

Teamwork

When parents learn of their child's diagnosis, they often feel completely overwhelmed and intimidated. At first, they may be willing to accept whatever the health care team says without question. As they learn more about their child's condition and the health care system, some parents feel frustrated, fearful for their child's health and future, and dissatisfied with the quality of care. As you learn more about your child's condition, and the "patchwork quilt" of the health care services, you may want to become an "advocate" for your child—asking questions, raising concerns, and making suggestions.

To become a successful advocate for your child, you will need knowledge and diplomacy.

This section provides tips on how to work with the health care team to make sure that your child receives the best care possible.

WORKING WITH THE HEALTH CARE TEAM

The health care system is made up of health, education, and social services. However, these services are like a patchwork quilt made up of federal, provincial, and community pieces. Your challenge is to choose and link the pieces so that your child gets the services that are needed.

How can we build a team of health care professionals?

Building a strong and supportive health care team for your child is well worth the effort even though it takes a lot of time, effort, and often patience, especially if your child has multiple needs.

Your child's health care team and the clinic's social worker can offer help about resources.

You may also have to do a bit of detective work on your own. Other parents who have been through a similar experience can be great sources of information and support. Many publications, support groups and community resources are listed in the *Additional Supports and Resources* section at the end of this guide.

Your child's CHD diagnosis will lead to new relationships with health care and community professionals and other relationships may change. These relationships will develop as your child grows and his or her care needs change. Some professionals may be involved for a short time, while others may be involved for many years.

Having the support of the team can be very helpful for the many challenges parents face in caring for their child. It can also help parents feel less isolated in dealing with the special needs and demands of their child's condition.



*"I kept my promise
to smile at people
yesterday and I was
thrilled with the
smiles I got back!"*

PARENT



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“Although Jessie is smiling and playing I have to say she is still not right, and I’ve told the staff I’m worried about her. I think the doctors are paying attention, because they are planning to make some changes. Aha! I may not be scientifically brilliant, but Mom’s instinct is unbelievable and I am discovering it more and more.”

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What should we expect from relationships with the team?

Your relationship with the health care team will be best if you can work together and rely on each other for information and support.

The relationship works when it is:

- on equal grounds—you and the team have important contributions to make,
- an honest relationship on both sides—you need to be able to trust the information from the health care team, and the team must be able to rely on the information you give about your child,
- showing respect for each other; your respect for the team’s expertise and the team’s respect for you as expert caregivers with valuable concerns and suggestions about your child’s care and treatment.

The team should also show that they value your child and are concerned for his or her well-being.

Good communication is a must. You can do your part by preparing for each visit:

- What do you need to ask the team?
- What information will you need to provide?
- What do you believe is in the best interests of your child and your family?
- Are there any things happening in your family that might affect your child (for example, financial problems or divorce)?

It takes time and practice to learn new ways of working with the team. It will also take time for both you and the team to develop respect and trust. For your child’s sake, the effort is worth it.

How can we get information and make decisions?

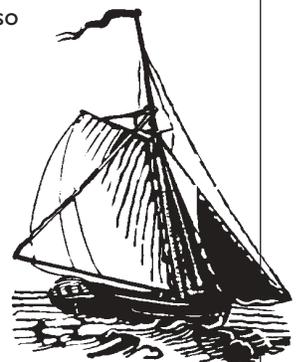
Some parents feel uncomfortable when they are not in control. It can be difficult to let others manage your child’s care, especially if you don’t understand what is being done. Sometimes being part of a team means letting others take charge. As you build your team and gain trust, you may grow more comfortable with allowing the team the control they need to care for your child.

When you first learn of your child’s condition, you may know very little about CHDs and the health care system. The more you learn, the more effective you will be as an advocate for your child. You can gain this knowledge by reading, talking to others, and asking questions.

How can we settle our differences?

You won’t always agree with the health care team. Your concern for your child may make you very emotional. It is natural to react strongly to anything that may seem like a threat to your child’s well-being.

Pay attention to what your body is telling you. Once you know that you are feeling anxious or angry, you can look for useful ways to express these emotions. Trying to hide your feelings can result in strained relationships with staff, family, and co-workers. These feelings can also build up into an emotional outburst that damages the trust and respect that you have worked so hard to get.



Is it all right to ask for a second opinion?

It is all right to ask for more information and for a second opinion. The doctor may not always be able to answer a question right away, but has quick access to information. Neither you nor the doctor should feel challenged if you ask for more information.

Second opinions may already be a part of the treatment that your child receives. Ask your cardiologist if a team of professionals will be discussing your child's medical condition and treatment options. If this is the case, you are already getting a second opinion.

Even when parents have full confidence in their child's doctor, they may need to know that a team of professionals has made the decisions. To keep your relationship with the team, think about how you can ask for a referral to another doctor without the current doctor thinking that you don't trust him or her.

It is not uncommon for parents to want to change doctors because of how their child's doctor communicates or provides care. It is *almost always* a good idea to discuss your concerns with the doctor before making a change.

In an emergency, you may not be able to get a second opinion. Transferring your child to another centre may be medically unsafe or too costly. When a second opinion is not available, you can gain confidence in your child's care by learning as much as possible about your child's condition, asking questions, expressing your concerns, and making suggestions.

PLANNING CARE FOR A CHILD WITH MULTIPLE NEEDS

How can we plan the care for our child with multiple needs?

A child with multiple needs usually needs many services. You will need to learn about the programs, policies, and referral steps of the various service providers. You will need to coordinate appointments and sort out information and instructions from many professionals, some of whom have not had a chance to talk to each another.

You may find yourself frustrated by the sheer number of professionals, agencies, services, and departments involved. You may even begin to feel that you have lost control of your own life and, worse, that of your child's. These are common frustrations, and there are no easy solutions.

Strategies

Here are a few strategies that may help:

Appointments

Tell booking clerks when you have appointments in other departments and, if possible, you would like to book all your appointments for the same day. This is helpful if you live out of town. Keep in mind, however, that too many appointments in one day can be overwhelming for both you and your child.

Coordinator

Choose a pediatrician or family doctor or other health care provider to act as a case coordinator—someone to help you get resources, coordinate meetings with specialists, understand the information you have been given, arrange appointments, and possibly even help you decide which specialist to call when there are problems. Choose someone with whom you are comfortable.

“When my daughter has a problem I’m never sure who to call because I’m not sure if it’s her heart, lungs, kidneys, or what. Sometimes I think, maybe I should just phone the doctor I haven’t bothered in a while.”

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“If it feels like a problem, then it is a problem. Come to us and we can help. There are ways around the stress.”

HOSPITAL
SOCIAL WORKER



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Case Conference

Consider asking for a case conference, especially if you are having trouble sorting out instructions from the different specialists in your child’s care. A case conference is a meeting (of one or more service providers) with you to discuss your child’s health, treatment, and care. A case conference may be helpful if you are not getting the information you need, if you are not sure what is going on, or if you are getting differing opinions.

FINANCIAL CONCERNS

Does the provincial medical plan cover the costs of our child’s care?

The cost of hospitalizations and operations is generally covered by your province’s medical plan. Hospitals differ in what they may provide for patient comforts or supplies such as specialized formulas, diapers, and clothing.

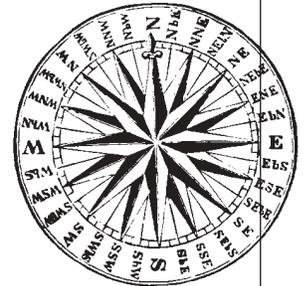
Many families find it financially stressful to have their child in hospital, especially if the child requires a long stay. Parents often have to pay for their own travel, accommodations, meals, and parking. If you have concerns about finances, or any supports you may need, other programs may be available. Different provinces have different financial programs. Ask a health care team member who to contact about your concerns (see *Additional Supports and Resources*, page 12-1). The staff can help you if you tell them that you need support.

What happens if our child needs treatment in another province or country?

Very specialized treatments may not be available in every province or even in Canada. In such cases, your cardiologist may make a request to provide your child with “Out of Province” or “Out of Country” services and will discuss this with you. In general, the direct costs for these medical treatments (if they are

not offered in your province or in Canada) are covered by your provincial medical plan. However, don’t confirm travel plans until the provincial medical plan has approved the request.

Although the cost of a specific medical treatment such as specialized cardiac surgery is generally covered by the plan, additional expenses for these services *may not* be covered. Ask to speak to a social worker or other health care professional who can tell you what expenses will be covered and help you get financial support if needed.



REFERENCES

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