

# Managing Stress When Parenting A Child With a Disability or Chronic Illness

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## PARENTS EMOTIONAL AND PHYSICAL NEEDS

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Parenting is hard, but it is a skill that is often assumed to naturally exist in parents. As tough as parenting can be, it becomes even more difficult when children are diagnosed with a chronic illness or disability. Parents go through a wide range of emotions including denial, anger, frustration, guilt, resentment, depression, and fear. All of these feelings are natural. After the initial shock and disbelief, parents may feel alone and helpless. It is an unbelievably stressful time, like nothing parents have ever experienced before in their lives.

When your child is first and foremost in your mind, parents must also learn how to cope with their own feelings and stressors. Parents will have days of wild emotional swings, with feelings of despair followed by moments of fulfillment. How you learn to take care of your own needs will determine how well you are able to effectively help your child. By pinpointing the sources of stress and setting up management strategies, you will be able to work through this inner turmoil while going through the process of building a relationship with your child.

## MANAGING STRESS

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Parents can easily become overwhelmed by all of the responsibilities they shoulder, especially when they also work outside the home. They have job-related deadlines and stresses, along with the child-raising responsibilities and daily household obligations that must be accomplished. With the added accountability of caring for a child with a chronic illness, they are at an increased risk of parenting stress.

With these responsibilities comes a wide array of emotional responses. Some days you may feel like running away because everything is working against you. Other days will turn out to be quiet and rewarding with feelings of accomplishment. All emotions are natural and normal. Having realistic expectations will go a long way toward helping to cope with whatever life holds. Learning effective coping techniques will be beneficial to both you and your child.

**EDUCATION.** First and foremost, education is a source of power. Parents should learn everything they possibly can about their child's condition, its symptoms, and causes. Simply learning about the numbers that are affected with this illness or disability will help parents to not feel so alone. They should also keep in mind that not everything on the internet will be factual, and find books by authors who have



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dealt with the illness. They can ask a physician for referrals to counselors or psychologists who could offer help. School staff may be able to give suggestions and guidance. Another good idea is to go to support groups where other parents can help by sharing their experiences. The more parents know the less isolated and more empowered they will feel.

**GET SOCIAL SUPPORT.** The best social support starts with those closest to the parents and their child. Family and friends are the ones most likely to offer support. By confiding in them, parents will have an outlet, and these family members will feel a part of the process. They will help to bring “normal” back to the upheaval parents have felt in their life throughout these recent events.

Parents should check in their community for support groups. Church groups or community education classes may provide invaluable resources. There are specific networks of families throughout the country who have experienced similar situations. Many have regular meetings which may be close to the family home.

There are even blog groups and online support groups to offer assistance with day-to-day difficulties and share the types of feelings that all parents in these situations experience.

These days, parents don’t need to get dressed up or leave the house to find a group that can share the pain or frustration and show a new perspective.

**DEALING WITH OTHER PEOPLE.** To lighten the emotional load, start by making a specific list of problems that are stressing you out, including school placement, homework, educating those outside the immediate family about the child’s problems, transportation to and from school and other related activities. Then, you can determine which things you have control over and what their ultimate goals would be. Even having them down in writing will give a sense of control and time to analyze future actions. You should determine what can realistically be accomplished, and learn how to say “no” when the item is not a priority on your list.

**FINANCIAL SUPPORT.** Chronic illnesses and disabilities tend to pull families apart for emotional reasons. They are also very draining on family budgets and resources because of the additional medical services, medications, counseling, and other money constraints that progressively grow over the lifetime of the disability. When researching the available financial help, you may feel overwhelmed and worried. However, no matter where you live, there are government programs and private



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programs available to help families. There are also other children's charities and even volunteer caregiver programs. Physicians or counselors in the community may be able to suggest what help is available.

**CAREGIVER SUPPORT.** Last, but certainly not least, the caregiver must give the child the gift of a healthy and confident parent. The only way for you the parent to do that is to take care of yourself. You can begin by making a schedule yourself; that is, what you will eat today, what kind of exercise you will accomplish, and how many hours of stress-free sleep you will carve out for yourself. Parents are a child's most important advocate. You need to make sure you are ready for the job.

Parents also need to find a small piece of time to call their own each day. Whether it is a 10-minute walk around the block or a phone call to an aunt, they need to have some "me time." It is important to clear the mind or occasionally just fill it with something that requires little to no mental work. By being a little selfish with regard to this time alone, you will regain some energy and emotional perspective. It is also very important to keep a list of respite service providers in the area that you can call to relieve you for a couple hours or a few days

while you get away. This time away can make an individual a much better caregiver.

Parents should make recreation and exercise a priority. The added endorphins will give extra energy to deal with everyday problems and perhaps view them in a different light.

**RECRUIT OTHERS TO HELP.** Parents who have a child with a chronic disability know that time is a rare and special gift. You should use it wisely, for example by sharing household tasks with everyone in the household. Parents, especially moms, don't have to do it all! You should ask for help with cleaning, cooking, even shopping.

It is important to set rules and boundaries in the household. The child with the disability needs to know his boundaries and limits as well. Without clearly defined expectations, children become dependent on others for everything. This tends to lower their self-esteem and encourage inappropriate social skills and poor behavior. Give them age-appropriate tasks, and they will develop a sense of accomplishment and pride.

Siblings can often have feelings of jealousy or anger, but their understanding of the illness and their coping strategies will change as they grow older. If they are involved as a family in



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caring for the chronically ill child, and also are able to savor the sweet kindness experienced in helping that brother or sister, they may be more forgiving and understanding of his needs. By addressing any fears they may have whether spoken or unspoken, parents may bring them closer together as siblings.

There is immense stress involved in parenting a child with disabilities. Spouses may also feel the effects of time constraints with constant caregiving. Parents' time together is important, but it often comes down to a matter of priorities. The child needs its parents to be available for certain acute illnesses or hospitalizations, but parents need to get away together occasionally too. The child deserves both parents to be healthy and happy.

Good family communication and flexibility will help all family members to see every challenge as an opportunity to grow. The entire family needs to learn how to cope together, and find ways to accept the world as it is now. Families should try to enjoy life, focus on one thing at a time, and not take on more than they can handle. Each family member will find their own coping strategies and share them with the others. Parents and children should revel in the glorious gifts of nature, enjoy changing seasons and holidays with friends and

family, laugh, have fun, and make time for joy in their lives.

## APEC IS HERE TO HELP

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APEC provides free training, information, and consultation to families. Visit our training calendar for more information about learning opportunities at [www.alabamaparentcenter.com](http://www.alabamaparentcenter.com) or call our center.

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