



Helping Your Child Cope with Chronic Illness

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Chronic illness in children and adolescents is more prevalent than most people realize.

It occurs in many forms, such as asthma, diabetes, inflammatory bowel disease, juvenile rheumatoid arthritis, and so forth. Proper medical management of these conditions is, of course, essential. But psychological management, or "coping," also proves to be a key component for a family adjusting to chronic illness.

It's important to understand what "coping" means. Webster's Dictionary states that to *cope* means "to contend with difficulties and act to overcome them." In fact, however, families often believe that children are coping with their illness only if they are not experiencing any difficulties. Effective coping means consider-

ing the situation manageable, even if it is difficult and anxiety-producing. This concept is important to understand, because there are many factors that determine how manageable a situation is. Each child and family is affected differently. Once you identify which factors specifically affect you and your children, you can learn to change them so that you can all adapt better to life with chronic illness.

Developmental Considerations

The issues relevant to your own child depend largely upon her age. Young children are concrete thinkers. For example, they may not be able to understand why they're in pain and may think it's punishment for something they did. They often have misconcep-

tions about what will happen during a doctor visit or hospitalization. Young children are less likely to ask questions, and they look to their parents for an indication of how they should be feeling and reacting.

To meet the needs of young children:

- provide age-appropriate explanations
- identify misconceptions
- be honest, but don't overwhelm them with information
- model positive coping by being calm and not overreacting

Older children and adolescents think more abstractly. They understand about internal physiological processes and can recognize that their psychological state affects their physical health. Of course, they are also passing through lots of developmental tasks (e.g., changing schools, dating, working, becoming independent). So, they are also more sensitive to treatment regimens that change their lifestyle (e.g., dietary restrictions), have cosmetic side effects (e.g., puffiness from steroids) or draw attention to them (e.g., going to the school nurse for medications). Therefore, their compliance with treatment regimens may be determined by how they decide to negotiate all of these issues.

To meet the needs of older

children and adolescents, educate them regarding:

- independent disease management (e.g., taking medication on their own)
- long-term implications of non-adherence to their treatment plans
- reconciling treatment needs with social needs

Coping and Communication Style

In addition to age, another individual difference to consider is a child's coping and communication style. Some people cope actively by repressing or internalizing negative feelings. They cope through denial and may express their feelings subtly through other behaviors, rather than discussing them (e.g., decreased activity level, decreased interest in social activities). This style is more likely to lead to psychological distress. Other people cope actively. They are more verbally expressive and assertive and cope by gathering information. Research has found that children who cope with stressful medical situations by seeking information adapt better to hospitalization and surgery.

To facilitate an adaptive coping style in your child:

- encourage open communication within your family (how are they feeling, what are their concerns)

- encourage communication with professionals and participation in treatment planning (teach kids to ask questions and to give input into compliance issues)
- seek psychological services if needed (when verbal or nonverbal signs of distress are present and not lessening)

Parent Coping and Modeling

A physiological condition will not only be affected by a child's coping style, but also by the way family members cope. Parents influence their children through their own behaviors. As an example, consider the following anecdote. Two healthy 5-year-olds return from their first day of school. Each child's parent asks how the day went and how their child feels about school. Both kids say they have a stomachache. Parent One tells her child he's probably hungry and then diverts the conversation to what the first day of school was like for him. If he expresses concerns about school, the parent explains that it's natural for kids to feel uncomfortable in new situations and gives him encouragement for the next day. Parent Two takes his child's temperature, drawing a lot of attention to the stomachache. He says what a horrible day it must have been for her, and, in doing so, communicates his own anxiety about his child's adjustment to school. If a pattern of this type of reaction is established, it is likely that the first child will learn to talk about feelings instead of responding to stressful situations with bodily complaints and will look for reasonable explanations for his stomachache. The second child will not be as likely to be able to identify her feelings and may learn to associate stomach pain with negative events.

So, parents' anxiety does have an impact on a child's anxiety and ability to cope. Since it is certainly natural to feel anxious about your child's illness, parents are also likely to benefit from learning coping skills. Once parents have a handle on their own anxiety, they can help children deal with theirs.

To maximize parent coping skills and model coping behavior for children:

- manage your own anxiety, and seek social support (join support groups, speak with friends and adult family members)
- practice stress management with your children (learn relaxation techniques, teach kids strategies for managing pain, teach kids to prioritize their needs so they aren't overwhelmed)
- model positive coping and help prepare kids for specific situations (e.g., what to do if they are teased)

Siblings

When one child in a family is necessarily attracting more attention than the others, even due to an illness, her siblings may feel slighted. Other times, they are simply very worried and do not know what to do. Common issues may include concern about the ill sibling, concern about their parents, resentment over the attention the ill sibling receives, anger and loneliness.

To maximize help siblings cope:

- provide information about the illness right from the start;
- include siblings in the learning process because they will be affected in some way
- encourage communication and expression of their feelings
- discuss ways they can be helpful (e.g., making a get-well card)

- praise them for being helpful and cooperative so that they receive positive attention
- seek social support (e.g., establishing relationships with other families in the same situation)

Peers and Social Issues

A study of healthy kids ages 10 to 18 found their greatest stressors were fear of being perceived negatively by others and being rejected by a friend. So, kids are already dealing with concerns about their social lives. Many of the everyday stressors that come with having a chronic illness develop from the need to cope with peer pressure and social situations. How well a child adapts to her illness may depend upon how the illness and its treatment interfere with her social functioning.

To help your child manage social concerns:

- identify social concerns early, *before* they interfere with disease management
- encourage positive coping responses/being comfortably assertive with peers
- role-play, coach and problem-solve with kids
- utilize social support such as support groups for kids with chronic illness, but also help kids establish positive peer relationships in places that are not focused on illness, such as school.

Also remember that peers may have a positive influence on coping, because friends are an important source of emotional support.

School

Along with social activity, school attendance is one of the best predictors of a child's effective, long-term functioning. If illness disrupts a child's participation in school activities,

the parents and the school may need to collaborate to assess any difficulties the child might be having and determine if they're related to illness management. Collaboration can also help minimize school absences. Kids with chronic illness may miss school because of physical pain, doctor appointments or anxiety about dealing with their illness at school.

To maximize school functioning:

- collaborate with the school to accommodate your child
- work with the school to make trips to the bathroom or nurse easier
- get homework assignments, and provide extra help if your child is hospitalized
- set guidelines with your child regarding expectations for school attendance (e.g., when is it acceptable to stay home and when is it not?). Set these guidelines *before* the situation arises, in order to avoid a power struggle.

The topics reviewed in this article commonly come into play as a child and family adapt to chronic illness, but they are certainly not absolute. Remember that each child and family is affected differently and copes differently. And most importantly, successful coping with chronic illness does not mean not experiencing anxiety over it; it means finding ways to effectively manage it.

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