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 = glossary definition

## Coping with a Chronic Illness

Pediatric heart disease is often a chronic condition that touches every aspect of family life. It impacts family relationships, social life, emotional state and financial resources, which can be overwhelming. If your child has a chronic heart condition, your family may seek support from resources to help you and your family cope.

### What Is Chronic Illness?

An acute illness may be serious but can be diagnosed, treated, and resolved. A chronic illness continues long after the diagnosis is made. There are many different types of pediatric heart disease. Some are very serious and require frequent follow up, monitoring and hospitalizations. Most however, require regular follow up and occasional hospitalizations, but allow the child and family to lead a very normal daily life.

If you have a child with pediatric heart disease you may feel overwhelmed with new responsibilities and not know where to start in figuring out what to do. The more you learn about your child's heart disease, the more in control you will feel. Many resources, some of which are listed in our "[Helpful Resources](#)" section are available to you such as:

- Local or hospital libraries for books or lists of professional organizations
- Support groups
- Reliable internet websites
- Healthcare professionals

As you begin to get used to the day-to-day management of your child, you will learn to cope with the new challenges of managing your child's illness. After a while, your daily activities will become routine and your family life will get back to normal.

### Relieve tensions

When you are first confronted with your child's illness and care, you may feel stressed. Some ways to cope with stress include:

- Recognize and communicate how you feel.
- Join a support group for parents or patients.
- Understand your own coping process.
- Seek group or individual therapy.
- Take care of your own health with proper nutrition, exercise, and fun (yes, fun!)

Remember, it takes time to mentally and physically adjust to this new diagnosis and the changes it brings to your life. Developing a sense of humor is a great survival tool for coping with stress. It is very important to stay hopeful. If you try to find the positive side of things, you will be teaching your child a valuable lesson, and maintaining your ability to cope as well. Children are incredibly positive and resilient and will look to you for their example.

### Family communication

Children with chronic illnesses are more likely than other children to experience frequent doctor and hospital visits. Some of the medical

procedures they undergo are, in fact, frightening or painful. [Pain and Your Baby](#) and [Pain and Your Child or Teen](#) are two resources that can help in dealing with such procedures. Hospital stays can also be frightening and lonely. In some cases, a young child may believe that he/she is being punished. Learn to talk with your child about his/her illness and the frightening procedures that might happen. Communication will relieve some of their anxiety.

Sometimes when one child is very ill, it can be difficult to provide the attention your other children need. Make a special effort to give your other children attention to work through the everyday changes in their lives also. [Siblings of Kids with Special Needs](#) is a good website from the University of Michigan that can help with this sensitive issue.

### **Finding the Balance between Dependence and Independence**

As your child grows up with their chronic illness, they will need to discover a balance between dependence and independence. Chronic illness may limit a child's activities a lot or a little, and the limitations may come and go. Consider these ideas for fostering independence:

- Encourage your child to participate in as many family jobs and activities as possible.
- Ensure that your child can maintain friendships with peers.
- Identify activities with your healthcare providers that are suitable for your child's condition.
- Allow for mistakes and messes.
- Provide consistent, appropriate discipline to ALL of your children. It is very important to teach your child with a chronic condition the same important lessons in life. This approach will also help your child feel normal.

### **Managing the Financial Crunch**

Financial planning is an important activity. Look at what you'll need to plan for and what resources (savings, insurance benefits, Medicare) are available. Read your insurance and disability policies so you understand what benefits are needed and when you're eligible. Keep copies of all letters and forms concerning insurance, bills, hospital records, and prescriptions. Some medical expenses are tax deductible, while others may be reimbursed through your insurance plan; but only if you keep good records.

One parent in a family may need to take time off work to care for a sick child. Family Medical Leave of Absence may be one alternative offered by an employer. If you can't work at a full-time job, you may be able to continue working from home. Some of the condition-specific organizations provide information about low-cost services. (See [Helpful Resources](#)) Your local departments of human services or local caregiver support groups are also a great resource. Family members may be willing to subsidize care; if they don't offer, ask them!

Trade services with other parents or caregivers. You might offer to cook dinner for a single mother in exchange for her shopping for your groceries. Be creative about the chores you trade.

### **Taking Charge**

Chronic diseases are often unpredictable and your family will probably feel overwhelmed and out of control now and then. You may at times feel tired, irritable or depressed. The couple relationship and sibling relationships may be tested during times of stress, such as a hospitalization. Be sure to take the time to step back, share feelings, and consider how you and your family can support each other. Look for resources in your own community to help you all.

### **Some Good News**

Data collected to date show that children with chronic disease often perform as well in school as healthy children. In addition, their self-concept and reactions to stress appear to be similar to those of healthy children. Recent PHN research shows that children with repaired complex congenital heart disease judged their physical health, self esteem, behavior and mental health to be better than their parents perceived these factors.

Some children with chronic illness have more behavioral problems which may be due to anxiety and feeling "different" from other children. Try to avoid treating your child with "kid gloves". Encourage your child to experience everything in life they physically can. The more normal

activities they participate in, the less different they will feel from others, and the more in control they will feel. If more help is needed, formal or informal support groups for children, individual or family therapy have been shown to be highly effective in helping kids to cope with their chronic illness.

[← My Child's Nutrition and Activity](#)

[The Loss of a Child →](#)

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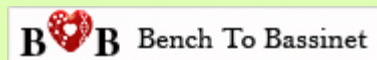
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