



University of Michigan Health System

Your Child

Development & Behavior Resources

Children with Chronic Conditions

What is a chronic condition?

All children will likely have many different health problems during infancy and childhood, but for most children these problems are mild, they come and go, and they do not interfere with their daily life and development. For some children, however, *chronic health conditions* affect everyday life throughout childhood.

We'll define a *chronic health condition* as a health problem that lasts over three months, affects your child's normal activities, and requires lots of hospitalizations and/or home health care and/or extensive medical care.

Chronic condition is an "umbrella" term. Children with chronic illnesses may be ill or well at any given time, but they are always living with their condition. Some examples of chronic conditions include (but are not limited to):

- Asthma (the most common)
- Diabetes
- Cerebral palsy
- Sickle cell anemia
- Cystic fibrosis
- Cancer
- AIDS
- Epilepsy
- Spina bifida
- Congenital heart problems

Even though these are very different illnesses, kids and families dealing with any chronic condition have a lot in common. Learning to live with a chronic condition can be very challenging for a child, for parents, and for siblings and friends. Read on for more information, support and resources.

How common are chronic conditions?

About 15% to 18% of children in the United States live with a chronic health condition (based on

the definition we're using). It's hard to estimate, though, because it really depends on how you define "chronic condition."

How might a chronic illness affect my child?

Children with chronic illnesses are more likely to experience frequent doctor and hospital visits. Some of their treatments may be scary or painful. Hospital stays can be frightening and lonely.

Children with chronic illnesses will feel "different" than other children. Their activities may be limited, and, in many cases, their families must change how they live to accommodate the child.

How do kids adjust to and cope with chronic illnesses?

The way children react to diagnosis with a chronic illness depends on several factors, including the child's personality, the specific illness, and their family. One big factor is the child's developmental stage. Kids' understandings of illness and their coping strategies change as they grow older.

Here's some information about how kids adjust at different stages:

- **Infants and Toddlers** are beginning to develop trust and an overall sense of security. They generally have very little understanding of their illness. They experience pain, restriction of motion, and separation from parents as challenges to developing trust and security. Parents can help by being present for painful procedures, staying with their children (when possible) during hospitalizations, and holding, soothing, and interacting with their baby as much as possible.
- **Preschool Children** are beginning to develop a sense of independence. They may understand what it means to get sick, but they may not understand the cause and effect nature of illness. For example, they may believe that throwing up causes them to get sick, rather than the other way around. Being in the hospital or adjusting to medication schedules can challenge the child's developing independence. The child may try to counter lack of control over their world by challenging limits set by parents. Parents can help by being firm with things the child does not have a choice over (never ask "do you want to take your medicine now?" unless there's really a choice—almost all children will say "NO!"), but by offering choices over flexible aspects of treatment. (For example, "Which to you want to take first, the pink medicine or the purple?" or "Do you want to sit on my lap while you have your blood drawn, or in the chair with me holding your hand?") Parents can help their preschool child be resilient in times of stress. Here are some tips for helping young children learn to cope with stress. Find out more about resilience (page thorough to find the section on preschoolers).
- **Early School-aged Children** are developing a sense of mastery over their environment. They can describe reasons for illness, but these reasons may not be entirely logical. Children this age often have "magical thinking." They may believe they caused illness by thinking bad thoughts, by hitting their brother, or by not eating their vegetables. Children also begin to sense that they are different from their peers. Parents can help by allowing children to help in management of their illness (with close adult supervision). They should also reassure their children that the illness is not their fault. Parents can help elementary school kids develop resilience in the face of a chronic illness. Find out more about resilience (page thorough to find the section on school-aged kids).

- **Older School-aged Children** are more capable of understanding their illness and its treatment, but they should not be expected to react as adults do. They may feel left out when they miss school or activities with their peers. Parents may feel the need to protect their children by restricting them from activities with other children. This is a natural reaction, but it can interfere with the child's independence and sense of mastery. To the extent allowed by the child's doctors, parents should help the child to participate in school or other activities. Find out more about resiliency in middle school kids (page through to find the section middle school kids).

Information and support can be empowering, and reading what other kids have to say can make a kid feel less alone. Here are some websites just for kids:

- Kidshealth.org has kid-friendly information on all kinds of health and illness topics.
 - Bandaides and Blackboards for kids, is a site for kids with chronic illnesses or other medical problems.
- **Adolescents** begin to develop their own identity separate from their family. Self-image becomes extremely important during the teenage years. That can be a problem when the teen's appearance is altered by illness or medication. Teens are also beginning to develop a real independence from their families. Parents who have been very involved in their teen's care for many years may find it difficult to let go of their role as primary caregiver.

Many teens will go through times of denial of their illness when they may neglect to take medications, follow special diets, or check blood sugars. In addition, the adolescent's body is rapidly changing, which may change the symptoms of the illness or the doses of medications needed. It is important to help the teen to gain control of their disease management. Keep in mind that even with chronic illness, teens are teens! Don't forget to talk about issues facing all teens: independence, college planning, sexuality, substance abuse, etc.

There are some great websites just for teens:

- Teenshealth.org has information for teens on all kinds of health and illness topics.
- Bandaides and Blackboards for teens has stories, ideas, advice, and poetry.
- On Chronic Illness Resources for Teens, teens share their stories of their experiences.
- Resilience for Teens—Got Bounce? offers tips from the American Psychological Association for building skills that can help teens cope in tough times.

What effects can I expect my child's chronic condition to have on our family?

Chronic illness doesn't just affect the person with the condition. The whole family must come to terms with the illness, make major changes in schedules and priorities, and somehow manage to remain a family.

Parents may struggle with their own feelings about the child's illness while trying to keep up a brave front for the child. It is normal to feel a sense of disappointment, grief or loss for the way you imagined your child's life would be (without a chronic condition). Divorce is somewhat more common in families with seriously ill children, mainly because of the great stress of parenting an ill child. While your child will need at least one parent with them during times of acute illness or hospitalization, it is important for you to find at least short times now and then to spend alone together with your partner.

Siblings of the ill child may feel left out, and later may feel guilty at any bad feelings they have toward their sick brother or sister. While less time will be available to spend with the other children in the family, parents need to let them know that they are still special and important. You can't just assume that they know this. If you can carve out just 10-15 minutes a day to really focus on each sibling, it will go a long way.

Caregiver burnout and stresses on relationships in the family can become overwhelming. Sometimes counseling can help everyone in the family make the adjustment more smoothly. Find out when your family should seek help and what kinds of help are out there from the American Association for Marriage and Family Therapy.

The most successful families tend to be those that are able to move on from seeing the illness as an intrusion toward working together as a team to face the new responsibilities of managing a long-term illness. They build on their family's strengths to cope with the new stress. Get some tips for how families can deal with stress in a positive way.

What can our family do to cope better, and to help our child cope better with the chronic illness?

- ***Stay involved and give information***

Discuss with your child (at their age level) what their illness is all about, and what will happen to them in the hospital. When you don't do this, kids may imagine the worst.

- ***Plan for procedures***

Unexpected stress is more difficult to cope with than anticipated stress. Some procedures can cause physical and psychological distress. Some children do better with several days to prepare, while others worry themselves sick. Good communication and flexibility are essential.

- ***Give them choices***

Some tasks for children with chronic illness must be done no matter what. Others are more flexible. Know what tasks are mandatory (scheduled medications, specific diets) and which are open for discussion ("as-needed" medicines, choice of foods within a given diet). Conflict may arise when a child tries to assert independence. As preschoolers, and even older kids test adults' limits, there is natural conflict with adults' demands. Children with chronic illness, more than other kids, need chances to make choices—to have control over any part of their lives they *can* control.

- ***Support their friendships and activities with peers***

Illness often interferes with routines and activities. For children and teens, a particularly devastating consequence can be the weakening or loss of friendships. Friends can grow apart as a result of these changes. Keeping kids involved with their peers and making extra efforts to maintain those connections can go a long way in helping a kid cope with an illness. Helping your child to find new ways to make and maintain new relationships is critical during this time. You may also need to help your child find ways to cope with teasing from peers. Here's help: [Easing the Teasing: How Parents Can Help Their Children](#).

Children need to feel like they belong. Their peer relationships are an important arena for them to do this. Try to help your child find interests and activities that provide opportunities to connect

with other kids with similar illnesses. Give them opportunities to spend time with friends. Teens need to be exposed to other caring adults they can trust. Contact with these adults should be encouraged in order to help shape the direction of their lives and provide stability. Most major hospitals and clinics can help you find support groups for parents, families, and for children affected by the illness.

- Finding a camp for your child with special needs—the basics on types of camps, benefits of camp, starting your search, and questions to ask—from kidshealth.org.
- To learn more about camps specifically designed for kids with chronic conditions, the Federation for Children with Special Needs has a summer camp listing (find it on their publications page), updated each year, which includes useful information on selecting a camp.
- The Hole in the Wall Camps are free of charge. There are camps across the United States and around the world.
- The University of Michigan C.S. Mott Children's Hospital offers Trails Edge summer camp for ventilator-dependent kids.
- Search for a camp on the American Camp Association website--you'll have options to choose camps for children with physical/mental challenges.
- Your local children's hospital may also have listings of camps near you for kids with chronic conditions.
- Once you've found the perfect camp, find out what you can do to get ready.
- Sleep-away camps for kids on medications—some things to think about in planning.

• ***Be hopeful***

Coping with a chronic illness can be discouraging and scary. It is incredibly important to stay hopeful. Don't ignore your worries or your negative feelings—they need to be recognized and addressed. But it's not helpful to dwell on them. If you try to find the positive side of things and keep your eye on the potential positive outcomes, you will be teaching your child a valuable lesson, and maintaining your ability to cope as well.

• ***Listen***

Be available so your child can talk about the problems they are facing. Ask them how it's going, and listen to the answer. Listen to their troubles and help them find solutions to their problems. Be able to recognize the warning signs of depression. If your child talks about suicide, take it seriously. Allow your child to express their fears; validate your child's feelings. There's nothing worse than feeling scared and confused and not being able to talk about it. Find out more about depression in children and adolescents with chronic illnesses. More on recognizing depression in children and adolescents—also available in Spanish, Chinese and Korean.

• ***Be flexible***

To help your child adapt to their illness, you will need to both recognize their limitations and help them to continue with life as usual, whenever possible.

• ***Have fun together as a family***

You can expect the whole family to be under increased stress. Maintaining your commitment to your family and getting support from each other may be harder during times of stress, but it is also even more important! Spend time together that is not focused on the illness. To carve out time for

family activities you may need to *schedule* family time, including one-on-one time for parents and parent-child “dates,” as well as whole family activities.

- ***Involve the whole family and even an extended support network***

Allow each family member to help in any way that they are willing and able. Seek support and help from people outside your immediate family, such as through your extended family, school, religious community, neighborhood, or children's hospital. People you know will generally be very pleased if they can help, such as bringing over a meal, having your other children over to play, or even just lending a listening ear. Often folks don't know exactly what you need—so don't wait for them to offer it. If someone gives you a generic offer of help, tell them what you need specifically, and ask if they can do it for you. You'll be surprised at how glad people are to be able to do what's needed for your family.

- ***Teach coping skills***

Parents need to help children learn new ways to cope with the special challenges of an illness. Discussing with a teen how their illness is affecting him or her and finding ways to help solve problems or cope with the feelings is very helpful. They can learn to build on their strengths and can even develop pride in their abilities to meet the challenges. You can do a lot to help your child cope with the stress that comes with a chronic illness. There are many ways you can help your child build resiliency.

- ***Don't let your kids hear more than you intend***

If your conversations are private have them away from your children. Kids hear more than you may think; don't assume they are sleeping when their eyes are closed.

- ***Coordinate with your child's school***

When your child with special health needs goes to school, good communication between your family and school is very important. Find out what you need to do to prepare, and print some pages of important information to share with the school from this link. It is also available in Spanish, Russian, and Vietnamese.

- ***Take care of yourself and your relationships***

Caregivers/parents need to take good care of themselves—otherwise, they won't be able to *give* good care! Talk with other parents who have children with special health care needs, carve out time to do something you enjoy, get support, find someone to listen to you vent, take breaks, spend time with your partner, and learn to deal positively with your stress. If you can keep your family routine as normal as possible, that will help, too. Your relationship with your partner will be stressed and undergo changes, but it can emerge stronger than before you faced the challenges of your child's illness together. Seek help if you need it.

- Keeping your Marriage Together When Your Child Fights for Life (although written for parents of children with life-threatening illnesses, this article applies to non-life-threatening illnesses as well).
- Becoming a Resilient Family: Child Disability and the Family System

- ***Make use of respite care***

Everyone needs a break once in a while—especially the parents of kids with special needs. *Respite care* is short-term, specialized childcare. Respite care services can help keep family caregivers from getting burned out.

- Respite Care, a publication from NICHCY, has helpful information, but the list of resources may be out of date. Use NICHCY's state resource pages to locate your state's vocational rehabilitation, ARC, and parent training and information center to find out whether any of these can help with finding respite care.
- The ARCH National Respite Network and Resource Center has a National Respite Locator Service, and State Respite Coalition listings.
- In Michigan, for a child under age 3, contact Early On for help finding respite care. If your child under age 20 needs special medical care, you may qualify for help from Children's Special Health Care Services. In some Michigan counties, the local ARC may be able to help. If you have the financial resources, you could try to find a private home health care provider or respite center in your area.
- You may want to use childcare services to give yourself a break. Find out about Choosing quality childcare for a child with special needs—this pamphlet will help answer your questions.

- ***Remember your other children***

Siblings will need extra attention, and may need counseling; they can experience jealousy, anger, and depression. It's important that you address their fears, concerns, and grief, and make sure they don't feel pushed aside.

- ***Stay organized***

Getting organized will lower the overall stress level in your family. One helpful tip is to keep all of your child's information in one place. A care notebook can become a lifesaver. Here are some resources for putting together your own Care Notebook. Write everything down-don't count on your memory. If you have it all in writing, you can relax a little more. Keep a running list of questions, so that you will remember what to ask at medical visits.

- ***Be aware of the risks unique to your child's illness:***

It's important to be very familiar with your child's illness, no matter how scary it is. If children feel like they know more than you, they will feel responsible for protecting you. Read as much as you can about your child's illness. The more knowledge you have, the more likely you will be able to obtain the best care for your child. If you want more information about your child's chronic illness or health condition ask your county public health nurses, or the child's health care provider. Keep a written list of questions that come up, so you can ask at each medical visit. Don't hesitate to call your child's doctor with your questions or concerns.

In addition, there are many national organizations for specific health conditions, and many of the resources and links on this page can help you find information specific to your family's needs. You can also research online and learn more about your specific health, illness and medical procedure questions at the University of Michigan Health System Health Library, Kidshealth.org (also in Spanish), or the illustrated MedlinePlus medical encyclopedia (also in Spanish).

What are some other sources of information and support for kids and families living with a chronic illness?

More information:

- *YourChild*: Siblings of Kids with Special Needs
- *YourChild*: Pain
- *YourChild*: Medical Procedures and Pain: Helping Your Child
- *YourChild*: Hypnosis
- *YourChild*: Biofeedback
- Here is a helpful list of resources from the Center for Children with Special Needs, part of Children’s Hospital and Regional Medical Center in Seattle , Washington . This rich source of information includes some Spanish, Russian, and Vietnamese resources.
- Children with a Chronic Illness: The Interface of Medicine and Health is an issue of the New York University *ChildStudyCenter Letter*.
- How to Care for a Seriously Ill Child: Suggestions for Parents
- Helping your child cope during procedures
- Moving on with Life is a helpful section of a brochure for families with kids who have cancer. It talks about how to support your child, and how to deal with siblings, family and friends.
- Supporting Students with Asthma is a news digest that draws on research to discuss how schools can help support kids who have asthma.

Organizations and websites:

- The National Dissemination Center for Children with Disabilities (NICHCY) has online information (including Spanish language information) about various disabilities and illnesses, as well as general information about special needs youth (birth to age 22). You can also call **1-800-695-0285**, or e-mail nichcy@aed.org with any specific questions. They can help you locate your local state resources.
- Our-Kids is devoted to raising children with special needs. They provide information and support for kids with special needs and their caregivers.
- The Starlight Children's Foundation is dedicated to the development of projects that empower seriously ill children to combat the medical and emotional challenges they face on a daily basis. They have developed free CD-ROMs for kids with diabetes, asthma, and cystic fibrosis and other conditions, and their families. They also run a social networking site for teens with chronic and life-threatening illnesses and their siblings.
- PACER (Parent Advocacy Coalition for Educational Rights) works for better opportunities and quality of life for kids and teens with disabilities and their families through parents helping parents.
- The Cystic Fibrosis Foundation funds research and provides information.
- The Juvenile Diabetes Research Foundation International funds research, and has some useful information on their site.
- The National Easter Seal Society offers services for people with disabilities and special needs and their families. They have local chapters.
- Brave Kids has message boards and a searchable resources directory that contains camps, respite care, adapted sports, transportation and much more.

Books for kids:

- Young People and Chronic Illness: True Stories, Help and Hope, by Kelly Huegel and Elizabeth Verdick
- My Book for Kids with Cansur: A Child’s Autobiography of Hope, by Jason Gaes
- Books for kids about going to the hospital.

- Books and movies about siblings of kids with special needs

Books for parents:

- When Your Child Has a Disability: The Complete Sourcebook of Daily and Medical Care, Revised Edition, by Mark Batshaw.

A really useful book to read and keep as a reference. Covers a wide range of medical and educational issues, as well as daily and long-term care requirements of specific disabilities. Discusses parent concerns like behavior, medication, and potential complications. Also addresses issues such as prematurity, early intervention, legal rights, attention-deficit/hyperactivity disorder, learning disabilities, genetic syndromes, and changes in health.

- Coping With Your Child's Chronic Illness, by Alesia T. Barrett Singer.

A good introduction and general guide to coping for parents of a newly diagnosed child.

- Whole Parent, Whole Child: A Parent's Guide to Raising a Child With a Chronic Illness, by Patricia M. Moynihan and Broatch Haig.

This book helps you answer the questions: "What kind of parent am I now? What kind of parent do I want to be? How can I help my child with a chronic illness lead the fullest life possible?" This book aims to help you keep your perspective, and will remind you that you are not alone.

Written and compiled by Kyla Boyse, RN, Lina Boujaoude, MD and Jennifer Laundry, MD.
Reviewed by faculty and staff at the University of Michigan.

Updated November 2012

[Back to top](#)

University of Michigan Health System, 1500 E. Medical Center Drive Ann Arbor, MI
48109 734-936-4000

© copyright 2015 Regents of the University of Michigan / Template developed &
maintained by: Department of Communication. Contact UMHS



The University of Michigan Health System Web site does not provide specific medical advice and does not endorse any medical or professional service obtained through information provided on this site or any links to this site. Complete disclaimer and Privacy Statement