

Babies and toddlers

The following sections apply to children who have just been diagnosed with a CHD and to children who are growing up with a CHD.

ADJUSTING

When your baby has a CHD

Finding out that your baby has a CHD can be very upsetting to the whole family. It can affect how you and your baby interact and how your baby develops.

Your baby may have seemed healthy, and now everyone has to adjust to the idea that the baby has a CHD. Your baby may look and act no differently than before, so it may be difficult to accept the diagnosis. This is a normal response felt by many parents, families, caregivers, and friends. Everyone involved may need some time to work through feelings (see *Coping with Your Child's Diagnosis*, page 3-1).

What do babies need to learn?

At first, your baby has simple needs such as feeding and comfort.

The first few months of a baby's life are important for you to get to know your baby and for your baby to get to know you and your family. Bonding happens during all of the daily things you do with your baby, such as feeding and diapering. It is a time for your baby to watch you and get to know your face better than others. At the same time, your baby learns to trust you and rely on you to provide for simple needs such as feeding and comfort.



Infancy is the time when babies begin to learn to communicate. At first, getting your attention is most important. Later, your baby will want other things.

Concern about strangers is an important step in every child's development. If your baby is in hospital when children normally learn the difference between family and strangers, there may be some problems. On one hand, you will want your baby to learn the difference between family and strangers, but on the other hand, babies of 8-15 months will normally become upset by so many strangers. Don't expect your baby to accept many different caregivers. It is important that children learn the difference between family members, who they can trust, and people outside the family with whom they should be more cautious. Your baby will need extra comforting and support in the hospital and especially during tests or caregiving routines with strangers.

During the first year of life, your baby will also begin practising the actions that lead to walking and talking. Mouthing toys, babbling, and listening to others talk all lead to speech. Swatting at toys, rolling over, pushing into a sitting position, crawling, and pulling up to a standing position all lead to walking. It is common for babies to begin to practise these skills at different times and walk or talk when they are ready.

Play is the most important thing in your baby's first years. Babies should have lots of chances to play, including watching others, physical play, pretend play, and even word play through

THE FIRST YEAR

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SWATTING AT TOYS, ROLLING OVER, PUSHING INTO A SITTING POSITION, CRAWLING, AND PULLING UP TO A STANDING POSITION ALL LEAD TO WALKING.



IT IS COMMON FOR BABIES TO BEGIN TO PRACTISE THESE SKILLS AT DIFFERENT TIMES AND WALK OR TALK WHEN THEY ARE READY.



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*“She loves to chatter
and throw her toys
over the side of
her chair with the
knowledge that one,
or all of us will
quickly come to her
rescue. She just got
her third tooth and
delights all of us when
she starts to laugh.”*

PARENT

songs and repetitive games. When babies have a chance to pretend, lead others, and direct the play, they gain a sense of control over the world around them.

Will our baby develop normally?

A baby with a CHD will look at life in much the same way all children do. Your baby will be interested in playing and exploring, trying new things, showing off, and being loved and cared for by the family.

Most parents are concerned that their child will not develop at the same rate as other children. In general, children with CHDs are as intelligent as other children. Children with CHDs may be slow in starting to speak and in developing their language abilities. Children with certain syndromes may also experience delays associated with that syndrome (for example, Down Syndrome). In general, the more complex the heart defect, the more “at risk”, the longer it will take the child to develop.

Children learn and do things at different rates. Chances are your baby will do most things around the same age that other babies do. The most important thing to remember is children need the chance to practise and feel a sense of pride in what they can do, no matter when it happens.

How might illness affect our baby’s development?

When babies are ill, they may not have some of the usual childhood experiences. For example, if you don’t get to feed your baby, your baby may not have as many hours of cuddling, or the satisfaction of being face-to-face, enjoying the feeding experience. It may take a little longer for your baby to get to know you.

Also, because you have a sick baby, you may become more anxious. Babies are sensitive to parents’ anxiety and may respond to it. The more you can remain calm, the more likely your baby is to stay relaxed as well.

In older babies, who feel sick or anxious, they may not be interested in new relationships. Babies may also ask for more physical attention than you might expect. It can be helpful to think of a baby’s “clinginess” as a way to find comfort.

Babies often cry when they feel unhappy or unwell. Understanding why your baby is crying a lot may make it easier to cope.

How might the hospital affect our baby’s development?

Being in the hospital can make it even more difficult than usual for babies and parents to deal with being separated from each other.

Some of the things that could affect how you and your baby bond include:

- not being able to hold your baby often enough,
- not enough time for you and your baby to have private time together,
- a lot of caregivers other than just you.

Despite these problems, there are many ways that you and your baby can learn to know and love each other. Talk to your baby’s caregivers if you have any concerns about this.

If you have had any time at home with your baby, you will likely have set up some daily routines, such as mealtimes, playtime, and bedtime. Being in the hospital upsets these routines and can upset your baby.

While in the hospital, your baby’s motor skills (small movements, such as holding objects, and large movements such as crawling and walking) can slow or stop during a long hospital



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stay. Some babies even forget some of the skills they have already learned.

Most babies improve over time, especially with the help of a **physiotherapist** or **occupational therapist** (see *Record Keeping*, page 13-4). At home, babies can get back to normal development as their lives become more normal and their own motivation pushes them towards their goals.

How can we stop worrying about how fast our baby is progressing?

Babies feel proud of themselves when they do something new. Once they have done it, they do it again and again. They like to do it even months after they have learned to do it perfectly.

When they are getting good at crawling, babies want to show off, so they keep practising. It is their natural way of strengthening their muscles and gaining the balance they need to pull themselves up to stand. Trying to push a baby to walk before he or she can do it can send a message to the baby that you are worried. The baby may wonder, "Isn't my crawling great enough? Is there something I'm not doing well enough?"

It doesn't matter how long it takes a baby to stand or walk alone. Being able to walk or stand and feeling proud of it is the most important part of building your relationship with your baby and building self-esteem.



How can we avoid being too watchful?

When a baby is sick, it is natural for families to be especially protective and careful with them. Even as the child grows up, whether or not there are health crises, parents are usually concerned and sometimes even fearful about their child's health.

Children do need protection and care, but they also need room to grow. They need to have the same chances for ups and downs that all children have. They need to try things on their own, to try to solve life's problems and to make mistakes.

Parents can help their babies in the long term, by letting them experience little struggles such as struggling to get a ball that is stuck under a chair, or dropping most of their favourite food while learning to feed themselves. Through struggle and mastery, babies enjoy triumph.

If you are too watchful or protective of your child, this may actually interfere with your child's chances to grow and develop self-esteem. Being alone at times gives babies the chance to learn skills like how to calm themselves down and to develop an awareness of their own body senses.

Without meaning to, parents sometimes stop a child from trying new things, or jump in to help rather than trusting that the child is able to solve problems. The child may get the message that "I'm not capable of trying new things", or "I'm not smart or strong enough to do things on my own".

All children need time alone as well as time with caring adults. Small babies are very aware of body language and the non-verbal (unspoken) signals we give to each other. They pick up body language messages even more quickly

ROOM TO GROW

Children need protection and care, but they also need:

**ROOM TO GROW
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TO MAKE MISTAKES.**



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PREPARING FOR TESTS

TELL YOUR TODDLER WHAT WILL HAPPEN IN VERY SIMPLE WORDS



BE THERE DURING THE TEST AND REPEAT WHAT YOU SAID BEFORE



KEEP A POSITIVE ATTITUDE



HELP THE CHILD FORM TRUSTING RELATIONSHIPS WITH THE HEALTH CARE PROVIDERS



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than spoken messages. To avoid sending your baby negative messages, it is important to learn to relax around your baby and believe in your baby's abilities.

How can we prepare our baby or toddler for tests?

It is usually difficult to prepare babies and toddlers for tests or procedures. When you are well-informed and prepared, it is easier to support your child.

Telling your toddler what will happen, in very simple words, and then being there during the test and repeating what you had said before, may help your child get ready and accept events.

Small children pick up feelings very quickly, and will be more nervous themselves if parents feel upset and worried. The best way a parent can help a small child cope is by keeping a positive attitude, and by helping the child to form trusting relationships with health care providers. For example, when your child sees that you are comfortable and cooperative with the clinic nurse, he or she is more likely to copy your behaviour.

Some procedures can be done on you first while the child watches. An example would be a blood pressure test or an oximeter reading. If you look relaxed during the test, your child may be more cooperative.

No matter how calm and supportive you are, your child will often be upset and cry during procedures. This is a normal response to an unfamiliar situation.

Why are restraints needed?

To do some tests, your child may need to be restrained. Toddlers may be frightened, restless, or unwilling to cooperate.

To be successful, most tests and procedures need extreme accuracy. Restraints may be used during a procedure to keep your child safe or to make the test results useful. For example, to get clear results, your baby will need to be very still during an x-ray.

While the films are taken, the x-ray technician may need to leave the room for a few seconds. In these situations, restraints are used for your child's safety.

For a blood test or IV, restraints prevent injury. If your child moves while the needle is being inserted, there could be injury to the vein, bone, tissue, or nerves.

Some ways to restrain a baby or small child include holding him or her closely or using a blanket wrapped snugly around wriggling arms and legs. Sometimes medication may be used.

The health care team will make sure your child is safe and comfortable.

Preparing for procedures by playing

Here are some things you can do to help your toddler:

- "play" the procedure before and after,
- talk about hospital visits so your toddler feels more familiar with tests and procedures,
- visit the playroom after a test is finished,
- get a medical play kit (helps children become comfortable with hospital equipment without frightening them).

Preschoolers

When your preschool child is newly diagnosed

Having a preschool child diagnosed with a CHD presents its own special challenges to the family. Your child may have seemed healthy, and now you have to adjust to the idea that he or she has a CHD. Your child may look and act no differently than before, so it may be difficult to accept the diagnosis. This is a normal response felt by many parents, families, caregivers, teachers, and friends. Everyone involved may need some time to work through his or her feelings. Parents in particular may feel grief at the changes in their child's future (see *Coping with Your Child's Diagnosis*, page 3-1).

There may be many other changes to cope with, such as a major operation, or medical needs for years to come.

Living with a preschooler with CHD

The preschool years can be difficult enough without the added stresses of a CHD—temper tantrums and tears are normal for preschoolers. Just giving medications can be a challenge. It may be helpful to remember that a temper tantrum is a child's way of making sure that someone is listening and paying attention to something that is bothering him or her a lot, either physically or emotionally.

Preschoolers have no real understanding of "health" or the need for treatment. Most children under six years of age do not understand what a heart is. They generally view painful or uncomfortable procedures as punishment, and may do whatever they can to avoid what you

and the healthcare team are trying to do for them. At the same time, young children sense the stress their parents are feeling and may respond with emotional outbursts.

The other children in the family may also be affected by the diagnosis and need extra attention and reassurance that the CHD is not their fault. There may also be changes in family activities, such as some outings may not be possible, and rough activities such as play wrestling may no longer be possible.

What do preschoolers need to learn?

During the preschool years, children generally have their own way of seeing things and it is not always clear to adults. If they don't know something, they simply "fill in the blanks" with their imagination.

From a young age, children look at the world as though they are the centre of it. This is part of normal, healthy development.

Preschool children learn how to behave and about how things work by watching and listening. They like to copy parents and others in pretend play.

Young children are also very sensitive about their bodies, and are concerned that their bodies are not hurt or injured. They worry, for example, that when they have a blood test, all the blood will run out, or that if they have surgery, their insides might fall out. These are normal thoughts for young children, but may take on new meaning if surgery is needed.



"My little buddy is unfortunately very fickle. She is fine with the nurses until I arrive, and then they become chopped liver! Thank goodness they are all so forgiving."

PARENT



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PLAY IS A GREAT WAY
TO REDUCE STRESS



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How might illness affect our child's development?

Children with a CHD often have less energy than other children their age. They may need to spend more time in quiet activities and less time outdoors in physical activities. As a result, they may learn to read and use a computer before they learn to swim or ride a bike.

Children who spend more time at home and less time with their peer group still need time to play and be with others to develop their social skills.

Sick children sometimes spend more time with adults than with other children. Families sometimes need to make a special effort to make sure that their children have normal childhood experiences.

Play is a great way to reduce stress. Children who play don't get bored and play can help them make sense of things that happen. Encourage play that is about "the hospital" even if your child's ideas make you uncomfortable.

How might hospitalization affect our child's development?

The hospital can be a confusing place for a young child. Children may be more afraid of their own fantasies than of what really happens. Taking time to explain what is happening can help ease their fears. However, most preschoolers will not understand a verbal explanation about a medical problem or treatment.

There is also a chance that children might view their hospitalization as a punishment for some unconnected event. Preschoolers need lots of reassurance that they have done nothing wrong.

Preschool children who spend a lot of time sick or in hospital may miss some of the normal childhood play and exploring. However, with planning, it is usually possible to play, to spend time with the family, and follow normal routines.

Children who spend time in hospital, even when physical activity is restricted, usually make up for lost time quickly when they return home. Family life helps motivate children to get back to normal fun and routines.

Parents may worry about how much activity is safe. By spending time with your preschooler, you will quickly learn to recognize how much activity your child can handle.

Will our child be treated differently from others?

Children with a CHD usually look the same as other children unless they have another medical condition that affects their appearance. They have interests, ideas, and can make friends like other children their age.

Some children with a CHD may not be able to keep up with other children during high-energy activities. You can arrange indoor play dates and activities for children who can't keep up so they are not disappointed. They might play active games for shorter times or take more breaks.

Children are usually aware of how much they can do, and they do as much as they can. They soon learn to persuade friends into play activities they can manage.

Will our child be able to attend daycare?	<p>For help finding a qualified caregiver, talk to the social worker or provincial ministry responsible for daycare.</p> <p>Most children with a CHD can attend daycare. The daycare will need to be aware of your child's health issues, needs, and activity level. If your child has a very complex CHD or any other disabilities, you may need to consider a specialized daycare. The clinic nurse or social worker can help you find information about resources in your area.</p> <p>Respite care may also be available. It is a service that gives parents a break from a child who requires a lot of medical care and attention. There may also be programs that help with the high medical costs of caring for a medically fragile child at home. Ask the clinic nurse or social worker about programs available in your area.</p>
<p>Most families need some form of childcare, especially if both parents are working.</p> <p>When considering returning to work, some of the things you may want to consider include:</p> <ul style="list-style-type: none"> ■ the financial and emotional need to return to work, ■ your anxiety about leaving your child, ■ the increased risk for infection, and the impact of the infection on your child's CHD, ■ your confidence in the caregiver's ability to recognize symptoms, give medications, and respond to emergencies appropriately 	

What resources are available to help with our child's development?

LOCAL RESOURCES FOR CHILDREN WITH DEVELOPMENTAL DELAYS	
Infant development program (birth to 3 years)	
Child development program (older than 3 years)	
Speech and language therapists	
Physiotherapy	
Occupational therapy	
Social workers	
First Nations advocate (in some hospitals)	
School nurses and school psychologists	
Public health nurses	
Dietitians	
Provincial health program for at-home care	
Respite program	
Condition specific resources (eg. Down Syndrome)	



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Many children with a CHD do not need any help to develop normally. To find out whether your child needs help, ask your pediatrician, clinic nurse, family doctor, cardiologist, or public health nurse about having your child's development assessed.

When your child reaches school age, the school nurse is another important person for checking your child's development.

If your child has a special need, there is usually a variety of programs available. The pediatrician is a helpful person for selecting the best programs for your child.

How can we prepare our preschooler for tests?

Remember that children have short attention spans, so keep explanations to one or two minutes. Explain what will happen using simple words and words that your child uses (different children will say 'owie' or 'stinging' or 'hurting' to describe the same experience). Try to use "soft language" or the least frightening language possible. For example "make a small opening" is easier to hear than "cut an incision", even for an adult.

- Talk about the test on the day of the test so your child doesn't have a lot of time to get worried about it.
- Be honest with your child about any discomfort that may be felt, but don't dwell on it. Let your child know that it is okay to cry (for example, "Even grown-ups get scared and cry sometimes"). It will be more reassuring for your child if you talk about how proud the child will feel about his or her behaviour, and how proud everyone else will feel.
- Explain that the procedure is not punishment.
- After your explanation, watch your child to see if he or she seems worried. Some children become quieter when they are

worried. If you think your child is worried, ask him or her to talk about it or show you what he or she thinks will happen, using a favourite stuffed animal, doll, or action figure.

- If you understand how the test is done, try play-acting the procedure (see *Appendix A: Diagnostic Tests*). Be creative in thinking of ways to show how the test will happen or feel. For example, you could show how your child will be asked to lie on the x-ray table, where bandages will be placed, or how an injection is given or an IV is inserted. Imitate the behaviour your child will need to do, such as opening the mouth, holding very still, or breathing deeply.

If your hospital has a child life specialist, he or she will have lots of suggestions on how to explain and demonstrate tests. There may also be toy medical kits that you and your child can play with together.

During the test:

- Your child may cry, even if the test is not painful. This is a normal response to an unfamiliar situation.
- Your child may or may not need restraints. If your child has been able to complete the test without restraints in the past, let the team member know. For more information about restraints, see *Why are restraints needed?*, page 7-4.
- If possible, stay with your child during the test. If you can't be there, arrange for a familiar person to be there, a family member, friend, or staff person.
- Bring along a favourite toy or teddy.
- Ask the person caring for your child to limit the number of strangers entering and leaving the room during the procedure, since this can upset your child.
- If possible, ask that painful procedures not be done in the hospital bed, so that your child does not think of pain when he or she sees the hospital room. This may not be possible if your child is in a special unit or isolation.



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School-aged children

When your school-aged child is diagnosed with a CHD

Having a school-age child diagnosed with a CHD can be a difficult time for a family. Your child may have seemed healthy, and now everyone has to adjust to the idea that the child has a CHD. Your child may look and act no differently than before, so it may be difficult to accept the diagnosis. This is a normal response felt by many parents, families, caregivers, teachers, and friends. Everyone involved may need some time to work through his or her feelings. Parents in particular may feel grief at the changes in their child's future (see *Coping with Your Child's Diagnosis*, page 3-1).

The diagnosis may also affect other children in the family. Younger children may need to be reassured that their sibling's heart problem is not their fault. Older siblings may feel over-protective and frightened that something will happen to the child. If possible, older siblings should be included in family discussions and decision-making.

What do school-aged children need to learn?

During middle childhood, family is still important to the child, but it is also the beginning of developing independence. It is a time when children begin to develop interests and strong friendships outside the family in activities such as sports and clubs. Friends are becoming more important, and often these friendships are based on similar interests.

School-aged children can begin to think logically and understand a series of actions. This means that they can understand what is happening to their bodies and why treatment is needed.

During the school years, children become more aware of themselves and how others see them. This is the beginning of self-esteem. Because school age children are developing more advanced communication skills, they need time to use these skills with others. Discussion is important, between children and their friends and between children and adults.

School-age children spend a lot of time figuring out the world and events in their lives by playing games and talking about ideas.

How might illness affect our child's development?

Children with CHD may lose some friends because the friendships have been linked to an activity that your child may not be able to do any longer. Children who have been in sports may find it hard to understand why they can not continue.

Here are some ways in which illness may affect development.

Independence

At this age, children find themselves drawn to activities where they can participate and do well. Children with a CHD may get disappointed when they realize they cannot take part in the same way anymore. However, many are able to take part in active sports and other activities. Try to support your child's interests as you would for any child.

You should also support your child's need for independence. This may happen at a time when you feel the need to draw your child closer to protect him or her from doing too much and getting an infection. With planning, it is possible to give your child some independence without an increased health risk.



"I love playing ice hockey. I almost quit because I get so tired, but now I play goal and I'm really good at it!"

CHILD



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"I explained to him and the other kids that his heart was like a jigsaw puzzle that was missing pieces and the surgeon could put the puzzle back together and make it right."

PARENT



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Understanding

Children who are old enough to attend school can understand simple explanations of what is happening to their body. Because they can understand what the heart does, they may feel quite frightened. They need reassurance and support from their family and friends.

Self-esteem

As children get older, they become more and more aware of what their body looks like and start to compare themselves to others. Children with a CHD become more aware of their physical differences and limitations. There is peer pressure to look and be the same as everyone else. School-aged children, especially those who will be having surgery, need a lot of support and understanding to help them cope with changes in their bodies. Questions about "Why me?" and "Why am I the one who is different?" are common for this age group.

Informing others

It is important that the family not try to hide the child's heart problem so that the child can feel normal. Let the school know about exercise restrictions (if any) and signs that the child needs medical attention. You may want to work with the school to plan how to handle a medical emergency.

School work

Children who miss a lot of school may have trouble keeping up with their schoolwork. Most hospitals have a teacher available who can help the child keep up-to-date while in the hospital. Schools can arrange for schoolwork to be done at home if the child is too ill to attend school, or for extra work before surgery.

Older children

As children approach puberty, and move toward independence in their teen years, they are capable of learning more about their medical conditions. They can also understand

more about living with their condition, and how to track their symptoms and treatment. You can help by encouraging questions and helping your child learn about his or her medical history.

How might hospitalization affect our child's development?

School-aged children have a basic understanding of their bodies, so they can understand what happens during treatment. Most of them believe that different organisms cause different illnesses. This means that children of this age are able to understand their condition, treatment, and why procedures are needed.

For younger children, things that happen in the hospital, such as having a needle to stop pain, do not make sense. For example, a 6-year-old boy admitted with stomach pain and vomiting was very upset that medicine was being given through an IV in his arm. He became very frustrated trying to explain that he should be getting medicine in his stomach to make it better, as his arm was not the problem.

Older school-aged patients are likely to cope much better than younger children, perhaps because they understand more, and perhaps because they can talk about their concerns. Therefore, the stress of the hospital may have less effect on their emotional development.

For a short time after surgery, children will have less desire to take part in play with other children due to physical restrictions and less energy.



Children’s normal routines such as going to school, being with friends, going to clubs and hobby groups will be affected. Some children will worry about this. In extreme cases, school-aged children can experience regression (going back to behaviour they had grown out of), depression, or loneliness.

Parents and the health care team can help to prevent problems by giving children time for normal play and being with friends. This can be done even if the child is in hospital for a long time or has to return to the hospital often. Most large children’s hospitals in Canada are set up to use the Internet, videotaping, and other communications systems to help children keep contact with home and school.

When children know what is happening, are involved in making decisions, and are given the chance for play and hobbies, they cope better with the stress of being in a hospital. Most hospitals offer group play activities that provide children with “social” time.

What should we watch for in our child’s development?

Once a CHD is repaired, you can expect normal growth. Most children with a CHD develop thinking skills at a normal rate. Children with complex heart defects or who have been cyanotic for a long time may be smaller and lighter than their peers, and may have learning disabilities. (See *Cyanosis-Blueness of the Skin*, page 2-11.)

To learn more about screening for delays in development and how to get resources and support if needed, see the *Local Resources for Children with Developmental Delays*, page 7-7.

Most school-aged children with a CHD are able to go to school with their peers. Children with cyanotic heart disease may have difficulties in school because of low energy levels and learning disabilities.

Children occasionally miss school because of doctor’s visits, tests, hospitalizations, and recovery from surgery. If your child misses a lot of school, you may need to get home and in-school support to help your child complete each grade level.

Parents are often concerned that their child may be doing too much. In fact, sometimes parents don’t realize how much their child can do. On the other hand, teens often think they can do less than the cardiologist recommends. To make sure that your child is as active as possible in activities he or she can safely enjoy, discuss activities with your child, the cardiologist, clinic nurse, and teachers.

Will our child qualify for help at school?

If you think your child may need help at school, ask for an assessment before school starts. See *Local Resources for Children with Developmental Delays*, page 7-7 for contact information. The assessment can also be done with the help of the family doctor or the school itself.



“Parents know their children better than we do. They know how they’ll react, so they know best how to prepare them - what to tell them and when. It really helps when they prepare their kids beforehand.”

LABORATORY
TECHNICIAN



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PREPARING FOR PROCEDURES

USE CORRECT TERMS FOR BODY PARTS AND MEDICAL PROCEDURES



USE VISUAL AIDS, SUCH AS PICTURES, BOOKS OR VIDEOS



BE HONEST ABOUT HOW YOU THINK THE TEST WILL FEEL



LIMIT THE LENGTH OF YOUR EXPLANATION



EXPLAIN THE PROCEDURE LONG BEFORE THE APPOINTMENT



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Will our child be able to attend after-school and other community programs?

It is good for your child to maintain as normal a life as possible. Some community programs may ask for a medical clearance if physical activity is involved.

What do we need to know about physical education in the school?

Most children can take part in physical education (PE) at school without restrictions. Ask your doctor if your child should have any restrictions. Schools often request a letter to explain exercise restrictions and any emergency plan that needs to be put in place. See page 7-13 for a sample letter regarding physical limitations.

Can our child travel by airplane?

Some children with a CHD require special help to get enough oxygen when flying at high altitudes.

Flying at altitudes of 5000 feet or more is generally not recommended for children with:

- moderate to severe pulmonary hypertension,
- severe congestive heart failure,
- significantly low oxygen saturation.

Ask your doctor if these apply to your child.

If oxygen is needed during a flight, contact the airline *well in advance* to make arrangements.

How can we prepare our child for procedures?

School-aged children have a reasonable understanding about their bodies and want to know what is happening to them.

Here are some guidelines for explaining procedures to your school-aged child:

- use correct terms for body parts and medical procedures,
- use visual aids, such as pictures, books, or videos,
- be honest about how you think the test will feel,
- limit the length of your explanation to your child's attention span (break up the explanation into a couple of shorter sessions if necessary),
- explain the procedure long before the appointment, unless your child has shown in the past that he or she is likely to become worried.

Provide opportunities for your child to express any concerns. Time with a trusted friend or family member, opportunities to draw, and opportunities for play-acting can be helpful.

Help your child learn and practise ways to control frightening or uncomfortable situations.

This might include:

- counting slowly,
- breathing deeply in through the nose and out through the mouth,
- relaxing by imagining pleasant situations,
- telling jokes or funny stories that will help distract him or her from the situation, if your child is responsive to humour.

Because school-aged children are reaching towards independence, they often do not want their parents present during procedures. Respect their wishes.

**RECOMMENDATIONS FOR PHYSICAL ACTIVITY IN SCHOOL
FOR CHILDREN WITH HEART DISEASE**

Please photocopy this letter to clarify your physicians guidelines for your child's activities in school.

DATE _____

TO WHOM IT MAY CONCERN,

_____, a patient of mine, has a congenital heart condition. The child's cardiac diagnosis is _____.

The following recommendations are guidelines for physical activity in school.

1. _____ May participate in the entire physical education program, including varsity competitive sports, without any restriction.
2. _____ May participate in the entire physical education program EXCEPT for varsity competitive sports where there is strenuous training and prolonged physical exertion, such as football, hockey, wrestling, soccer, and basketball. Less strenuous sports such as baseball and golf are acceptable at varsity level. All activities during the regular physical education program are acceptable.
3. _____ May participate in the physical education program except for restrictions from all varsity sports and from excessively stressful activities such as rope climbing, weight lifting, sustained running (i.e., laps) and fitness testing. MUST be allowed to stop and rest when tired.
4. _____ May participate only in mild physical activities such as walking, golf, and circle games.
5. _____ Restricted from the entire physical education program.
6. _____ Additional remarks: (see other side)
7. _____ Duration of recommendations: _____.

If you have any questions about these recommendations, please contact me at _____ .
TELEPHONE NUMBER

Sincerely,

CARDIOLOGIST'S SIGNATURE

* Source: Cook E.H. & Higgins, S. S. *Congenital Heart Disease*. In Jackson, P. L. and Vessey, J. A. *Primary care of the Child with a Chronic Condition* 3ed., Mosby St. Louis 2000.

Teens and transition

TRANSITION

As children develop into young adults, they need to be able to take care of their own health rather than rely on their parent. This shift is called “transition”.

The teenage years are a difficult time for most young people. It is a time when they are trying hard to fit in with everyone else, but at the same time trying to find their own unique place in the world. If you are the parent of a teenager with a CHD, this time of life can be particularly stormy for you and your whole family.

CHDs are most often diagnosed in infancy so the parents are the ones who learn about CHDs and make decisions about their child's health care needs. As children develop into young adults, they need to be able to take care of their own health rather than rely on their parents. This shift is called “transition”. You may hear health care professionals talk about “transitioning” to adult care.

Transition planning involves youths with CHDs, their families, and the health care team. Transition care is planned specifically for each teen based on their personal traits such as emotional strength, intelligence, physical abilities, personal goals, and support from family and friends. Planning may start whenever the child or youth is interested in learning more about the heart condition or care needs. In general, the health care team will begin formal education and planning for transition at about 10 years of age (around the grade 5 level).

Because teens are reaching for their independence, the following section is written for them rather than for their parents. It includes self-advocacy, gaining independence in health care, puberty and sexual development, peer and social supports, education and vocational planning, recreation, and making choices that will not limit their health. As a parent, you may find the information in the section helpful, but the greatest success will likely come if your teen reads it and takes responsibility for his or her own health.



Finding answers. For life.

REFERENCES

- | | | |
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