

HOW PARENTS CAN HELP THEIR CHILD COPE WITH A CHRONIC ILLNESS



Parenting a chronically ill child is a challenge. Having a child with a chronic illness is stressful for any family. Parents of a chronically ill child are often faced with difficulties and decisions that other parents will never have to face. A major task parents of a chronically ill child face is the responsibility of helping their child cope with his or her illness. Here are some suggestions.

***Educate yourself about your child's illness.** It is very important that parents understand their child's illness. The more parents

know about their child's condition, the more they will know about how much can be expected from their child (for example, what activities, sports, and chores their child is physically able to handle). Being knowledgeable about the disorder allows parents to know which behaviors and symptoms are normal, and which are not. Having knowledge about their child's illness will also enable parents to thoroughly answer any questions their child may have about his or her illness. Parents should ask their child's health care providers for information (books, pamphlets, videos) about their child's illness. Parents can also check their local library for information. Parents should not be afraid to ask their child's physician and the other medical staff questions about the illness and treatment plan. Many parents are afraid to say they don't understand something the physician is telling them. Parents should not let this happen to them. Parents should ask questions until they understand. It is also common for parents to have questions they then forget to ask the physician. 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.

***Explain the illness to your child.**
Many parents of a chronically ill child have a difficult time deciding how much to tell their child about the illness. On one hand, they don't want to cause their child unnecessary anxiety, and on the other hand, they don't want to be misleading. It is usually best for parents to be open and honest with their child about the illness. Children are very perceptive, and they will very likely 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 child can understand. Young children sometimes think an illness is punishment for something they have done. Therefore, it is also important to let young children know that the illness is not their fault. Parents should make sure their child knows that they are available to answer any questions the child may have, and they should try to answer questions in an honest and straightforward manner. Parents must be careful, too, not to provide too much information. Parents can do this by gearing their explanations toward their child's level of understanding. The child's health

care providers can give parents specific suggestions regarding explaining the particular illness.

***Help your child deal with his or her feelings about the illness.** Sometimes it's hard to predict how a child will react to the knowledge that he or she has a chronic illness. Parents should make an effort to help their chronically ill child deal with any emotional reactions he or she might have. They can do this by providing support, listening to their child, and discussing their child's feelings. Some children may resist discussing their concerns or feelings in order to protect their parents from becoming upset. It is critical that a chronically ill child 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. Parents should also keep in mind that a child's thoughts and feelings about the illness may change over time. This is why it is important to keep the lines of communication open at all times.

***Prepare your child for medical procedures.** Children need to know what to expect in their lives. Facing unknown medical procedures can cause the chronically ill child quite a

bit of anxiety. Many parents may think they are protecting their chronically ill child by not telling him or her about upcoming procedures that may be uncomfortable or painful. However, it is usually a good idea for parents or health care staff to take time to prepare children for upcoming procedures. They 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. Obviously, the information provided needs to be geared toward the age level of the child. Providing information often allows children to prepare themselves instead of worrying about the unknown. Most pediatric hospitals have child life specialists who help prepare children for hospitalization, surgery, and various medical procedures. Parents should 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.** Parents should try as much as possible to treat their chronically ill child like any other child. At the same time, they need to take into consideration their child's illness and any special needs that he or she may have. This can be

quite a balancing act for parents. It is very important for parents to encourage participation in various activities that involve other children of the same age.

***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 from his parents. Discipline provides children with structure and security, which is very reassuring to a child. Adequate discipline helps children learn to control their own behavior, too. Parents should make 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. Parents should also make sure that other family members and anyone else who cares for their children use consistent discipline, too. Recommended discipline techniques include praising appropriate behavior, using time-out with young children, and restricting privileges for older children.

***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 their chronically

ill child do his or her share with regard to household chores. Encouraging responsibility is one way to help the chronically ill child lead as normal a life as possible. Parents must use their judgment in assigning chores that their chronically ill child is able to carry out with success. They should be consistent in their requirements, and they should be prepared to provide consequences if chores are not completed. Parents should also remember to acknowledge and offer praise for chores that have been done well.

***Maintain family routines as much as possible.** Parents should, as much as possible, maintain regular family routines (e.g., wake-up times, mealtimes, bedtimes, regular activities, etc.). Children typically do best when their daily routines are predictable and consistent. 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. They 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. Parents must find someone (e.g., a close friend, a clergy member, a counselor, or a support group) to whom they can talk about their 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. If parents of a chronically ill child let their worries and anxieties show, they run the risk of increasing their child's anxieties. Children follow their parents' example on how to react to difficult situations. If parents are not handling the stress well, then the chances are great that their child will also have problems coping.

***Prepare your child for the reactions of 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 and/or management of the illness. It may help for the parent and child to role-play examples of

providing explanations and answering questions others might ask. The issue of how to handle any teasing should be discussed, too. Parents can also demonstrate how to handle teasing (e.g., ignoring, giving a quick humorous response) through role-playing.

***Be mindful of what your child can overhear.** Parents should try to be careful about what is said within earshot of their child. They should try to avoid letting their 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. They should 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 exercises, etc.).

***Look for role models.** Many children with chronic illnesses feel different and isolated. Being around others with the same illness often helps them in this regard. Many states offer camps for children with specific illnesses that are ideal for helping to nurture friendships between children with the same illness. Parents can ask their child's health care providers for more information about these camps. Parents should also try to contact others in their area with the same illness who are coping well (their child's health care provider may be able to offer advice regarding this subject). Children often benefit from having contact with others who have the same illness and are coping well. Such contact provides exposure to good role models and can provide hope to children who are not

coping well. It can also help children to know that someone famous had the same illness they have. Parents should try to do some research and identify people who are very successful despite having the illness.

***Handle advice from others appropriately.** Often many well-meaning friends and extended family members offer parents advice about how to handle their child's treatment differently (e.g., they disagree with the physician's advice). The best way to handle this is for parents to thank them for their concern and then say that since they (the parents) know all the specifics of their child's medical status, they (the parents) are the ones who will make the medical decisions based on consultation with their child's health care providers.

***Help your other children cope.** A chronically ill child demands a lot of parental attention. It is no wonder that brothers and sisters often feel jealous, angry, and lonely. Siblings also worry about their ill brother or sister, worry about their parents, and worry that they might get the disorder, too. Therefore, it is important for parents to spend time with their other children to provide a sense of security and to help them cope. Parents should explain the

illness to their other children and try to get them to ask questions and to express their concerns. Parents need to maintain open lines of communication with all of their 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. Whenever possible, parents should try to schedule and spend individual time with their other children to help them feel important and loved.

***Work closely with your child's school.** Many chronic illnesses disrupt a child's schooling. 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. Parents should also talk about how special services (e.g., specialized instruction, physical therapy, etc.) can be arranged if necessary.

Hopefully the above suggestions will help your child cope effectively with

his or her chronic illness. Parents who are concerned that their child is having significant problems coping should discuss these concerns with their child's health care provider. If necessary, they should request a referral to a mental health professional with experience working with children with the same illness.



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