

# PARENTS AS PARTNERS #2

## Building a Partnership – 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  
and knowledge  
of the healthcare  
professionals



the best decisions  
about your  
child's health

## 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://fcrc.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 health care 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.*

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://frc.albertahealthservices.ca>

Alberta **Children's** Hospital

