as possible, **consider the child's individual voice.** For some families this meant recording the child's voice on a high-tech device or a voice recorder, saying common messages so that they could hear their own voices. Many families who did this, treasured the recording and encouraged other families to do this as early as they could. When this was not possible, some families recorded the voice of the child's friend, in order to match the age and gender of the recorded voice. Many parents said that it wasn't just about the sound of the child's voice but the kinds of things that he or she would have wanted to say. By including jokes, sayings or common phrases, a child's unique personality is able to shine through in a meaningful way. One mother shared this example: **"One of his things isn't very nice but he used to always say, 'You idiot,' right? So I put that on there… if we're all, all of us crowded around trying to figure out what he was trying to say, he could sit there and go, 'I'm frustrated, you idiot,' which is really how he felt."** Including personalized messages like this helps to maintain the unique and special connections within relationships.
- **Ask about messages that are not in the tool.** If you are using a tool that has preset messages or pictures in it, like a picture book or a high tech device, your child may want to express something that is not included in the tool. In this case, you can ask, "Is it something that isn't in here?" to find out if that's the case. Then you can use "yes" or "no" questions to find out what your child is thinking, and to decide whether that new message should be added to the communication tool.

Techniques

Most families found that they used special ways of asking questions – offering two choices and "yes" or "no" questions – (described on page 10) and reading their children's body language and facial expressions (see page 12) to communicate with their children. In addition, some families also used the following techniques to communicate with their children:

- **Signals** – some families made up signs or signals using their hands or their faces. For example, a child could hold an imaginary cup up to his mouth to signal that he was thirsty, or pretend to be chewing to show that he was hungry. A couple of families used simple sign language, especially by using the first letter of a person's name to refer to that person. (The website: www.babysigningtime.com has DVD's that teach simple signs that kids of all ages could use).
- **Pointing** – children would often point to things to show what they wanted; for example, they might point to a window to say they wanted to go outside, or they might point to a tv or even to pictures in a book or on picture boards. If a child is uncomfortable, he can point to the part of his own body, or a picture of a body to tell others where he feels the discomfort.
- **Lip reading** – some children had trouble producing sounds or words but were still able to make the shape of words with their mouths. Doing this allowed them to express a wide range of messages. For children who had trouble hearing, a few parents said that by mouthing words slowly, and exaggerating their mouth's movements, their children could figure out what they were saying. Lip reading can be difficult to learn, requiring extra practise and patience. If a child has problems with vision, or if the tumour affects the muscles in his face this would not be the best technique to use.
- **Physical presence**, touch and hugs – when it was too hard to use words, being close to one another and sharing affection were great ways of expressing emotions and love.
- **Make lists** – many parents said that it was very important to keep three kinds of lists, and to keep adding to them:
    1. Signals, including what the signal looked like and what it meant;
    2. Common questions that caregivers would ask, or things that the child would ask or say, or issues or needs that the child had;
    3. Clues to a child's needs, like body language, time of day or anything else that would help figure out what the child wanted or needed.

Parents found that these lists helped them to remember or think of what to ask, but they were also a great help when someone else was caring for the child who was less familiar with their communication strategies.

Tips about communication in general

- When possible, try to **adapt familiar communication tools** to meet a child's changing needs rather than introducing brand new tools. As one parent explained, **"There's nothing like familiarity because it creates that safety, that whole contentment and feeling connected."**
- Even if the child can't talk, **keep talking** to him. One child's sisters said how important it was to keep saying "hello" and "goodbye" to their brother on their way in and out of the house, to keep including him in their interactions even though he could not talk. Avoid asking the child questions that he'll be unable to answer – stick with "yes" or "no" questions – but do keep including him and asking his opinions.
- **Teach siblings how to communicate** using the new tools or techniques. This helps to encourage their interaction and maintain their sibling connection even though they are relating in a different way than they used to.
- **Use communication strategies to play games with your child.** This can help him to become more comfortable with the strategies and to gain practise communicating. For example, children who are able to say "yes" can play Twenty Questions; children who are using a communication book secretly choose a message while others try to guess what it is. Families can play Charades by having the child point out one message for another person to act out and others to try to guess what it is.
- **Try to be patient with yourself, your child and the process.** There is no easy way to do this. Try to stay calm, take deep breaths and take care of yourself. One parent reflected on, **"the frustration level that she felt and our having to be patient and to say, 'It's okay, take your time, we'll figure it out, I know it's hard.'"** Parents clearly told us that they and their children often felt frustrated and helpless. In the midst of this difficult process, one of the important things for children to hear is: "I know that you know what you want to say."

Challenges

Regardless of what tool or technique was used, children and their families faced a number of challenges. Children often felt frustrated that they couldn't easily express themselves and that their abilities were changing. Parents felt equally frustrated that they couldn't "fix" the situation.

Some children were reluctant to use certain tools, as one **father explained, "She was sort of insulted by things like the big keyboard that we borrowed. She would refuse to use the stuff until she absolutely had to."** If a child refuses to use a certain tool, try telling her that she does not have to use it right now but that you want to show her how it works anyway. **One mother said, "I would tell him, 'Here's something that we might think about doing later, but we might not.'"** That way if you need to reintroduce it later, it will be familiar.

On the other hand, one mother told us that her daughter continued to want to use her laptop, even though she was no longer able to use her fingers to type. Because of how strongly this child felt, her mother helped her to hold her hands over the keyboard to help her type. This mother explained how important it was for her to help satisfy her child's desire even though it was not an effective means of communicating. Since there were other reliable communication strategies that they could use as needed, this mother found it helpful to continue to assist the child to use the laptop as well.

On one hand, it is important not to force children to use a communication tool that they do not want to use. On the other hand, if they have not already had the chance to learn and practise communication strategies, it can be even more challenging for them to use new techniques to express themselves when their abilities change unexpectedly.

One father talked about how important it was to practise a number of signals for answering "yes" or "no" questions with his child: **"We said, 'You might lose your motion, you might not be able to move your hands… that's why you [will] have to [be able to] say "yes," so we are preparing you to say "yes" in various different ways.'"**

For these reasons, **we recommend that families talk about and practise a range of communication strategies rather than focusing only on one.** It is also helpful to adapt old strategies as much as possible, so that the child can keep using the same approach in a slightly different way, rather than learning something completely new.

For example, use a picture board with many small pictures at first and if the child's vision starts to change, narrow down the number of pictures, spread them out and enlarge them so that they're easier to see. Practising a variety of techniques and adapting them (rather than starting something totally different) are ways of helping children feel familiar with different communication strategies.

Sometimes you may need to communicate in the midst of a crisis situation or while your child is distressed. This may be brought on by physical and/or emotional pain that the child is feeling. It is important to know how to calm yourself and your child so that you will be able to work together and communicate effectively to manage these situations. One mother explained, **"In a crisis situation, I think she found it comforting to hear my voice. Mostly I would talk about favourite things that I knew that she liked; for example, family vacation memories, when funny things happened to other people and we were all laughing… anything. Just to fill the air with my voice and take her to a happy place, while rubbing her arm and talking."**

Practise calming techniques together on a regular basis. Some examples are deep breathing, blowing bubbles, soothing touch or focusing on each other. These techniques are helpful because when you and your child are calm, you will be able to communicate more effectively, which is especially important in an urgent situation.

Deciding what to try

Choosing a strategy for communicating with a child depends on a number of factors. The first things to consider are the child's abilities. One father suggested, **"Whether it's a keyboard or a magna doodle, you could rank them [according to] their up-sides and down-sides and that'll help you choose which tool's the best."** If you have access to a Speech Language Pathologist, talk to her for recommendations and advice about choosing and learning to use different communication strategies and ask about any low-tech or high-tech tools that might be available.

Another important factor is personal preference. If you can, consult with your child's team to find out what strategies might be best suited to your child's needs and preferences. Then, considering your child's personality, decide which ones to try out with your child. Together you can decide which ones work best. Parents said that some children seemed more open to using something that was familiar, or that felt like play, such as drawing, writing or using a Magna-doodle.

Many parents explained that the emphasis of communication should be on the connection between people, rather than the content of the message. One parent told us that using a high-tech communication device seemed to get in the way of personal interactions more than using "yes" or "no" questions did. **He felt his child would rather "Get all the love [she] could and through that love, be able to communicate rather than have an introduction of a new thing [that interferes with] the relationship… They want to talk to their parents, to see their parents' eyes, to see what reaction the parents have when they say 'no' to something or when they say 'yes' to something… Expressions and things like that, a machine cannot replicate at all."**

Remember, no one knows your child better than you do. The parents we spoke with said, **"Kids will show you how they can communicate, you just need to be looking for their cues, and use your instincts and intuition."**

When to change communication strategies

While it is often easier for a child to keep doing what is familiar rather than trying something new, sometimes there is no choice. If a communication strategy is no longer working, or if your child is getting more frustrated or as one father suggested, **"When the error rate gets too high, when it takes five strikes to hit the right key then it is probably time to try something new."**

Communication Topics

Quick Tips:

- For a list of some of the most important and common messages about the child's physical or medical needs, see pg. 25.
- When exploring emotional issues, ensure you understand the child's unique perspective rather than thinking about it only from an adult perspective. In other words, focus on how the child is thinking and feeling, not how you would think or feel in that situation (see pg. 28).
- Talking about abstract topics like emotions, spirituality and the future requires caregivers to ask more questions in order to help a child express what she is thinking and feeling (see below).
- Although some of the things children wonder about may lead to emotionally difficult conversations, children cope better when their questions are answered than when they don't have that information and then make up their own answers (see pg. 25 & 27).
- Children need reassurance that all of their feelings – even the hard ones – are natural (see pg. 29).
- Try to offer them a long list of emotions to choose from, using familiar words (see pg. 28).
- Children benefit from participating in familiar activities and talking about "regular," day-to-day topics. Try to adapt activities so that a child can continue to participate, and keep talking about "regular, everyday stuff," like what their friends and family are doing, upcoming plans, as well as reminscing and "remember when...?" (see pg. 30).
- It is natural for children to wonder about the future, spirituality and death, regardless of their prognosis, and it can be very hard for them to initiate these conversations. If they do, try to respond calmly, honestly and concretely and remember that it's okay to say, "I don't know" (see pg. 31).
- It can be extremely comforting for a child to know how they will be remembered if they were to die. These are emotional and difficult conversations but also very helpful (see pg. 34).
- Developing and becoming familiar with communication strategies for different topics will happen over time and with support. Family, friends and the child's team at the hospital can help (see pg. 24).

Communication Topics

When we asked parents, "What were the most important things to be able to talk about?" they said, "Everything was important." Making sure that a child was comfortable, that her needs were being met, that she felt loved and cared for were all very important, but so was "having regular conversations" about friends, jokes, hobbies and day-to-day activities. Two messages that parents said were important to include in any communication strategy were "I need help" and "stop."

Some messages were easier than others for children to express. Messages that were more concrete and specific – feeling hungry or uncomfortable, or wanting to do something – were easier for children to express because they could point to a picture or an object, or answer "yes" to questions about these topics. Abstract topics like emotions, spirituality and the future were more difficult to discuss because there weren't objects for a child to point at, in order to get her message across. In these situations, caregivers need to ask a lot more questions in order to help a child express what she is thinking and feeling.

Some of these conversations can be more challenging, not only because of the abstract nature of the topic but for emotional reasons as well. Even reading about some of these communication topics may be difficult. However, we encourage you to give yourself a chance to read and think about what other parents shared with us so that you can feel somewhat prepared for conversations you may have with your child. Please remember to be patient and gentle with yourself as you read this chapter, taking the time to reflect and decide on how these ideas might work for you and your family.

Another important thing to consider is that there are some topics that children and teenagers may not feel comfortable talking about with their parents. Just as parents naturally want to protect their children, children and teenagers also wish to protect their parents, which, for them, may mean avoiding certain topics if they fear it will be upsetting. First of all, it is important to reassure children and teenagers that it is the situation – not the child – that would be upsetting, and that as a parent, supporting your child means talking about those difficult things as well. Second, some children find it important to have someone besides their parent to talk to, who they trust and who they will not worry about upsetting by expressing their thoughts or fears. This might mean arranging for the child to be able to speak privately with a family member, a friend or a professional, such as a child life specialist, social worker, nurse, chaplain, teacher, or someone else who they trust, and helping that person become familiar with the child's communication strategies. Reassure your child that you understand their need to talk with someone else, and that it is okay for them to do so when they want or need to.

Parents' suggestions about how to talk about important issues with children fell into three categories: topics to discuss; messages for children to be able to express; and questions for parents to ask. Whether a child expresses a message herself, or a parent or caregiver asks questions to find out what the child is thinking, will depend on the kind of communication strategy being used. In this section we will present the topics that parents said were most important, as well as specific points for parents to address with their children by asking the child questions; in some cases a child may be able to express these messages independently.

It may seem overwhelming to think about all of the topics or messages your child may want to express, and the charts, lists or strategies you could use to help your child communicate. Remember that it does not have to happen all at once. As one parent told us, **"Those are things that evolved… I didn't think of these things overnight. And I didn't even think of all of them, it was a collective." Developing and becoming familiar with communication strategies will happen over time and with support.** Family, friends and your child's team at the hospital can all help you with these tasks.

Important topic: physical needs

Important Messages:

Child's messages	**Parents' questions**
Ouch / I'm in pain / Something's hurting	"Is something hurting?" "Are you in pain?" If "yes," ask: "Can you show me where it hurts?" Point to different parts of your child's body, or to a picture of a body, or even name different body parts – "Is it your head?" "Is it your stomach?" – and ask your child to let you know when you've said, or pointed at the part of the body where he or she feels pain. Remind your child how to signal "yes."
I'm uncomfortable	"Are you uncomfortable?" If "yes," ask (one at a time, slowly, until your child indicates "yes"):"Do you feel stiff / numbness / itchy / dizzy / hot / cold / weak?"
I need to move / I need to change positions	"Do you want to move / change positions?" If "yes," ask (one at a time, slowly, until your child indicates "yes"):"Do you want to sit up / lean back / lie down / roll over / move over / sit somewhere else / lie down somewhere else / go outside?"
I need to go to the bathroom	"Do you need to go to the bathroom?"If "yes," ask (one at a time, slowly, until your child indicates "yes"): "Do you need to use the toilet or a new diaper / take a shower or bath / brush your teeth / brush your hair / wash your face?"
I'm hungry	"Are you hungry?" If "yes," offer food choices, one at a time, slowly, until your child indicates "yes."
I'm thirsty	"Are you thirsty?" If "yes," offer drink choices, one at a time, slowly, until your child indicates "yes."
I need my walker / wheelchair	"Do you want your walker / wheelchair?"

Besides these specific messages, parents explained that they had had important conversations with their children about the fact that their abilities were changing, and in some cases, children's questions about how their abilities would continue to change. Although these could be emotionally difficult conversations, when their questions are answered, children are able to cope better than when they don't have that information and then make up their own answers.

Important topic: medical issues

Important messages:

Child's messages	**Parents' questions**
I need pain medicine	"Do you need some medicine for pain?"
I need more oxygen	"Do you need more oxygen?"
What is that?	"Are you wondering about this medicine / medical equipment?"
What will it feel like?	"Are you wondering what this medicine / procedure will feel like?"

In addition to these messages, parents also said their children wanted to know about their medical equipment including feeding tubes, IV's, and about tests and procedures that they would have. Usually kids want to know what different medical equipment is for, how it all works and what procedures will feel like. Children benefit from knowing what to expect about a test or procedure – where it will take place, who will be there, what steps are involved and what it will feel like. This information helps children by giving them a chance to rehearse what will happen in advance, allowing them to practise coping strategies. Some examples of coping strategies that children can use during procedures are deep breathing, blowing bubbles, holding your hand, listening to music or a story, using guided imagery or squeezing a stressball. Then, when the procedure happens in the way that they expected it to, they develop trust in their caregivers and a sense of confidence and control in their abilities to cope with difficult experiences. If a child needs to have the same procedure again in the future, repeating the routine in the same way will offer comfort and help the child cope.

When explaining medical procedures to children, it is important to:

- Be honest
- Use language that is clear and simple
- Check in with them by asking "Does that make sense or would you like me to try to explain it in a different way?"

By giving children honest, accurate information, we build their trust. Especially when a procedure will be uncomfortable, people may be afraid of upsetting children by telling them the truth. For example, a parent may not want to tell a child that he needs a needle, fearing that he will resist the nurses or be upset on the way to the treatment room. Unfortunately, when children are caught off guard by a needle or other unpleasant things, they do not have the chance to react and then calm down and to try to cope with the experience before it is time for the procedure. As well, children will learn to doubt caregivers and may begin to think that things are being kept from them even when they're not.

Instead, if children are nervous or scared, help them practise coping strategies that they can use *before* and *during* the procedure and reassure them that they'll be okay afterwards. This way, even though they may not like certain procedures, they learn that they can count on their caregivers *to help them prepare, make it through the experience and be proud of themselves for that achievement*, rather than fearing that they could be surprised by something unpleasant.

Children may want to know why treatments are needed. One mother explained how challenging this could be: **"There were things that he didn't like that were difficult to discuss and explain why he had to have them. It's not like you can say, 'Well this is going to hurt but you'll be better,' so you did have to find a way to tell him 'No, we have to do this' without lying or making a false promise and making him understand that he did have to cooperate."**

Children may also want to know about how treatments work, how to know if they're working and what happens if they don't work. Some of these are very difficult things to explain but if a child has a question, it is more helpful for him to have the chance to explore the answer honestly and openly, than to rely on his own imagination which is often worse than reality. When a child finishes or stops a certain treatment, he will likely wonder what that means, whether it might be because the disease is gone or whether it can't be cured. These questions can be overwhelming for children to think about on their own; talking about them together can be very reassuring, and offer support for the child even when there aren't clear-cut "answers."

A few parents said that they'd asked their children, early on in the course of the illness, what kind of information they would want to be told about their illness, treatment and side-effects. It can be very helpful to discuss this with your child so that as communication gets more difficult for him. you already have an idea of what he may want to know. You can refer back to that conversation, saying something like, "When we talked about this before, you said you wanted to know all about what the treatments would feel like; do you still want to know about that now?"

Try to describe medical processes, and address your child's questions honestly, using words that are clear and understandable to him. You can ask a Child Life Specialist or a Social Worker at the hospital to help you explain these things to your child. You can also read more about coping with medical procedures on page 40.

Important topic: emotions

In order to talk about feelings many families used charts with pictures of different facial expressions so that a child could point to the face that showed how they were feeling. A parent could point and look to the child to indicate whether or not the parent was pointing to the right picture. Other families would use a list of feelings, and would ask the child about each feeling, one at a time, slowly, until the child indicated that the parent had said how the child was feeling.

Whether you use a chart with pictures or you read a list of feelings, it is helpful to offer a wide range of feelings so that your child is able to express her true emotion, rather than settling for another feeling that is "close but not quite." On the other hand, if your child is getting overwhelmed, use a shorter list or chart with four to eight simpler feelings like happy, sad, scared, mad, bored, etc. The longer list of feelings could include:

Happy	Scared or afraid	Exhausted or tired
Sad or depressed	Angry or mad	Annoyed or irritated
Upset	Lonely or alone	Confused or mixed up
Embarassed	Scared or afraid	Pleased or glad
Shocked	Frustrated	Peaceful or relaxed
Worried or anxious	Bored	Lots of feelings at once

Try to use words that are familiar to your child and make sense given her age. If she is used to saying "mad" instead of "angry," choose "mad." It can be very helpful to include the child in creating this list of feelings. If you can, tell the child each of the feelings that could be included in the list and ask her to say "yes" to the ones that she thinks should be included. Make sure to also ask if there are any others that you may not have thought of, but that should be included. Involving the child in writing this list ensures that she is familiar with all the words and that she also has some control.

Strategies for talking about emotions

One mother shared her approach to talking about emotions with her child:

"When we would talk about feelings, sometimes there's just no way for her to communicate, so we would try to empathize and tell her our feelings and frustrations and say, 'Do you feel that way? Do you feel angry sometimes? It's okay.' So hopefully that might help her. Sometimes [we were] crying because we were upset and let her know it's okay to feel that way. We tried to really imagine how she was feeling, not how a grown up would feel."

This example shows two strategies for talking about emotions.

1. The first strategy is to ask a child if she feels a certain way. For example, asking "Are you feeling happy?" or "You look frustrated, are you feeling that way?" By asking a child whether or not she feels a certain way, she has the chance to express that emotion and also has a sense of control since she can answer "yes" or "no."
2. The second strategy is for parents (and others) to share how they are feeling and to ask whether the child has felt the same way. In addition to giving the child a way to express her feelings, this approach can also give children the comfort of knowing that they are not alone with the feelings they have. However, it is also important to recognize that children may feel differently than their parents and this is perfectly normal. To reassure a child that it is okay for her to feel differently, you might say something like, "I've been feeling pretty sad and I wonder if you have, too. You know, it's okay to feel sad and it's okay not to, too."

Children need to be reassured that all of the feelings they have are natural. Their emotions are likely to be more intense and conflicted than they ever have before, and they may feel a range of different emotions all at once. Let your child know that even though they're not "easy" or "comfortable" feelings to have, all of those feelings are natural, understandable and "okay."

Another parent told us how important it was for her family to learn how her daughter felt about "everything," including needing privacy from her brothers, fears about treatment, and concern about her peers knowing about her illness. Because they had had these conversations already, these parents found that when these children were unable to speak, **"At least if they give you a scowl you kind of get a sense of, 'It's got to be a, b, or c.'"**

The way you communicate throughout this experience will be uniquely shaped by your family's values, belief systems, the personalities of your family members and your previous experiences communicating, especially about other difficult topics. In order to support each other through an extremely difficult experience, parents approached these discussions in a range of ways. Some had discussions as a family about emotional issues and the physical changes in the child who was sick; other parents had individual conversations with each of their children at different times; still others encouraged their children to express questions or concerns that they had as they came up but did not plan specific discussions. These are some examples of different ways that families tried to keep the lines of communication open. While we know that open communication helps children and families cope and support one another, it is important to know that there is no "right" way to go through this experience.

Important topic: activities

As one mother said, **"Being bored is a very big part of being a kid,"** especially when a child is not able to do all the things that he or she used to do. For these reasons, it's helpful to have a list of things that a child ***can*** do, that he can choose from.

This list is likely to change over time, as the child's abilities change. Some of the most common activities that parents said their children enjoyed were:

Listening to music	Watching a movie	Hearing a story
Going outside	Going for a walk	Going on a trip
Arts and crafts	Making food	Playing videogames
Writing or emailing	Playing a game	Visiting someone

Many of these choices will require that you ask more specific questions. For example, if your child wants to watch a movie, you'll need to figure out which movie he wants to watch. If he wants to go on a trip, he may mean a trip to the shopping mall or the park or somewhere farther away. The parents we spoke with told us it was important for them to keep lists of these options so that they didn't always have to remember all of the possibilities. These lists were also very helpful when someone else was looking after the child and may not have known all of his preferences.

In addition to wanting to participate in regular activities, it is also important to children and teenagers to continue to be part of regular conversations about "everyday stuff," like upcoming events and activities, past experiences, what's new with friends and family members (see also, "Important topic: people and pets," below). The parents we spoke with shared some of their strategies for talking about these things, including recalling past conversations, memories and stories that begin with, "remember when?" In order to help it feel more like a two-way conversation, parents said that they tried to fill in what they thought the child would say, based on the way that the child's eyes and facial expressions responded to what the parent was saying. For example, a parent might say, "From the look on your face, I think that you think that story was ridiculous, I can almost hear you wondering, "What was he thinking?!" Am I right?" In this way, you can help express a child or teenager's voice and personality on their behalf, and help them to continue to participate in conversations about "normal" or "everyday stuff."

Where is____ ________?	I'd like to visit: ________	I'd like to talk or send a message to: ________	Can you tell me what's new with: ________

Parents told us that engaging in these kinds of conversations with their children relied entirely on their instincts and intuition, their past experiences with their children, knowing their child's personality, how they'd responded to things in the past and what they'd be likely to want to talk about. Paying close attention to their facial expressions and body language was very important.

Important topic: people and pets

Maintaining relationships with family and friends is very important for children and teenagers. For this reason, it is important for them to be able to ask to see a special person, or to send them a message or hear what they're up to. Many families created a chart with the names and photos of family members and friends to help their children indicate who it was that they were thinking about. In the same way, playing with or talking about pets was also important.

Interestingly, a number of parents told us that their children had been asking about people who had died, including grandparents, family friends and others. Children asked questions about where they were now, whether they were "okay" and often commented that they missed these people. It is natural for a child who has a serious illness to be thinking about life and death and loved ones who have died. It can be a safe way to wonder about these things, an indirect way for children to show you that they're thinking about death, and a way to start a difficult conversation. Also, when children realize that their loved ones are still remembered and loved after they've died, it offers them the reassurance that they too will be remembered and loved after their death. (We'll talk more about this in the next section: "Important topics: the future, spirituality and death.")

As with the other topics, try to include your child in creating the list of people and pets they might ask about. Here is an example of what a "people and pets" page could look like:

Message:

People (add names):

Mom	Dad	Brother
Sister	Grandma	Grandpa
Friends	Pets	People who have died

Important topics: the future, spirituality and death

For some children and families, these were three very distinct topics but for others, questions or discussions were about all three of these important issues at once. It is natural for children and teenagers to wonder about these topics, regardless of their prognosis, especially as they feel their bodies changing and sense the emotions in the people around them. It can be very hard for children and teenagers to initiate conversations about spirituality and death, especially when they fear that talking about these things will be upsetting for others. They may try to ask their questions in indirect ways, such as asking about the death of a pet, or of someone they know, or general questions about God or heaven that do not seem to be specifically about the child's own death. These may feel like safer ways to be asking such hard questions. Because of how difficult it can be for children to bring up these topics, it is very important to support them in having these conversations rather than avoiding or changing the subject.

If your child has questions about death and spirituality, try to answer his questions as honestly, clearly and calmly as you can. He may ask you questions that you don't have answers to. That's okay. You can say that you're not sure, or that many people wonder about questions like that and it's okay for you and your child to wonder about these things together, even without finding any answers.

Some of the biggest struggles parents faced were about whether and how to tell a child that he was going to die. Research and our own clinical experiences suggest that children and families benefit from having open and honest conversations, and families who do this, do not later regret having had these conversations. Whether you decide to talk with your child about death and spirituality and how you do this is up to you and will be a very personal decision based on your experiences and your beliefs. Parents we spoke with had a range of perspectives; some did not talk with their child about death at all, some were open about everything, and most fell somewhere in between.

One parent explained that she did not feel that she could tell her son that he was going to die, but she did want to prepare him as much as she could, so she said **"You might go to heaven before mommy, you might go now, you might go in 40 years, nobody knows. But let's talk about it and let's decide what you're going to do up there."**

Many parents told us that even though it was so hard for them to talk about these things, they also recognized that after they had spoken with their child about death or spirituality, their child seemed comforted and relieved, and that they did as parents, as well. **One parent told us, "The day that I [told her she could die] I thought that it would be like one of the worst days of my life… it actually wasn't because she felt liberated… I think she realized that, 'Oh good, Mom and Dad kind of know that that's kind of a possibility too, it's not just me.'" Another parent remembered similarly, "I'll never forget it, and she knew, I mean she wasn't devastated by it, she wasn't shocked… we told her… she was a great kid and all that and she started saying, 'I think you guys are great, too.' It was at that point I think that I realized she's known for quite a while that this is it and she's not going to live."**

A number of parents told us that there was a time when they realized their child knew more about what was going on than they'd suspected. One mother shared this conversation: **"She said, 'I'm going to miss you.' And that was hard. And that's when I knew, 'She knows.' It was just one of those, 'Oh boy, this kid knows a lot more than we're giving her credit for.' I said, 'I'm going to miss you, too.'"**
A few children had written wills and had thought a lot about what they wanted people to do with their things, and the hopes they had for their family and friends after their death.

Unlike most of the other topics outlined in this section, there is not a specific list of messages or questions to ask about the future, death or spirituality. How you talk about these things will be very personal, as many parents told us that they followed their instincts or their "gut" and paid close attention to their child's cues. One parent explained the way that she figured out what her son wanted to talk about. She said, **"I'd go through [a list of topics]; I kind of had a feeling what he wanted to talk about but I didn't want to say; I didn't want to scare him. At the end I said 'Do you want to talk about heaven?' 'YES!' He was just so relieved that I finally said it… that's all he wanted to talk about in the end."**

About the future

Some children asked questions about the future like, "When will I go back to school?" or "When will I get better?" Although on the surface they may not have seemed to be questions about the child's mortality, that was often at the heart of what they are asking. Similarly, a few children said they did not want any more treatment, or asked what would happen if their tumours did not go away. One mother shared her response to this question, explaining, **"Without trying to instill fear in her about death, regardless of my own feelings, I said, 'The doctors said that if your bump didn't stop growing then you would die.' And I said it warmly but without any sadness or fear – not that I didn't have any but I didn't show any. And she started to cry and I said, 'Why are you crying?' and she said, 'Because I'm not going to see you anymore' so that gave me the opportunity for me to start crying as well and she said, 'And I'm sad about that,' and I said, 'I'm sad about that, too.' So she spoke a lot about… what would happen when she dies and a lot of [her questions] we couldn't answer."**

For some children, thinking about the future meant writing a will, giving their toys to siblings and friends, thinking about organ donation or even being involved in planning the funeral or memorial celebration. Parents often worry that talking about these things with their children will cause them to be depressed or to lose hope. On the contrary, if a child is already thinking about these things, the opportunity to share their thoughts and feelings about them with loved ones can offer tremendous comfort and relief, a sense of control and the opportunity to plan their own legacy.

About spirituality

Some children asked their parents questions about angels or heaven. Many of the children wanted to talk about what they would do when they were in heaven or how their families would feel their presence. Families who shared these beliefs talked about who else was in heaven; one family had a picture book of all the family members and friends who had died and would be waiting for the child in heaven. Whatever your beliefs are, you can share them with your child.

Many people do not know what they believe, or may believe that there is nothing after death. If this is the case for you, you can explain to your child many people have different beliefs, and you can say that you're not sure what will happen, or that you're not sure whether any of them will happen, but you can ask your child what he thinks, or would like to think.

Regardless of whether or not you hold spiritual beliefs about what happens after death, you can talk with your child about how she will always be part of your family even though she will not be physically present. Things she taught others, personality traits, values and hobbies that she shares with others, are all deeply meaningful ways that her life will continue to impact her loved ones.

About legacy and remembering

You can also talk about how you will remember and honour your child at holidays, family events, birthdays and other special times. Some families have a special meal or celebration, wear a special piece of clothing or jewelry, listen to a certain song or musician or make up their own unique rituals at these special times. Others may plant a memorial tree or garden, hold a fundraiser or create a scholarship in the child's name. Some children have their own ideas about how they would like their family to remember them, and many children enjoy being involved in family discussions about this. Not only does it reassure the child that she will not be forgotten but it gives her a clear idea of exactly how her family will remember and feel connected to her.

Memories offer another incredibly powerful connection that survives beyond death. Looking through photo albums and talking with your child about the memories you share that you will continue to carry with you, can offer tremendous comfort. **One parent described spending time "remembering" together, saying, "A lot of it was just to reiterate, 'Yes, it was a short life, but you had a good life. We had a lot of fun together. We did a lot of cool stuff together and remember this and remember that.' Not only did it help the whole family, but it helped the child who was dying to know, 'Yeah, this was a lot of fun and I do remember this and I do remember that' and it helped [the family] to also say, 'In your memory we're going to continue to do this stuff. We're going to continue to go camping, we're going to continue to do these [special things] and we'll always remember you when we do them.' It was a nice way for this child to know, 'You know, they're going to be okay without me and they won't forget me.'"**

Caring for Your Children and Yourselves

Quick Tips:

- It is natural to feel frustrated in a situation like this. Reassure your child that it is okay to feel this way and try to help her express her frustration through play or communication (see pg. 38).
- Children and teenagers often feel self-conscious about their bodies and abilities, and may feel uncomfortable around other people. At the same time, they miss their friends and activities. By talking with your child you may be able to find a way for her to feel more comfortable with friends in a safe environment at home or in another familiar setting (see pg. 39).
- Knowing what to expect and practicing coping strategies can help your child cope with medical experiences (see pg. 40).
- Children and teenagers worry about how their family would cope if they died. You can let them know that although it would be difficult, the family would take care of each other (see pg. 42).
- Avoiding discussion about illness or death does not protect children from the experience that they and their families are going through. Instead, help them by encouraging them to share their fears with you and remind them that you will care for them no matter what (see pg. 42).
- Siblings of children who are seriously ill need special care, too (see pg. 43):
    - Help them learn to communicate and play with their sibling in a new way.
    - Explain (1) how the tumour has affected their sibling; (2) the tumour is not contagious and (3) was not caused by anything that they did or did not do.
    - Make sure that they know they do not feel responsible for their sibling's care.
    - Thank them for their patience and the ways they've helped while their sibling has been ill. Let them know that you know it's been hard for them, too.
    - Help them find ways to be independent and in control of some aspect of their lives while knowing they can count on you to care for them no matter what.
- Parents shared important advice for others (see pg. 46):
    - Get to know your child so you can help her be herself and meet her needs.
    - Have important conversations sooner than later.
    - Keep communicating with your child regardless of her abilities.
    - Try to work together with other family members, friends.
    - Whatever information or help you need, ask for it.

Supporting the child who is sick

In addition to telling us about the ways that they communicated and what was important to talk about, parents also shared some ideas about the difficult things that their children faced and recommended some ways to support them. Here are examples of some of the challenges and concerns that parents described and the things that can help kids deal with them.

Feeling frustrated

Frustration was a very common experience for kids and families and it is easy to see why. When a child finds that he can no longer do something that used to be easy to do, or realizes that so much about his body or his life is beyond his control, frustration is a natural reaction. As one parent said, **"She was frustrated with herself when she couldn't do things."** The loss of independence and needing help with things like eating or going to the bathroom can be very upsetting, especially as children realize that they will not regain the ability to do those things on their own. Because it can be so hard for kids to express their feelings, this kind of frustration might come out in different ways, like being impatient or getting angry. One mother described her son's experience, saying, **"He'd get really frustrated and he'd be in a hurry, like if he needed to go to the bathroom or if he were in pain, he'd be angry."** One way to help children cope with these feelings is to help them find ways to express themselves. Some ideas include:

- Adding a message to a communication board or book that says, "I'm frustrated," or as one child said, "This sucks," so that they can express those thoughts more easily;
- Giving a child a stress ball or play-doh to squeeze his feelings into;
- Using washable markers to draw a target using pictures or words to represent the things that are frustrating (you may need to help or do the writing for the child), and helping a child throw water balloons or squirt syringes at the target to wash the images away.

People often want to cheer kids up when they are feeling upset, so sometimes they try to distract them by talking about something fun or focusing on an activity. However, when children have these strong feelings, they need ways for their feelings to be expressed and heard, and to know that someone else understands, before they feel ready to move beyond those feelings.

Communication can be very challenging itself, as one parent said, **"It was totally frustrating on both our parts; she would get so frustrated because we couldn't understand and we would get frustrated in turn, trying to be more creative and figuring out what we could do to help."** A mother and father shared that although it was difficult, their strategy was, "…**to be patient and to say 'It's okay, take your time… we'll figure it out, I know it's hard.'"** This is a great way to respond for two reasons:

1. First, when children sense that the people they're communicating with are feeling frustrated or impatient, children feel extra pressure and may feel rushed, helpless and even more frustrated, making it even harder for them to express themselves. Saying **"It's okay, take your time,"** reassures a child that they don't have to worry about that extra pressure.

2. The second part of these parents' message, **"I know it's hard."** is also helpful for kids to hear because it let them know that you recognize that they're doing their best, and that it is very hard to do what they're trying to do. This can also help children take some of the pressure off of themselves by reminding them that the difficulty they're having is not because they're just not trying hard enough. So in addition to trying to be as calm and as patient as possible, reassuring kids of these two messages can be very helpful.

Feeling self-conscious

As their bodies and their abilities changed, it was common for children to feel less comfortable around others. One parent said, **"She became really self-conscious of her situation and her appearance"** and explained that her child did not want her classmates to know about her brain tumour. Children and teenagers are often fearful of being seen or treated "differently" from others. In the case of being "different" because of an illness, one parent explained, **"Children at that age have difficulty relating to… somebody that's sick… They don't know what to say, other than 'How are you feeling?'"**

Educating a child's peers about her illness, explaining that a tumour is not contagious and that it is the reason for the child's changing abilities, and helping them learn helpful communication techniques can be a very good way to help children understand and relate to one another. There may be someone at your child's hospital like an Interlink nurse, a Child Life Specialist or a Social Worker who can arrange to participate in a visit to your child's classroom to talk about these things. Teachers and other school staff are often very helpful in organizing this. On the other hand, some children feel strongly that they do not want other people to know about their illness and would not be comfortable with someone speaking with their classmates. Sometimes it can help to talk with a child about what she is afraid would happen if others found out, and you may be able to dispel these fears, and facilitate the connection. However, if a child does not change her mind, it is important to respect those wishes in order to avoid that child feeling embarrassed, helpless or even vulnerable. There are so few things that a child in that situation can control, deciding what information to share may be one of the few things that she *can* control.

A few parents described their children feeling self-conscious about communication, specifically. One parent said, **"She couldn't hear a lot of what they were saying, so that was difficult for her." Another parent explained that her daughter was "Deeply upset that her friends couldn't understand her… so we'd set up a big chat night and everybody would get on-line."** MSN and other online chat systems, email or even written letters can be great ways to help children keep in touch with their friends without having to feel so self-conscious. If your child is comfortable with you teaching others how to use communication strategies, with time and practise, her feelings of self-consciousness may decrease.

Missing familiar people and activities

Familiarity provides so much comfort to children and teenagers. Parents talked about their children being concerned about missing out on things like school, swimming, visiting friends and special occasions like birthday parties and holiday celebrations. When it's possible to help children continue to participate in these kinds of activities, even if it means that they'd be participating in a different way than they used to, it can be very helpful for them. On the other hand, some children may find that there are some things that they do not want to continue to be involved in anymore. If this is the case for your child, try to help him explain why he feels this way. It may be that he is self-conscious (as we've already discussed) or feeling afraid of how others might treat him, in which case you could talk to him about anything that could be done to help make the situation more comfortable or inviting. In some cases a child may feel uncomfortable or even unsafe in different environments. Whatever the situation, respecting a child's wishes as much as possible will help him to feel more comfortable, safe and to have a sense of control.

Being at the hospital can interfere with a child's routine and sense of familiarity and can make him feel disconnected from friends and family. Some strategies to help with this include: bringing familiar things from home like a pillow, blanket, pictures, games and toys; making a sign or poster for the door with the child's name on it; and helping him to stay in touch with family and friends through email, messaging programs or sending messages back and forth by writing letters or even using a video-camera or a web-camera.

Whether a child is at home or in the hospital, play is a great tool for helping him cope with changes and difficult experiences. Through play, children learn, explore, make sense of their environment, express themselves and have some control over their worlds. When children are sick, it is all the more important for them to have these opportunities, so finding ways to continue to play will be very helpful. One father explained that there were times when this could be difficult, not only because his child did not have the same abilities to play as she used to, but also because as a parent of a sick child, it was easy to worry about all of the possible risks involved in different play activities. For example, a child playing outside might trip and fall. But this father recognized that these risks were outweighed by the benefits of play for his child. **He explained, "It's hard for the adults to understand that and to allow that because you're thinking 'Oh my goodness, what if something happens?' And the problem is, if you don't let the kid play, they probably will not be able to cope... [Keeping them from playing will] remind them all the time about how sick they are and they know how sick they are, you don't have to tell them."** Through play, children are able to feel comfort and familiarity, and feel like a child for a while, rather than feeling like a sick child.

Coping with medical experiences

Play is also a great way to help children cope with difficult experiences. In times of stress, play may be the furthest thing from our minds, but it may also be the most valuable tool. One father talked about the importance of creative problem-solving and said, **"The ability to have a plan and be creative in the midst of [stressful situations], singing songs on the way to ER, those little things... We had a bag with a lot of wrapped gifts so every time we go to SickKids we have them choose one and then on the way we say 'Okay, you can open your presents now.' Play is the most important for them....playing in any form."**

For many families it is not possible to have a bag of wrapped gifts, but to make it a surprise, you could wrap up some of the child's own toys, or pack a bag of simple toys or games. Blowing bubbles, bringing paper and crayons to draw or playing X's and O's or cards or even games like "I spy" or "Twenty questions" are all simple and useful distractions. For older children and teenagers, think back to what has helped them before; listening to music, playing a videogame or reading a book may be useful distraction techniques. Guided imagery, deep breathing and other relaxation techniques can also help children of all ages cope with anxiety related to medical issues.

Another parent explained how she used play to help her child take her medicine when she was reluctant to do so. **"We had a bag of marbles... they were all very original. She would pick marbles that would symbolize the pills that she would have to take. Other marbles would [represent] treats. She'd put her hand in [the bag], mix them all up and pick out a marble. Two out of three times it would be a treat and one out of three times it would be a pill. We'd just keep on playing that game until she was done all her pills."** Again, these "treats" do not need to be fancy; they may be as simple as a sticker or the child's choice of bedtime story.

A few parents talked about how important it was to be honest with their child about what was happening, what medical procedures would feel like and any other questions or concerns the child had. A father said, **"The one thing is that the kid needs to know that she can trust us all the time... Number two, she needs to know that when we tell her something, it's gonna be the truth and the whole thing."** He explained that his daughter did not like getting needles, but when he knew she was going to have one, he would tell her, even though he did not like to give her bad news. **"Whatever was hard to say, we still had to say it to her."** That way she learned that she would never be caught off guard since she knew that if she was going to need a needle, her father would tell her. If he didn't say there would be a needle, she could relax and feel comfortable because she trusted him.

Knowing they'll be cared for

Parents highlighted that it was extremely important for their children to know that they would be well cared for. This included two things:

1. One important aspect was knowing that the health care team would continue to care for them. When they know that a disease or a tumour is not curable, children may think that that means there will be no more medical care. Knowing that they will still be looked after and that their pain and other symptoms will still be managed is very important.

2. The second thing that was extremely important was knowing that they were not alone and that their parents and their family would always be with them and love them "no matter what." **"We said, 'We are going to be with you, we are not going anywhere and we are going to stay here.'"** When children are struggling

with how they're feeling and the ways their bodies are changing, this may be the most valuable comfort that you can offer them. One mother shared this example, **"At one point she'd… thrown up yet again and said, 'Mommy, I'm falling apart'… what am I supposed to say? What am I supposed to say? And I said, 'You know, you're right honey, but Mommy and Daddy are going to be here all the time… we're going to be here no matter what' and she said, 'Mommy, I'm not afraid.'"**

Children's concern for the family's future

Another common and important concern that parents told us about was children's worries about whether their parents and their families would be okay after they died. One parent explained, **"It's a common concern for children as well as adults. If you're faced with [the fact] that you know your life's going to end, the first thing you think about is, 'Wow, how's my family going to manage without me?' And it's what you'd think, it's what anybody would think… 'How are people going to cope once I'm gone?' And I think if you can address those [questions]… you've taken a load off of that child's mind."** Parents said it was very important to address these concerns by letting their child know two things: that the family would be sad and would miss the child after he died but at the same time, the family would be alright. Families did their best to try to ease the child's burden of worrying about how his loved ones would cope. One mother described that the most important messages were, **"… expressing that we love her. When she was talking about being sad that she was going to be gone, communicating that we would be sad as well, but that she didn't have to worry about that."** Another mother explained that she wanted her son to know, **"… '[when it's time] to go to heaven, you go. Mommy and Daddy will be fine.' I found it very necessary for him to know that I was upset, that I would miss him, I would tell him 'If you go to heaven before me I will miss you every day, I'll be sad'… but I wasn't gushing all the time."**

The importance of communicating

Parents told us that they often felt helpless and frustrated that they were not able to change the situation and protect their child from what was happening. Of course that is natural. Sometimes in an attempt to protect a child, parents avoid talking to the child about her illness, or letting her know that she could or would die. Although this is done with the best intentions, it does not have the impact that parents hope for.

Some of the unintended, possible consequences are:

- When children are not invited to talk about their illness, they learn from others' example not to raise the issue themselves. Without having someone to talk to about their thoughts and worries, they are left to wonder on their own, using their imaginations to answer their own questions.
- Children are very sensitive to the emotions of the people around them and know when others are upset. They can recognize when something is being kept from them and can only wonder what that might be, often imagining the worst.
- Children are more aware than anyone of the changes occurring in their own bodies. Although they may not know what will happen in the future, they have learned that unpredictable changes can continue to occur. If they do not feel able to talk about their illness or the future, they are left to face these questions and fears on their own.

With these things in mind, **it is clear that protecting a child from talking about her illness does not protect her from the difficult experience she is already living.** Instead of letting this make you feel helpless, try to see that it actually offers you an important opportunity. You are not helpless. Even though no one can change what is happening, there is a great deal that you can do to help your child through this experience. As we've discussed in this section, there are some very important messages that will offer your child comfort, reassurance and security:

- Your child is not alone. You will be there to support her throughout this experience.
- Your child can trust you. You can truthfully prepare her for things like medical procedures and other events so that she feels less anxious and surprised by these things. Staff at the hospital can help you figure out how to do this.
- Your child will be well cared for. You can reassure your child that you, your family and your child's health care team will all be working to make sure that your child has what she needs to feel comfortable and taken care of.
- Your child will always be part of your family. If your child is dying, or thinks that she could die, you can talk about all of the things you will remember and all of the ways that your child will continue to have an important place in your family.
- Your family and people who know and love your child would be awfully sad if or when she died, but your family members and friends would support one another through their grief.

Although these things cannot change what your child is going through, they can make her feel supported in the knowledge that she will not be alone. Nothing can take away the pain that your child and your family will struggle with, but these important messages can offer comfort, reassurance and strength as you face what is happening, together.

Supporting siblings

As a parent you may not only be supporting a child who has a brain tumour, you may also be supporting his siblings. There are some issues that are common for children who have a sibling living with a serious illness. For example, many children in this situation have questions about why this happened, worries about their own and/or their sibling's health and concerns about their parents' emotional struggles. It is also very common for children to wonder if they are somehow to blame for a sibling's illness and to worry that they may also "catch" the illness. Even if a child has not expressed these worries, it is helpful to say something like, "I just want to make sure you know that there is nothing you could have done to make this happen and that this is not the kind of illness that you can catch from someone else." Siblings may also have questions about the future. The suggestions in this book about how to talk with a child about his own illness and the future, as discussed in the previous sections, also apply to talking with the child's siblings.

If you are supporting more than one healthy sibling, try to share the same information with all of them, and have conversations with them together whenever you can. This will help to avoid difficult situations such as when one sibling says something that the other child has not heard before, or when one sibling asks a question that the other child does not know how to answer because he does not know what the other child has been told. Sometimes there is a large age difference between siblings so parents will have to use simpler language with younger children and offer more details for older children. Emotionally, it can be very difficult for older children to have to keep information from their younger siblings, even when it seems to be in their best interest. For this reason, even when there is a big age difference between siblings, it is still helpful to discuss what's happening with them all together.

Many of the parents we spoke with shared their suggestions about how to help brothers and sisters. One of the things they felt was most important was to make sure that siblings were able to continue to spend time together at home or in the hospital. Another very important thing was to help all of their children learn how to use the new communication strategies. This helped children continue to interact with their siblings, maintaining their relationships. Parents said that encouraging children to say "hello" and "goodbye" to their sibling when they come home and when they go out – although it may seem to be a small thing – made a big impact. Simple things like this help a sick child continue to feel recognized and included in the family's day-to-day activities despite his changing abilities.

Brothers and sisters may be reluctant or nervous about learning new communication strategies, and may be afraid of doing it "wrong" and looking silly if they do. Just like teaching communication strategies to a child who is sick, it can help to use games to help teach these strategies to their siblings as well, and to practise with them until they feel more comfortable. They may also need your help to understand why their brother or sister isn't able to talk the way that they used to. Since they may not be able to see any physical evidence of something stopping their sibling from being able to speak, some children wonder why their brother or sister just doesn't try harder. It helps to explain that our brains are like computers that send signals or instructions to all of the other parts of our body to make it work, including our arms, legs, stomach, heart, lungs, eyes, ears, mouth, etc. When a person has a brain tumour, it interferes with, or "mixes up" some signals so that things don't always work the way they're supposed to. This is why some children who have brain tumours aren't able to speak the way they used to.

Similarly, children may not know how to interact or play with their brother or sister since their abilities have changed. They may also believe that their sibling doesn't want to play with them anymore. Again, it is important to explain that these changes are caused by the tumour rather than being the child's choice. Then you can help your children find new ways of playing or being together. Healthy siblings can read stories to their brother or sister, watch movies or listen to music together. They can also play "for" their sibling. Some examples of this could be to make a beaded bracelet or build a lego tower asking their sibling what colour bead or lego block to use next. They could also draw a picture or write a story based on their sibling's ideas about what to draw or write. When thinking about how to help children play together, consider what they used to do together and try to find ways to adapt those activities. Children may have a hard time trying new things; it can be easier and more comfortable to do what feels familiar.

Healthy siblings will also need opportunities to play for themselves rather than to feel that they are responsible for their brother or sister's needs; they will need your help to find a balance between feeling helpful without taking on too much responsibility for their sibling. Since so much of the parents' time and focus is on helping the child who is sick, his or her siblings often feel lonely. Even when they understand why their brother or sister needs the extra attention, siblings need extra support to make sense of, and express their emotions. Many children struggle with feeling neglected and at the same time, feeling guilty for wanting their parents' attention when their sibling is ill.

Your family may already have been living with your child's illness for many months. If this is the case, her siblings have been dealing with these changes and struggles, needing to be patient, helpful and understanding, for a long time.

This is a challenging experience for children of all ages. Rather than being "easier" or "harder" depending on the child's age, the challenges vary – children's needs will be expressed and need to be addressed according to their developmental stage and unique life experiences. Regardless of age, all children and teenagers need to feel that they will be taken care of, that their parents care about them unconditionally, they need opportunities to be independent, to be a unique individual and to feel control over some aspects of their lives.

All of these factors affect a child's ability to handle parents' focus shifting away from them and onto their sibling. It is important to recognize and tell the child how much you appreciate all that they've done throughout their sibling's illness, including their patience and efforts to care for themselves and help the family. Try to be specific, telling the child exactly what you've noticed him doing. Let him know that you recognize how challenging it has been and will continue to be and encourage him to let you know when he's struggling and needs help.

Talking to your child about how he is feeling, helping him to understand that all of his emotions are natural and encouraging him to express any questions or fears that he has, will be very important and beneficial. There may be people at the hospital or at school, like Child Life Specialists, Social Workers, Counsellors or volunteers who can help support children when a sibling is ill. There are also organizations who can help as well; see page 48 for a list of websites, resources and organizations.

Parents' advice for other parents

The parents we spoke with shared some very personal insights into their experiences that may be helpful advice for others. Some of these are reflections or quotes about a parent's outlook or important things that they tried to keep in mind.

About relating to children:

- **Know your child.** A father explained that in order to know what a child is thinking, feeling or trying to express, **"You have to know your child. If you haven't, you better get to know your child."** Recognizing that her daughter needed privacy and independence, one mother told us, **"I also had to let her be a teenager… and give her an outlet to express herself without going through me… [just] because they're ill or dying or whatever doesn't mean that they don't have that right to be that kind of individual."** This mother gave her daughter a journal, so that she didn't always feel she had to rely on her mother in order to express herself.
- **Keep communicating.** When children can no longer express themselves to others, it can be hard to know whether or not to continue to talk to them. One mother explained, **"I just stopped asking her anything because it was hard to see [her try so hard] to say something… it was really hard [because she could hear] everything from her mom but she couldn't answer."** One of her child's health care team members reminded this mother that even though she could not respond, the child could still hear, so this mother continued to talk to her child but stopped asking her questions. Hearing loved one's voices and sensing their presence offers tremendous comfort to children even if they cannot respond. Along these lines, a father told us that as a family, **"We were sort of intimate… [we were] on a different level in terms of communication… We were hugging, holding hands, which certainly replaced any… oral communication."** Communicating through touch, including a hug, gently squeezing or rubbing a child's arm, can convey love, warmth, affection and provide great comfort to a child.
- **Have important conversations sooner than later.** Reflecting on what she went through when she realized how sick her daughter was, one mother explained, **"It's a shock and the anger and everything [you feel] comes at you for days, weeks, whatever… As soon as that shock leaves you I think most parents faced with that situation finally say, 'Okay, we need to get some stuff across'… Your instinct kicks in and says, 'It's time to tell your kid that you love them and you're proud of them'… Whatever issues you had, you get on it pretty quick and you let that child know that things were good and you're proud of them and if you have to apologize for something, you do it."**

Parents also suggested having important conversations about things like illness, life, death and spirituality as early as possible. Although these can be emotionally difficult conversations to have, they get even more difficult when children and teenagers have a harder time communicating.

About relating to one another, as parents and as a family

- **Try to work together.** Reflecting on how hard it can be for couples facing this experience as parents, one father suggested that it is important for couples **"To learn to be able to come together rather than to go apart in this journey. I think each one has to understand that it's not my journey, it's not my wife's journey, it's not the child's journey, it's our journey, right? And when I mean "ours" I extend it to everybody around us, too, like grandparents, friends, best friends. So why not include all of them as much as possible?" The same family explained, "We promised ourselves one thing and we kept that promise to make every single day the best day ever… that doesn't mean spending a lot of money, it means pouring your energies into whatever – the best day – rather than worrying about how clean the house is… and also worrying about when she's going to pass away. Basically we said we're going to make every day the best in our entire lives."**

Asking questions, asking for help

- **Whatever you want to know, ask. "We needed to know what's going to happen in order to prepare ourselves as well as to prepare [our child], so we asked them what would happen in the weeks and the months to come, and the stages. And that was, I think, the most important… information that we could ever have."** Health care professionals do not always know how much, or which information is helpful for parents, and may have a hard time knowing what to share. If parents do not ask questions, professionals may think that means that they do not want the information. If there is anything that you have wondered or worried about, please do not hesitate to ask a member of your child's health care team.
- **Whatever you need, ask.** Parents talked about a range of services that they found helpful. Different services will be available depending on the hospital or the community where you live. Ask a member of your child's health care team to help you find resources near you. Some examples of people or services that might be helpful to you include social work, child life specialists, home-based nursing, occupational therapists, physical therapists, speech language pathologists, massage therapists, hospital or hospice volunteers, counselors at your child's hospital or school or members of a religious community. One parent explained, **"I think the greatest link that we can give these kids who are so sick and possibly dying… is a big hug… They're looking for a link between this horrible news they've been given and their ultimate prognosis, and the link is helping them feel that they do not need to be alone… that there are people who have all of their expertise and that's called 'the team', everybody coming together."**

Resources

Resources

Here are some web-based resources for families caring for a child with a brain tumour. Most of these links where generously shared by the B.r.a.i.n.child website: www.sickkids.ca/Brainchild You can find this list by clicking: “Resources and Links.”

Support – Websites geared towards adults

The Assistance for Children with Severe Disabilities (ACSD) program, formerly known as the Handicapped Children’s Benefit (HCB), provides financial assistance to qualifying parents. This provincial program will vary depending on where you live. http://www.children.gov.on.ca/htdocs/English/topics/specialneeds/disabilities/index.aspx

Childhood Cancer Foundation of Canada Providing information, resources, and support to families, children, and teens living with cancer. (1-800 363-1062 or 416-489-6440) http://www.childhoodcancer.ca/

Ontario Parents Advocating for Children with Cancer Providing information on resources for families and parents of children with cancer. http://www.opacc.org/

Neurofribromatosis Society of Ontario Providing support and services to families with children who have NF. http://www.nfon.ca/

Families of Children with Cancer is a volunteer organization devoted to **education**, **support**, and **advocacy** for families living with the effects of childhood cancer who are (or were) treated at the Haematology/Oncology Program at Toronto’s Hospital for Sick Children (SickKids). We serve families who are in treatment, off treatment, or bereaved. The support group meets Wednesday evenings on **8A**. They maintain a **Family Resource Library at SickKids**. Their Web site has an excellent set of Web resources on cancer. http://www.fcco.org/

The mission of Gilda’s Club is to provide a meeting place where men, women, and children living with cancer, as well as their families and friends, can join with others to build social and emotional support as a supplement to their treatment of choice. Gilda’s Club offers support and networking groups, lectures, workshops, and social events in a non-residential, home-like setting. http://www.gildasclubtoronto.org

Starlight Children’s Foundation - For seriously ill children and the people who love and care for them, who seek support from organizations that can provide respite from the day-to-day stress of serious illness, the Starlight Children’s Foundation provides innovative, creative and fun entertainment therapies that bring lasting joy and enrichment to the lives of seriously ill children and their families. http://www.starlightcanada.org/

- Wishes - Starlight also grants wishes to provide a special once-in-a-lifetime experience to children between the ages of 4 -18 who are seriously ill: http://www.starlightcanada.org/WhatWeDo/OurPrograms/wishgranting.htm
- Coping with Chemo – They have also created a series of online animated stories called webisodes that help children and teens with cancer learn how to cope with the challenges of having cancer and undergoing chemotherapy and other treatments. http://www.chemo.starlightprograms.org/

The Basal Cell Carcinoma Nevoid Syndrome Life Support Network is an American-based support group that provides healthcare, counselling and support services to children and adults manifesting inherited, metabolic or genetic disorders and diseases most commonly known as BCCNS, NBCCS, and/or Gorlin Syndrome. There is also a Delphi Forums discussion group for BCCNS. http://www.bccns.org/

Teens Living With Cancer A site for teens with cancer who have lots of living to do! You'll get straight information - we know what it's like. All pics and stories are of "real" teens with cancer. You can connect with others like yourself. http://www.teenslivingwithcancer.org/

Health related

AboutKidsHealth Provides families with up-to-date, evidence-based information about all areas influencing child health and family quality of life in a format that is easy to understand. Click 'Resource Centres' then click 'Brain Tumours Home'. http://www.aboutkidshealth.ca/

The Brain Tumour Foundation of Canada is a national, not-for-profit organization dedicated to reaching every person in Canada affected by a brain tumour with support, education and information, and to funding brain tumour research. They publish a **free Patient Resource Handbook** providing reliable, informative and free guide to living with a brain tumour for patients, their supporters and friends. Make sure to specify the paediatric version when you order. http://www.btfc.org/braintumour.nsf/eng/home

Established in 1994, the Current Oncology Web site is a portal through which health professionals of all levels gain access to articles and information covering the broad field of oncology. The web site includes NEED LINK patient support groups from across the country. http://www.current-oncology.com/index.php/oncology

Resources for Children

Super Sibs! To honour, support and recognize brothers and sisters of children with cancer. This is for children from the United States and Canada between the ages of 4 and 18 with a sibling who has been diagnosed with cancer. http://www.supersibs.org/

Carl/Carla Can Sing The Barbara Parry Paediatric Oncology Association provides the "Carla Can Sing" package free of charge to children with cancer in Ontario. http://web4.uwindsor.ca/carla_can_sing

Songs of Love A non-profit organization that will write and record a song personally for seriously ill children. This is a free service, sponsored by donations. http://www.songsoflove.org/

Hospice & Palliative Care

Virtual Hospice An online resource offering a wealth of information and support on palliative and end-of-life care, loss and grief. http://www.virtualhospice.ca

Canadian Directory of Hospice Palliative Care Services. This on-line directory has been designed to provide you with information on the availability of hospice palliative care services across Canada. Here you will find a listing of programs and services, their contact information, the population they serve, and where they provide care. http://www.oulton.com/chpca

TRAC-PG (Team for Research in Adolscent and Childhood Palliation and Grief). This website is for families, health care providers, researchers, volunteers and decision makers interested in learning together about the care of seriously ill and dying children and their families. http://www.tracpg.ca/

Grief support

Bereaved Families of Ontario Provides compassionate non-denominational mutual aid support for families and individuals who have lost a significant person (child, sibling, parent, grandparent, grandchild) to death. http://www.bereavedfamilies.net/

Winston's Wish This UK-based organization offers practical support and guidance to families, professionals and anyone concerned about a grieving child. The "Serious Illness" page provides information about communicating with children about a loved one's illness, including siblings, and the "Young People" page provides information written specifically towards teens. http://www.winstonswish.org.uk

Wish-granting agencies

The Children's Wish Foundation (1-800-267-9474 or 905-427-5353) Grants wishes to children coping with a high risk, life threatening illness.

English website: http://www.childrenswish.ca/index_2007.php/en/welcome

French website: http://www.childrenswish.ca/index_2007.php/fr/welcome

Make-A-Wish (1-888-822-9474) Grants the wishes of children with life-threatening illnesses. http://www.makeawish.ca/

Sunshine Foundation The Sunshine Foundation makes dreams come true for children between the ages of three and 18, living in Canada, who are challenged by severe physical disabilities or life-threatening illnesses. http://www.sunshine.ca/

Other Helpful Web sites

CarePages Private personalized Web pages provided to you as a free service by **SickKids**. CarePages are fully secure, password-protected and comply with all patient privacy regulations. http://www.carepages.com/sickkids

Caringbridge Offers free, easy-to-create web sites that help connect friends and family when they need it most. http://www.caringbridge.org/

Chai Lifeline Canada a not-for-profit organization dedicated to helping Canadian children suffering from serious illness as well as their family members, passionately devoted to alleviating the burden of those facing medical challenge. http://www.chailifelinecanada.org/

Never-Ending Squirrel Tale Web Site Practical tips and encouragement for the parents of kids with cancer written by other Moms and Dads. An uplifting and practical web site to encourage and empower parents of kids with cancer when they feel the most discouraged and powerless. http://www.squirreltales.com/

Tools

Tools

In this section we have put together samples of tools that you can use to help you communicate with your child. Here is a list of tools and instructions on how to use each one:

- **Body outline** - This drawing can be used to help a child show you where they feel a certain sensation. If a child is able, ask her to point to the place on the body where she feels pain or discomfort. Alternately, you can point to different body parts asking her to let you know when you're pointing at the right spot. Start with any part of the body that she often feels pain or discomfort, then move on to other body parts. Remember to ask if the feeling is on the front or the back or on the inside of the child's body.
- **Pain scale** - Use this tool to find out how much pain a child is feeling. Ask the child to point, or to let you know when you're pointing to the face that shows how she feels. One at a time, point to each face, and explain, "These faces show how much something can hurt or be painful. This face [point to left-most face] shows no pain. The faces show more and more pain [point to each from left to right] up to this one [point to right-most face] - it shows very much pain. Point to the face, or let me know when I'm pointing to the face that shows how much you hurt right now." Score the chosen face 0, 2, 4, 6, 8, or 10, counting left to right, so '0' = 'no pain' and '10' = 'very much pain.' Do not use words like 'happy' and 'sad.' This scale is intended to measure how children feel inside, not how their face looks.
  - Underneath the pain scale are words to describe different kinds of discomfort that a child might feel: hungry, thirsty, headache, stomachache, hot, cold, itchy, sore, numb, tired. Ask the child to point, or you can read the words one at a time and ask the child to let you know when you've said the right word.
- **Feeling faces** – These faces each show a different emotion. Ask the child to point, or to let you know when you're pointing to the face that shows how she feels.
- **Alphabet board** – Use this tool to help a child spell a message. Ask the child to point, or to let you know when you're pointing to the right letter. It helps to write each letter that the child chooses on a piece of paper to help her keep track of what she is spelling.

Important note: A special technique called "Parent-Assisted Scanning" can be used to make it easier to use charts like the Feeling faces or Alphabet board. To use this technique, a parent or caregiver would start by pointing to the top row of the chart asking the child, "Is the message/feeling/letter in this row?" If the child said "no," the caregiver would move on to the next rows, one at a time pausing for the child to scan and respond. Once a child lets you know that you're pointing at the right row, point to each of the messages in that row, one at a time, until the child indicates that you've pointed to the correct letter. This technique can take some getting used to but with practise, makes communicating with charts easier and faster.

- **Frequent message pages** – These are pages for you to write lists of messages that your child uses often. There are different pages for different topics including: people and pets who your child might want to ask about or see; activities that your child might want to do; and signs or signals that you and your child use to represent different messages.

How to use the “Yes/No” Bubble Diagram

Start by asking broad questions and then ask questions that get more and more specific based on the child’s responses. You can use the bubble diagram as a guide to help you do this.

The bubble in the centre at the top says, “It looks like something is bothering you.” This is a “level 1” question. If a child indicates “yes,” that something is bothering him or her, you can ask more specific questions, one at a time, until the child says “yes” again. Following the arrows and starting from the left, you can ask a level 2 question:

- “Is there something you need?”
  - If the child says “yes,” follow the next set of arrows to the level 3 questions:

    “Do you need medicine?” “Do you need to eat or drink?” etc., pausing in between to give the child a chance to respond.
  - If the child says “no,” move on to the next level 2 question:
- “Is something in your body in pain or uncomfortable?”
  - If the child says “yes,” follow the next set of arrows to the level 3 questions:

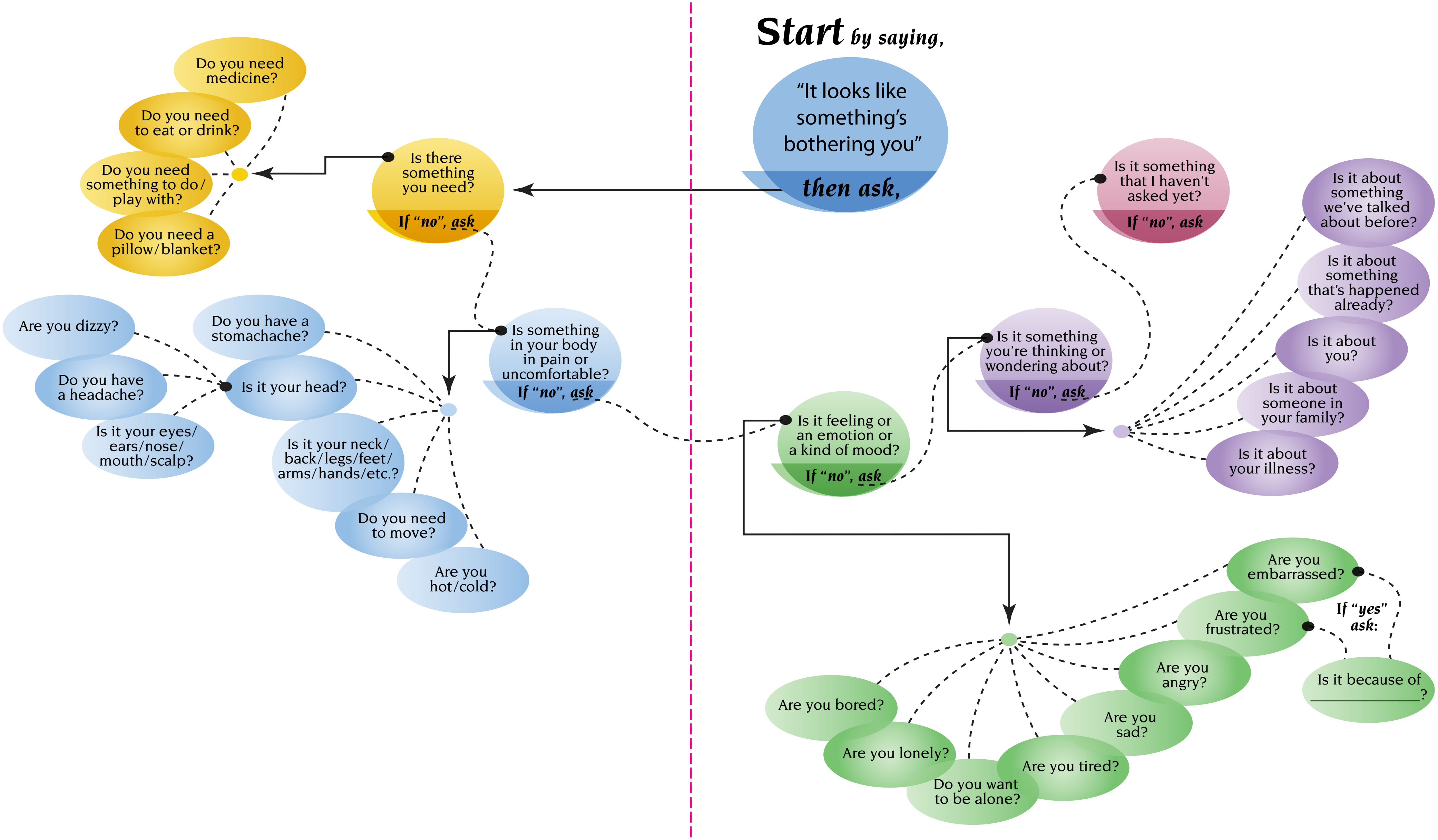
    “Do you have a stomachache?” “Is it your head?” etc., pausing in between to give the child a chance to respond.
- If the child says “yes,” continue to ask specific questions to find out what kind of sensation the child is feeling.
  - If the child says “no,” that it is not something in his or her body, move on to the next level 2 question:
- “Is it a feeling, an emotion or a kind of mood?”

Continue asking questions in this way until you have figured out what the child is trying to express. However, there may be times when it feels like you’ve asked a million questions and still do not know what the child wants. This happens to everyone sometimes and can be very frustrating for you and the child. When this happens, tell the child:

  - “I know that you know what you want to say. This is really hard for both of us but I want to try to help.”
  - Then ask, “Should I keep trying to figure out what you’re thinking or should we take a break? I’m going to ask you that again and wait for you to show me “yes” after the one that you want me to do.”
  - Then repeat these two options, pausing in between for the child’s response.

It is especially important to be patient with the process and with yourself during these conversations. As much as you can, trust your instincts about your child’s wants and needs, even though you won’t always be able to easily identify what you’re child is trying to say.

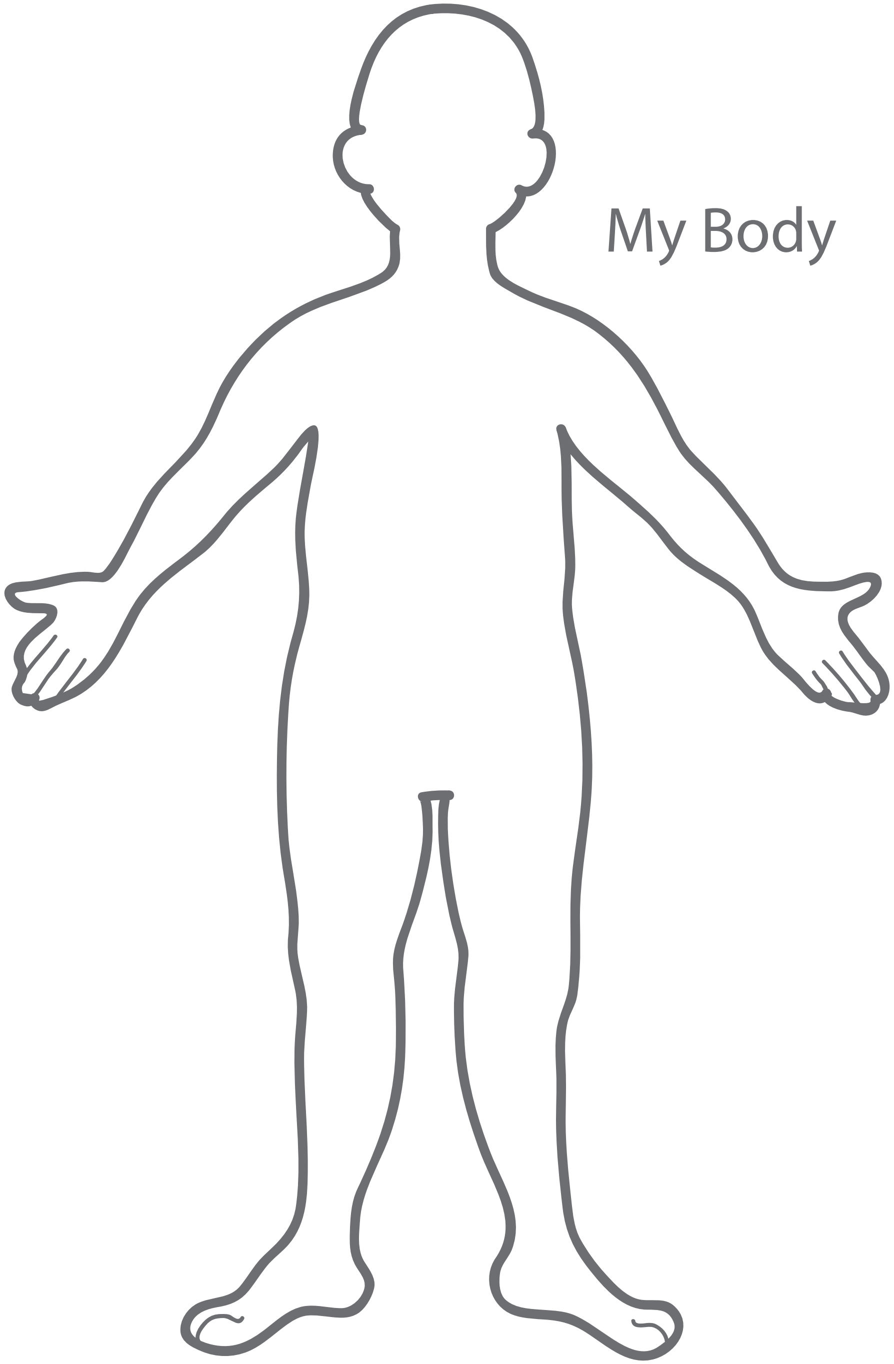
Notes

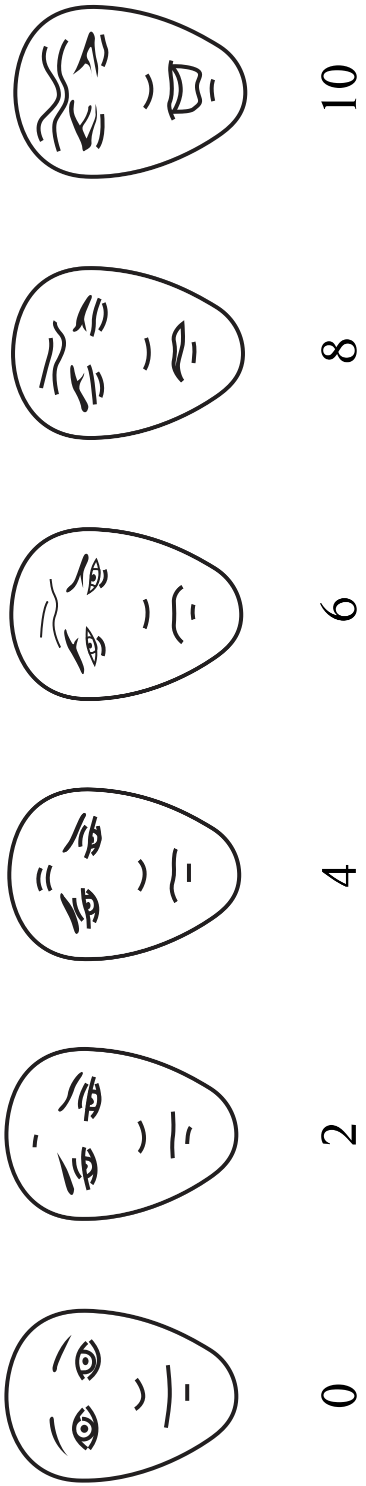


Try to find out exactly where the discomfort is by pointing and asking the child to let you know when you're pointing to the right spot. Then ask if it feels: sore, pinched, hot, cold, itchy, numb, tense, stiff, prickly, or tingly.

Keep asking questions that are more and more specific to figure out what the child is thinking about.

My Body





hungry | thirsty | headache | stomachache

hot | cold | itchy | sore | numb | tired

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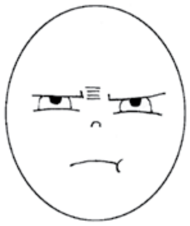
shy


comfortable

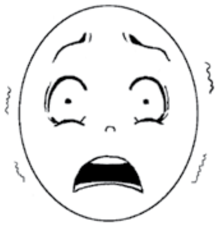

annoyed


curious


bored


hopeful


sneaky

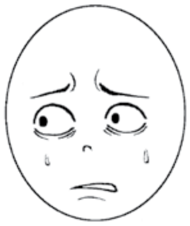

scared


suspicious


angry

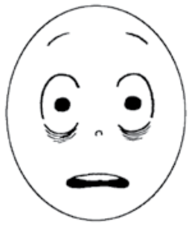

happy


surprised


anxious


confused


exhausted


shocked


excited

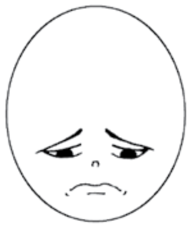

frustrated


embarrassed


proud


sad

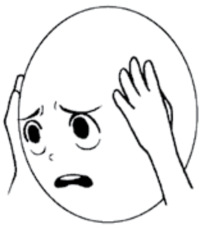

disgusted


depressed


lonely


guilty


cautious


overwhelmed

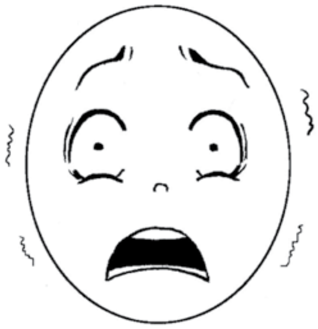

jealous


contempt


grateful

happy

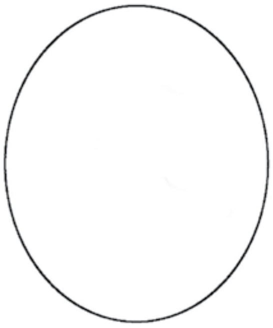
comfortable



scared

angry

sad



something else

A	B	C	D	E	F	G
H	I	J	K	L	M	N
O	P	Q	R	S	T	U
V	W	X	Y	Z	space	

People and Pets			

Activities		

Signs or Signals	Messages

Signs or Signals	Messages

Notes

Notes