

COPING WITH CHILDHOOD CHRONIC ILLNESS

All parents have hopes, dreams and expectations for their children. When disease strikes, these expectations are shattered the moment the doctor utters the diagnosis. Some parents describe it as a physical blow, like being slapped. As the numbness wears off, parents are forced to begin to cope - to accept the diagnosis, mobilize their emotions and get on with their lives. But their lives are forever changed. Taking care of a chronically ill child is one of the most draining and difficult tasks a parent can face. A child's chronic illness affects the lives of all family members emotionally and physically. Roles and routines change and the demands of caregiving must be negotiated. Financial resources may be strained. It may seem at times as if the medical professionals that care for the child become part of the family. Family member's emotions may be on a continuous roller-coaster ride. Members find themselves focused on the needs of the ill child. On the other hand, families may come together and grow closer. They may reassess their priorities and in doing so, find rewards they had not expected on their journey through illness. They may find strength in themselves and one another. Whatever the outcome, all will find chronic illness to be a family experience, one that is shared by all.

COMMON EMOTIONS EXPERIENCED

At the time of diagnosis, you might feel shocked, numbed, or disbelieving. You might also look for a reason for your child's illness and perhaps feel guilty, asking yourself if something you did or didn't do caused your child's illness. These reactions are common to all parents whose children are ill. The following is a description of other common emotions experienced by parents of children with chronic/life threatening diseases. Parents may experience some, all or none and in no particular order.

- ANGER** is a normal reaction for both parents and children. They are angry at a number of things, many of which they don't recognize. There is anger at the disease for causing pain, for frightening them, for stealing a portion of their childhood. *Spouses* are angry at one another for not being there for each other; for not taking care of the ill child; for not going to the doctor soon enough; for giving the child bad genes. *Children* are angry at their parents for not protecting them.; at their siblings for remaining healthy; at their friends for going on with their lives. *Siblings* are angry at the sick child for being sick; for getting all the attention; for making their lives difficult at school and at home. Parents are angry at their children for being sick; for causing so much heartache and anguish; for costing money the family can't afford. Everyone is angry at family and friends who don't understand what they are all going through; who make uncaring and insensitive remarks; who do unhelpful things and cast blame; who abandon them when they are most needed. ANGER is everywhere. The problem is not that anger exists, but rather recognizing and coping with it.

- DENIAL** is a powerful tool that can be used to a person's advantage. Denying feelings of hopelessness can keep people on track and focused on the task at hand. Denial of limitations may allow for a child to set goals and push themselves beyond expectations. However, denial is no longer a coping skill if it prevents parents from obtaining immediate help, or recognizing an ongoing problem. Denial is not adaptive in an adolescent if it results in their refusing treatment.

- GRIEF** is commonly associated with death. But people grieve about other things. In chronic illness, there is grief for the loss of the way things were. "Nothing will ever be the same again" is a phrase one hears over and over. The feeling of loss is different but no less acute than grief from death. Different chronic diseases affect children differently, but most affect children's lives in negative ways, bringing similar losses such as: loss of energy, loss of carefree physical well being, restriction of activities, disruption of life due to medical treatment, isolation from family and friends, feeling self-conscious, embarrassed, or stigmatized if the disease makes them different than others.

- DEPRESSION** often goes hand in hand with a chronic illness. There are many reasons why a child may be at risk for depression. Some of these include: the symptoms of the disease (pain, nausea, physical changes which may be embarrassing), as well as the sporadic nature of the disease. Being unable to predict a flare-up of symptoms can make a child feel helpless and out of control. The treatments themselves may lead to depression, either due to side effects of medication or the difficulty of the regimen the child must follow. The loss of social contact, either as a result of less energy or time, or due to healthy friends' assumption the child cannot act like them may also be upsetting to a child and result in depression. The chronic disease may also be stressful to the family, and the resulting stress may give rise to conflict which may in turn lead to depression in the child. Chemicals in the brain that cause some of the symptoms of the disease may also cause depression in a child. Finally, there is a genetic link to depression. If a first-degree relative (mother, father, sibling) has problems with depression, the child may have an increased risk for depression.

HOW DO KIDS ADJUST AND COPE WITH CHRONIC ILLNESS

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 key factor is the child's developmental stage. Kid's understandings of illness and their coping strategies change as they grow older.

- INFANTS AND TODDLERS** seek to establish trust and security from caregivers and generally have little understanding of their illness. They experience separation from parents, pain, and physical restriction as challenges to developing trust and security. Parents can help by being present for all procedures, staying with their child (when possible) during hospitalizations and interacting with them 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 the illness. Being in the hospital or adjusting to medication or a new treatment regimen can challenge the child's sense of independence. Their **perceived** lack of control over their world may result in their challenging limits set by parents. Parents can help by being firm with things a child does not have a choice over (taking medicine) but by offering choices over flexible aspects of treatment. For example, "Which do you want to take first, the white medicine or the pink?" or "Do you want to sit in my lap for the blood draw or in the chair?"

- EARLY SCHOOL-AGED CHILDREN** are developing a sense of mastery over their environment. Just at a time when they begin to become more independent, they are forced back in the dependent role. They can describe reasons for their illness but their reasons may not be entirely logical. They often have "magical thinking" believing that somehow their illness may be caused by bad behavior, hitting their brother or not eating their lunch. It is at this time they begin to sense they are different from their peers. Parents can help by allowing children to help in the management of their illness (with supervision), as this increases compliance. Parents should also reassure their children that the illness is not their fault.

- OLDER SCHOOL-AGED CHILDREN** are more capable of understanding their illness and its treatment, but should not be expected to react as adults do. Being included and accepted by their peer group is an important focus at this age. They may feel left out due to missing school and activities due to treatment or physical limitations. Parents may become overprotective, restricting them from activities with other children. While this is a natural reaction, it can interfere with the child's independence and sense of mastery. Parents should help facilitate their child's participation in school or other activities to the extent allowed by the child's doctors. Don't be manipulated into allowing activities that shouldn't be done, but compromise when you can.

Information can also be empowering, and reading what other kids have to say can make a kid feel less alone. www.Kidshhealth.org has kid-friendly information on all kinds of health and illness topics.

- ADOLESCENTS** begin to develop their own identity separate from their family. Many resent the return to dependence which the illness often forces. Parents who have been involved in their teen's care for many years may find it difficult to let go of their role as primary caregiver. Self-image is also extremely important during adolescence, and can be fragile when appearance is altered by illness or medication. Many teens will go through times of denial of their illness, neglecting to take medications, follow special diets or check blood sugars. Their rapid body changes also affect the symptoms of the illness or the doses of medications needed. It is important to help teens gain control of their disease management. Connecting with other teens living with chronic illness reduces the isolation often felt. **Encourage Online** (www.encourageonline.org) is a place for teens (and their family and friends) living with chronic illness to talk, connect and have fun with others who understand.

ROLE AS A PARENT

While the tasks of parenting may change temporarily when a child is ill, the parental roles should not. The basic parent-child relationship is the same, and the more positive it is (e.g., loving, firm, helpful, kind, respectful) the less difficult the challenge of living with a chronic illness will be. It is important that parents not change the way they relate to their child. Doing so, especially easing up on discipline and changing rules for behavior, can send a frightening message to a child: *things are far worse than I have been told*. Changes like these also become a source of rivalry between siblings as they want the same rules as the ill child. Similarly, parents set themselves up for nasty problems once treatment is completed or the child accommodates to his or her illness.

Chronic childhood illness takes away everyone's sense of control. Routines are what give people a sense of control, they provide structure to our day. They get things done and provide a means for planning for the future. It is important for parents to establish a routine for the family. They need to find a balance between the needs of the ill child and the other children and themselves. If parents can effectively keep a sense of normalcy in their relationship, treatment and going to the clinic will become more of a normal part of a child's routine, not the focus of it. As parents, it is important to take each day as it comes, to forget about long range planning, at least for awhile, and focus on what is happening now. Your success in modeling this for your child will help them to cope with the roller coaster ride that is characteristic of living with a chronic illness.

SUPPORT FROM OTHERS

Very often parents say "you really find out who your friends are" when you go through the experience of a child's chronic illness. Some people just don't know what to do or say. They often mean well but can end up saying something hurtful or just plain stupid. Establishing the boundaries of privacy is a crucial task, and you are the only one who can do it. It is impossible for your friends to know how much you want or need to talk about the experience unless you tell them. This does not however, guarantee that they can meet your needs, but they surely cannot if they are unaware of what those needs are.

In order to receive help, you have to ask for it. Many parents are frustrated by those general offers for help, such as "If there is anything I can do, don't hesitate to call." They are unsure of the sincerity. One way to find out—put it to the test. "*Can you babysit Friday night?*" Be specific about what you need, "*Could you let me know when you go to the market? It would be great if you could pick up a few things for me.*" Sometimes parents don't ask because they are reluctant to be a burden. In some cases, they are determined not to let the illness "change" their lives and therefore they are not willing to make any modifications to their routine. Parents need to learn to accept help from others, and for some, this may be the first time they do so. Allowing others to help out is one way to keep the lives of siblings from being too disrupted. Accepting help positively affects both parties: the friend or family member feels good about being able to provide help, and feels less helpless than if just standing by unsure of what to do. In turn the parent feels supported, and less isolated, and the assistance allows them to focus on what is important, spending quality time with the siblings.

RELATIONSHIP WITH HEALTHCARE PROVIDERS

The nature of a chronic illness is just that, *chronic*, and therefore a good relationship with healthcare providers is crucial. Everyone has the same goal, managing the disease. It is natural for parents to be intimidated by the amount of new information they must assimilate quickly. It is equally natural not to understand everything that one is told the first time or even the second or third. Parents should feel comfortable enough to ask to have things explained and repeated until they understand. It is important to recognize that as a parent, you are an expert on your own child, and notice subtle changes in illness severity, response to medication and pain tolerance. As such, parents need to be partners with their child's healthcare providers, focusing on the common goal of improving the quality of their child's life, both medically and psychologically. While there may be times of stress and disagreement, parents and providers should discuss these issues away from the child. If parents have some ambivalence about the course of treatment, medications or even the child's treating physician, they should be careful not to share these concerns with their child until they find some resolution. Such ambivalence, if shared, can cause a child to lose confidence in their doctor and/or parents, lose hope in having a successful course of treatment, and result in noncompliance of medical regimens and lifestyle modifications.

SIBLINGS

Brothers and sisters often feel left out when a sibling becomes ill. Sometimes when a diagnosis is made suddenly and treatment decisions need to be made immediately, parents become so absorbed in caring for the ill child, siblings are often left with little information as to what is happening. When this happens, their fantasies are often far worse than the reality. It is important for parents to take the time, as soon as possible, to explain to siblings about the disease and give them an opportunity to ask questions. Long after the ill child's condition becomes stable, it is often the siblings who develop emotional problems as serious, and even longer lasting than those of the ill child. The following are some ways to help siblings cope:

- **Keep siblings informed of the child's condition, and be honest.**
- **Make sure they understand they were not the cause of the illness. Never assume they don't blame themselves.**
- **Encourage them to visit the sick child in the hospital as often as possible.**
- **Share your own feelings of anger, sadness, fear and worry with them.**
- **Let them participate in the care of the sibling, but don't expect it.**
- **Try not to blame the family's inability to do things on the sick child.**
- **Help them feel that although much of your time is being taken up by the sick child, they are still as important as ever. Try to find some time to spend exclusively with them. If you are in the hospital, make time every day to call and find out what is new and important—show you are interested in them.**
- **Inform their teacher about what is going on at home. This is just as important as informing the teacher of the sick child.**
- **To prevent them from being jealous of all the presents and attention the sick child gets "just for being sick," ask others not to buy gifts for the sick child except occasional small, "being in the hospital" presents.**
- **Use babysitters that the children know and like.**
- **Don't expect them to treat the sick child any differently.**
- **Try to arrange special outings, privileges and time for the siblings, whether with the parents, friends or others they like.**
- **Try not to diminish their concerns, frustrations and accomplishments by comparing them to the sick child. The reality of their world is important too.**

MARITAL STRAIN

A child's chronic illness affects the entire family, and results in major changes in schedules and priorities. Parents often find themselves spending a significant amount of time apart, one focusing on the ill child and the other handling the house, siblings, insurance issues and work. With a shortage of time to take care of critical needs, it is the marital relationship that takes a back seat. It is unfair to say that having a child with a chronic illness will increase the likelihood of divorce. However, marriages that had problems and were not stable prior to diagnosis of the child tend to be the ones that cannot weather the storm. Those which were healthy tend to become stronger. Many parents report that their marriage becomes the major source of strength during such stressful times. Due to time spent at appointments and/or the hospital, many roles are reversed., such as fathers participating more with preparing meals and driving children. With increased responsibility, parents have little time for each other. It is important for them to set up times to communicate, as well as relax together. Many parents report feeling guilty going out or having a good time when their child is not feeling well. Parents need to recognize that children often object to their parents leaving whether they are healthy or ill. In trying to create a structured, balanced routine for their family, alone time for parents is necessary. Parents must take the time to recharge themselves, both individually and as a couple. A short time away can replenish one's resources, increasing the patience, attention and positive energy they can offer to their child.

WHAT CHILDREN WANT AND NEED FROM PARENTS:

- **Honesty from parents and health care providers**
- **The ability to confide in a few close people—and the assurance that those people will understand**
- **Parents who will remain strong for them and who will keep the family functioning as it was before the illness struck**
- **Parents who will allow them the opportunity to engage in "normal" childhood activities as independently as possible**
- **A positive attitude about survival that is supported and reinforced by family, close friends and health care providers**
- **The ability to fight the disease**
- **A positive self image regardless of the physical effects of the disease and its treatment**
- **The ability to continue peer relationships, even to the point of having to overcome physical limitations and others' fear of their disease**
- **Hope**

10 TIPS FOR COPING WITH CHRONIC ILLNESS

1. **Focus on the joys and accomplishments of today—a smile, interest in a favorite toy, contagious laughter—not on what tomorrow may or may not bring.**
2. **Join a support group or form a relationship with a family facing a similar diagnosis/situation.**
3. **Nuture your sense of humor—it's true that laughter is sometimes the best medicine.**
4. **Don't be afraid to reach out to family and friends for support**
5. **Research and ask questions to learn all you can about your child's condition, diagnosis and potential therapies.**
6. **Your feelings are valid, so be easy on yourself to not feel guilty when you have had a bad day. Find a way to release your anger, sadness, jealousy and elation.**
7. **Find friends who are good listeners and be prepared to leave some behind who can't relate or who just "don't get it."**
8. **Arm yourself in advocacy. Learn about your child's special financial and educational needs. Begin early to explore and prepare for what is and is not available.**
9. **Ask for help! Let go of the things with the least importance. Concentrate limited resources on things that matter.**
10. **Care for your other children too. Schedule and spend time with siblings as best you can.**

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