

How Parents Can Help Children Cope with a Chronic Illness

Parenting a chronically ill child is a challenge. The journey through your child's medical care will be one of the most stressful periods in your family's life. Life changes dramatically when your child is diagnosed. You will learn a new vocabulary and develop a new way of living. Parents of a child diagnosed with a chronic illness are often faced with difficulties and decisions that other parents will never have to face. Chronic illness doesn't just affect the person with the condition, it impacts the entire family. The families that seem the most successful tend to be those that are able to work together as a team to face the new responsibilities of managing a long-term illness. Here are some suggestions that may be of assistance to families in coping with a chronic illness.

Educate yourself about your child's illness. It is very important that parents understand their child's illness. Information can be empowering. The more information parents have about their child's condition, the more the family can be prepared about what can be expected. Having knowledge about your child's illness will also enable you to discuss any questions your child may have about his/her illness. Many parents express they are afraid to ask questions or tell a physician they don't understand something. Remember, learning about your child's diagnosis is a process. It is common for parents to have many questions and it can be helpful to ask the physician to repeat information. Parents are encouraged to ask questions until the information is clear to you. Some parents find it helpful to keep a small notebook in which they can write down questions (and answers provided by the medical staff when the questions are asked) regarding the illness and treatment plan. Your child's medical care is a partnership with the medical team. Parents are an integral member of the care team.

Discuss the illness with your child/siblings. Many parents of a chronically ill child have difficulty deciding how much to tell their children about the illness. Some parents worry explaining the illness may cause their children unnecessary anxiety and stress. It is usually best for parents to be open and honest with their children about the illness. Children are very perceptive and usually know when their parents are not being totally honest with them. This may lead to confusion and mistrust. Parents should provide information in simple language their children can understand. It is best to answer any questions your children may have with an honest and direct manner. Many parents have questions about how to explain the illness and what to say. Your child's health care providers (child life specialists, social workers, psychologists) can give parents specific suggestions regarding explaining the particular illness.

Understand how your child processes information at different developmental 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. Children at this stage can be most afraid of being separated from their parent and of medical procedures they cannot understand. It can be helpful for parents to be present for painful procedures, staying with their children (when possible) during hospitalizations, and holding, soothing, and interacting with 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 nature of illness. Children at this stage are afraid of being hurt and of pain. It is usually best to be honest about tests and procedures that may hurt and explain that the treatment is being done to help make them better. 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 do you want to take first, the blue medicine or the pink?" or "Do you want to sit on my lap while you have your blood drawn or in the chair with me holding your hand?")
- Early School-aged Children are developing a sense of mastery over their environment. They can understand reasons for illness but these reasons may not be entirely logical. They may believe the illness was caused by something they did. They should be reassured that the illness is not their fault. Children at this stage are more likely to understand that they will need to take medicine and undergo other treatments in order to get better.
- 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 development of self-esteem. To the extent allowed by the child's doctors, parents should help the child to participate in school or other activities.
- Adolescents begin to develop their own identity separate from their family. They are most likely to think about their illness in terms of its symptoms and its impact on their daily activities such as school, sports and relationships with friends. Teenagers are capable of understanding the relationship between their symptoms, their illness and the role of treatment. They can understand complex explanation of the illness and may have many detailed questions. Adolescents may want to be more involved in making decisions about their treatment. Encourage adolescents to monitor and manage their own treatment as much as possible. Encourage adolescents to share their ideas and concerns with healthcare professionals. Self-image becomes extremely important during the teenage years. Adolescents have a unique set of concerns surrounding their physical appearance and their ability to fit in with their peers. It is important to speak honestly about the possibility of any side effects due to the illness or treatment. If an adolescent's chronic illness reaches an unstable state to non-adherence with the medical treatment, it is helpful to encourage discussion of what is happening rather than reprimand.

Help your children deal with their feelings about the illness. It can be difficult to predict how a child or sibling will cope with the knowledge of a chronic illness. It is helpful that parents make an effort to help their child deal with any emotional reactions he or she might have. Providing support, listening to their child, and discussing their feelings can increase their coping with the illness. Some children may resist discussing their concerns or feelings in order to protect their parents from becoming upset. It is important that children feel that he or she can talk to his or her parents about any concerns or feelings without fear of being judged negatively or causing parents to become overly upset. A child's thoughts and feelings about the illness may change over time. Maintaining an open communication will help parents know how they can best support their children.

Understand your own coping process. A chronic illness changes your frame of reference and impacts routines and future plans. Parents may have many emotions and feelings about the child's illness and try to maintain a strong, brave face for the children. It is normal to have many emotions. Some parents express feeling overwhelmed, sad, disappointment, grief and frustration for the way you imagined your child's life would be (without a chronic illness.) It's okay to have wishes. It's okay to have fears. It's okay to feel angry. Caregiver burnout and stresses on relationships in the family can be overwhelming. Some families benefit from the support of a counselor to help make the adjustment of living with a chronic illness and learn how to relieve tensions.

Prepare your child for medical procedures. It is helpful for children to know what to expect in their lives as much as possible. Facing unknown medical procedures can cause children increased anxiety and stress. Many parents may think they are protecting their child by not telling him or her about upcoming procedures that may be uncomfortable or painful. Preparing a child for upcoming procedures can actually decrease anxiety and stress for the child. Children sometimes worry more about the unknown. Parents and the medical staff should explain why the procedure is being done, who will be doing it, what equipment will be used, and whether or not it will be painful or uncomfortable. The information provided needs to be in the context of the child's developmental level. Most pediatric hospitals have child life specialists who help prepare children for hospitalization, surgery, and various medical procedures. Parents can request information from their health care providers regarding how they can best help prepare their child for specific procedures.

Help your child lead as normal a life as possible. It is helpful for parents to treat the child with the chronic illness like any other child as much as possible. At the same time, parents need to consider their child's illness and any special needs that he or she may have. This balance can be quite a challenge for parents. One way to provide some normalcy to children is to give your child responsibilities. Just as the chronically ill child needs discipline, he or she also needs to be given responsibilities. Parents should require that the child with the chronic illness shares with regard to household chores. Encouraging responsibility is one way to help the child with the chronic illness lead as normal a life as possible. Parents must use their judgment in assigning chores that your child is able to complete with success. Be consistent in your requirements and be prepared to provide consequences if chores are not completed. Also, remember to acknowledge and offer praise for chores that have been done well. Children need to feel like they belong. Peer relationships are an important area for children to feel connected. It is important for parents to encourage participation in various activities that involve other children of the same age and to give children opportunities to spend time with friends.

Don't be afraid to discipline. Many parents are reluctant to set limits with their chronically ill child. However, just like any other child, the chronically ill child needs discipline and structure from his parents. Setting limits on unacceptable behavior, maintaining normal routines as much as possible and avoiding overindulgence provides children with structure and security. This is very reassuring to a child. This may seem impossible, particularly if parents have feelings of guilt. Setting limits in regards to your child's behavior will increase your child's adjustment to his illness and maintain normalcy is your child's life. Parents should be sure that discipline is consistent, both between parents, and from day to day with individual parents. Children need to know what to expect from their parents. Recommended discipline techniques include praising appropriate behavior, using time-out with young children, and restricting privileges for older children.

Maintain family routines as much as possible. Children typically do best when their daily routines are predictable and consistent. Parents should, as much as possible, maintain regular family routines (e.g., wake-up times, mealtimes, bedtimes, regular activities, etc.). Of course, this is not always possible, but an effort should be made to maintain regular routines and schedules for all family members.

Take care of yourself. This may seem like a difficult task for many parents of a chronically ill child. However, it is very important for parents to take care of themselves. Parents must get the rest and nourishment they need in order to have the energy required to care for their child. Parents who are exhausted and stressed-out often have a difficult time making good decisions regarding their child's care and are often unable to provide quality support to their child. Find someone (e.g., a close friend, a clergy member, a counselor, or a support group) that you feel comfortable expressing your concerns, anxieties, and fears. It is critical that parents look after their own physical and mental health for the benefit of their whole family. Children are very perceptive. They know when their parents are upset or worried. Children follow their parents' example on how to react to difficult situations. If parents are having difficulty coping, the child's may also struggle. To the extent possible, spend time with your partner, friends and hobbies.

Prepare your child for the communicating with others. Children with chronic illnesses often don't know how or what to tell others about their illness. Parents can help their children by suggesting various simple and concise explanations of the illness. It may help for the parent and child to role-play examples of providing explanations and answering questions others might ask.

Teach your child coping skills. Children need to learn new way of coping with special challenges of an illness. Validating your child's feelings and normalizing their experience can help them feel more comfortable with their thoughts and emotions. Discussing with a child how their illness is affecting them and finding ways to help solve problems or cope with the feelings is very helpful.

Be mindful of what your child can overhear. Try to avoid letting your child overhear conflicts (between family members or with medical staff) about treatment or other issues that relate to their child's illness (e.g., financial). It is important that children view their family and medical staff as a cohesive team that is competent and supportive.

Let others help. Parents should not try to do everything themselves. Let family members and friends help. When others ask how they can help, parents should have a list of things that need to be done from which they can choose (e.g., grocery shopping, errands). Parents should have others help in a way that decreases their stress and will allow them some time to relax.

Give your child some choices. Many children with chronic illnesses tend to think they have little control over their lives. Therefore, it is important for parents to help their chronically ill child build a greater sense of control. This can be done by offering the child choices whenever possible (e.g., diet, activities). When appropriate, it can also help to have the child participate in making choices regarding treatment (e.g., what arm to get a shot in, when to do exercise, etc.)

Connect with other families. Many families and children diagnosed with a chronic illness feel different and isolated. Being around others with the same illness often helps decrease isolation and provides support. Parents should also try to contact others in their area with the same illness who are coping well (your child's health care provider may be able to offer advice regarding this subject). Such contacts can provide children and families with hope about living with the illness.

Address siblings coping. A chronically ill child demands a lot of parental attention. Sometimes siblings may feel jealous, angry, lonely, and ignored. They may wish they had medical problems to get more attention. Siblings also worry about their ill brother or sister, worry about their parents, and worry that they might get the disorder, too. Siblings may act out and display inappropriate behaviors to attain parents' attention. They may feel guilty for their own good health or have negative thoughts about their sibling. It is important to address siblings' fears, concerns and grief so they feel valued and supported. It is important to explain the illness to their other children and encourage them to ask questions and express their concerns. Maintain open communication with all of your children. It often helps children feel like a more important member of the family to help care for their sibling (when appropriate) in some limited way. Exclusive time with parents will be especially valuable to siblings. Whenever possible, parents should try to schedule and spend individual time with their other children to help them feel important and secure. Let each child know he or she is special and loved- don't assume they know it.

Work with your child's school. Many chronic illnesses disrupt a child's learning. It is important for parents to meet with teachers, the counselor, and principal to explain their child's illness and the potential impact on school (e.g., frequent absences, fatigue, activity restrictions). Parents should talk about what the other children in the class should be told about their child's illness. They should try to develop a plan to help their child keep up with schoolwork when he or she can't attend school. If your child's illness is impacting his school learning or accommodations need to be made by the school due to the child's diagnosis, parents can request a 504 plan or an IEP (Individual Education Plan) at any time to coordinate this. A 504 plan can make accommodations such as extend excused absences due to medical appointments and hospitalizations, modified physical education, etc. Individualized Education Plans (IEP) can make modifications to your child's school curriculum based on your child's needs. The hospital social worker may be able to assist your family during this process.

Managing the financial aspects of your child's illness. A chronic illness can have an impact on a family's financial resources and increase the stress in the household. Many families experience a significant decrease in income when a child is diagnosed with a chronic illness. Some parents may even have to take an extended leave of absence from their employer to care for the child's medical needs. The loss of income can increase financial burden on the family. Some of your child's treatment may not be covered by your health insurance or your family may have difficulty with high deductibles. Also, be aware if your health insurance policy has a maximum lifetime benefit. Explore if there available resources in the community that may be able to provide some assistance. Your child's social worker may aware of resources in which your family may be eligible.