

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
and knowledge
of the healthcare
professionals



the best decisions
about your
child's health

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.



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://fcrcc.albertahealthservices.ca>

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