

# PARENTS AS PARTNERS #1

## BUILDING A RELATIONSHIP WITH YOUR HEALTHCARE TEAM

*You are a Partner In Your Child's Healthcare*  
**YOU KNOW YOUR CHILD BEST**

Your experience  
and knowledge  
of your child

+

the experience  
and knowledge  
of the healthcare  
professionals

=

the best decisions  
about your  
child's health

## KEY PIECES TO A COLLABORATIVE RELATIONSHIP

### HONESTY

Be an open and honest partner. Let the healthcare professional know what is happening in your family and what else you have done to help your child. It is important for families and healthcare professionals to acknowledge and discuss openly any concerns or issues.

### RESPECT

Being considerate of others shows respect. You can do this by introducing yourself and calling the healthcare team members by name. You also show respect by listening without interrupting and following through on what you have agreed to do.

### TRUST

With honesty and respect as the base, trust will develop over time. Begin with the belief that the healthcare professional wants to help and has the knowledge and skills to do so. Consider each meeting as a new opportunity to work together.

### APPRECIATION

Showing your appreciation goes a long way. People feel valued when their efforts are acknowledged.

*I really appreciate you taking the time to answer my questions today.*

## Emotions Are Powerful

"When I first heard my child's diagnosis I was in shock. I had trouble taking anything in at first so I started writing down what people told me. Sometimes I was too upset to process anything and had to ask for time to think. Once I was so angry I yelled at the nurse - when I calmed down I apologized and we worked things out."

## Share, Share, Share

As the constant in your child's life, you have valuable knowledge that will help your healthcare team understand and treat your child.

Talk about...

- Your observations of your child's symptoms and behaviours
- What you have learned about your child's condition
- The impact on your family
- Important family beliefs and values
- Concerns that may be impacting your child's well-being
- Your intuition - your gut feeling on what's going on
- Any difficulties you may have with carrying out the recommended treatment plan

## Prepare For Your Appointment

- Observe your child at home and bring notes of what you saw
- Bring information about your child's history
- Bring a list of questions
- Prioritize your concerns
- Bring list of medications with doses
- Remember your healthcare team has your best interests in mind

**Everyone has time pressures. Doctors get called away, you get stuck in traffic, children get sick...**

**To respect each other's time:**

- Call if you are late or have to reschedule
- Bring something to do while you wait
- Talk about what is most important to you first
- Leave space in your day for potential delays

## COMMUNICATING WHAT YOU WANT TO KNOW...

Throughout your journey with your child's health there will be times you want to know every detail of your child's care and other times when you want to leave the care to the healthcare professionals and only be informed about decisions.

You can tell the healthcare professional how much you want to know and how you want to receive the information.

Created by parents who have years of experience partnering with their child's healthcare team. For more information visit the website of the Family and Community Resource Centre at the Alberta Children's Hospital.

<http://fcrc.albertahealthservices.ca>

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# PARENTS AS PARTNERS #2

## BUILDING A RELATIONSHIP - SHARING INFORMATION

### You are a Partner In Your Child's Healthcare **YOU KNOW YOUR CHILD BEST**

Your experience  
and knowledge  
of your child



the experience  
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## GIVING INFORMATION...

**Write it down...** There's a lot to remember. Keeping a health journal will help you keep your child's healthcare information organized. A Family Health Journal is available at the Family and Community Resource Centre at the Alberta Children's Hospital or at <http://fcrs.albertahealthservices.ca>

*"My journal has helped me to remember names of people treating my son, to follow up with recommendations and tests, and to provide information to healthcare professionals quickly and accurately."*

*"Over the years, I have found it helpful to provide healthcare professionals a list of the major medical events in my child's journey. This helps to take the pressure off of me to remember dates and details of everything that has happened in the past. Being prepared for the "history question" allows me to focus on the current issue."*

### Help the team see your child as a "person" not just a "patient"

- ✓ Involve your child in the conversation, if possible
- ✓ Talk about your child's likes and dislikes
- ✓ Explain what comforts your child
- ✓ Share photos
- ✓ Describe how the treatment is impacting day to day life

### Consider what your child is hearing...

Your child is usually in the room when their medical condition is being discussed. Ensure your child is comfortable with the conversation and included whenever possible. Sometimes, you may want to request a private conversation without your child there.

### Help others to better understand about your child. Here are some ideas from experienced parents:

- ❑ Create a top ten list of "Things You Need to Know About My Child".
- ❑ Scrapbook a couple of pages with pictures and key information.
- ❑ Prepare a "This is Me" book to share with caregivers.
- ❑ Develop a package of information for school staff in non-medical language.
- ❑ Share a story written by the child about their healthcare experiences.

# GETTING INFORMATION...

## Learning More

- ❑ Ask your healthcare professional for information.
- ❑ Check out the Family Resource Centre at your Children's Hospital.
- ❑ Avoid random searches on the Internet.
- ❑ Ask a librarian for help with searching for information – at the Alberta Children's Hospital you can contact the Child Health Information Specialist in the Family and Community Resource Centre.
- ❑ Look for an organization that supports families with a related health condition.
- ❑ Talk to other parents who are in a similar situation. For example, Family to Family Connections at the Alberta Children's Hospital or the Glenrose Rehabilitation Hospital will help you connect to other families.

*I've taught my child to say "I don't understand what you're saying. Can you use words I can understand?"*

## Get to Know Your Healthcare Team

It is helpful to learn the names and roles of the members of your healthcare team and to try to understand what they can and cannot do in their roles. In each clinic or unit look for a key contact person who will be able to answer your questions and pass on information to the other team members.

## Asking Questions

Don't be afraid to ask lots of questions and to ask again if you don't understand or remember. There are no bad questions – keep asking until you feel comfortable.

**Use open ended questions** that encourages people to say more; not closed questions that can be answered with a yes or no.

*What symptoms does a child with this condition usually experience?*

**Try probing for more detailed information** if you want to know more.

*Can you help me to understand why you think my child has this condition?*

**Explore possibilities rather than asking for a specific answer.** It isn't always possible for your healthcare team to give you an exact answer or diagnosis.

*How might this condition affect my child's day to day life?*

## ANOTHER OPINION

When you have a difficult decision to make, it may be helpful to explore options with another healthcare professional. It is okay to ask for another opinion.

*There's a lot to think about to make this decision. I think it would be helpful to talk to another healthcare professional so I can feel confident with the choices we make.*

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# PARENTS AS PARTNERS #3

## WORKING TOGETHER - MAKING DECISIONS

### You are a Partner In Your Child's Healthcare **YOU KNOW YOUR CHILD BEST**

Your experience  
and knowledge  
of your child



the experience  
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the best decisions  
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### Becoming Part of the Team

- ❑ Get to know your child's healthcare team and let them know how you want to participate in decision making.
- ❑ Share with the team what is important to you and your child.
- ❑ Express your family's values, needs, and preferences.
- ❑ Share your observations about your child.
- ❑ Ask questions to improve your understanding.

*"It takes time and energy to build a strong and effective team to support your child and family. Team members will change over time – it's a continuous process."*

You need information to make informed decisions. It is okay to ask lots of questions. For ideas on how to get the information you need, see Tip Sheet 2.

**I** messages are a respectful way to help others understand what you are feeling and thinking.

**I** feel helpless when I see my child like this and I can't do anything.

**I** feel more confident trying this at home now that I've done it with you.

**I** am confused because I am hearing many different opinions.

**I** am overwhelmed by the number of therapy exercises we are supposed to do everyday.

**I** feel more in control when I have all the information.

### Find Support For Your Participation

As a parent, it can sometimes be a challenge being part of a healthcare team. Consider finding an individual on the team who will help you participate. This would be someone you feel comfortable with who understands your situation well.



*"I found it helpful to connect with another family who has lived through making a similar decision. They understood the challenge we faced."*

*"I talked to my community physiotherapist to get her opinion on the impact that surgery would have on my son's day-to-day activities."*

## Making a Decision

1. Work together with your healthcare team to clarify the main concern. Members of the team may have different perspectives so some discussion may be required.
2. State what decision has to be made.
3. Explore the options together. What are the expected outcomes and the risks for each option?
4. Decide on the timeframe to make the decision. Ask for time to think about the options and consult with others.
5. Make the decision.

## Assumptions can create misunderstandings

*I have learned that it is important to check out my assumptions with the healthcare professionals to avoid misunderstandings.*

*"I'm assuming you set this appointment up – is that correct?"*

*"Am I right in thinking you will be the person who follows up on this?"*

## Waiting for Decisions

Your healthcare team may suggest a "wait and see" approach before further decisions are made. This may be suggested because your child needs time to heal or more needs to be learned about your child's condition. Determine your next steps:

*What should I look for? At what stage should I be concerned? When will we re-evaluate? Do I make the appointment?*

When you are concerned about the wait time, you may want to ask for further action. Explain your concerns and discuss possible options.

*I already see a significant difference between Jane's speech and that of her peers. I've heard that it takes a while to get in to see a speech language pathologist. If we wait before booking an appointment it could be a year before she is assessed. Could we start the process now?*

## Summarize any decisions that have been made to confirm your understanding.

*Just let me summarize our decisions today. We are going to try the new medication for six months. I will let you know if there are any side effects. You will schedule an appointment for six months from now to discuss how well the medication is working. At that time, we'll decide whether we need to pursue the new treatment.*

## TOUGH DECISIONS

When crisis situations happen, it can be difficult to make decisions.

It may help to seek out others who can help you clarify your thoughts and values. In the hospital, you can find a social worker, hospital chaplain, or medical staff who will help you with this process.

Sometimes, you may decide you do not want to make the decision. That's okay. You can focus on supporting your child and ask the healthcare team to decide what to do. They will ask for your agreement.

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# PARENTS AS PARTNERS #4

## WHEN WE DISAGREE - DEVELOPING A SHARED UNDERSTANDING

### *You are a Partner In Your Child's Healthcare* **YOU KNOW YOUR CHILD BEST**

Your experience and knowledge of your child



the experience and knowledge of the healthcare professionals



the best decisions about your child's health

**As a partner in your child's healthcare, you are encouraged to participate in decisions about your child.**

At times, this may involve differences of opinion and challenges in communication. The way you deal with these situations is important for building and maintaining a strong relationship with your healthcare team. The key pieces of a collaborative relationship are honesty, respect, trust and appreciation (see Tip Sheet 1).

*"I try to remember that my body language can say as much as my words."*

### **Set The Tone**

You can encourage positive communication by acknowledging any difference of opinion or conflict. State your desire to move forward.

*We seem to have a difference of opinion. Can we clarify options and create a plan to move forward?*

### **Keep an Open Mind**

You may not have all the information. There may be possibilities you have not considered. Be willing to reconsider your position after you have gathered information and considered all the options.

### **ASK FOR HELP FROM OTHERS**

You may be tired, emotional, or uncomfortable with conflict. Consider asking someone to help you work through a difference of opinion you have with a healthcare professional. You could ask a trusted family member, friend, Elder, or another professional such as a social worker or chaplain.

*"When my child was in ICU, I was overwhelmed and exhausted. I found it difficult to participate in decision making. I talked with a social worker and she was able to support me and help me express my concerns."*



*"My child's doctor and I did not agree on the need for a referral for my son. She wanted me to wait and I wanted to get it done right away. As we discussed it further we came to understand the reasons for each of our positions. My doctor was concerned she wouldn't be able to follow through because she was leaving her position while I was concerned about the long wait to get in. We decided she would put in the referral and I would make sure my son's new doctor followed up on it. Exploring the reasons behind each of our positions helped us to resolve our difference of opinion."*

## Working Towards a Shared Understanding

When you have a difference of opinion, the following steps will help you work together to come up with a solution:

1. *Plan ahead. Consider what you will say and what questions you need to ask. Set up a time to talk.*
2. *Start the conversation by indicating your desire to understand the other person's point of view and to work together in the best interests of your child.*
3. *Listen to the other person without interrupting. Allow them to explain their position.*
4. *Ask open ended, probing questions to clarify and get the information you need.*
5. *If necessary, explore the reasons behind each of your positions. Ask "why" questions to get a better understanding.*
6. *State your understanding of each position.*
7. *Discuss possible solutions and form an agreement on next steps.*
8. *Restate the agreement you have made.*

### Respectful Ways To Ask For Clarity:

*Help me to understand why...  
So if I understand you correctly,  
you are saying...*

*"Making important decisions for your child can be very emotional; especially when the whole team does not agree! I have found that when I have an emotional reaction, it is often because of my fear and worry. Taking a moment to breathe deeply and calm myself helps to turn my focus back to the needs of my child. I know that my healthcare team has the best interests of my child in mind and that together, we can create a plan that everyone can agree on."*

### If you can't reach a shared understanding...

- Ask to speak with a manager to help resolve the difference.
- Get a second opinion.
- Seek out a different professional for your child's care.
- Express your concern to the AHS Patient Relations Department.
- Consult a Clinical Ethicist at your hospital if it is a medical ethics decision.

*When I have lost control I apologize for any inappropriate words or actions and acknowledge my emotional response – "I'm sorry, it is difficult for me to separate my emotions from this situation."*

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