

# Parenting Children with Disabilities

## What are the Effects of Disability on Children?

A serious disability affects a child's ability to participate in common daily activities and might make it difficult to go to school, make friends, and generally have a normal life. It can be physically painful, frightening and might make the child angry or withdrawn. It can make the child feel different and isolated. The situation is compounded when other children talk about a child looking different or being afraid of "catching" the disability. Some children cope well with the pressures of a chronic illness while others need special support.

## How Do Children Cope with a Disability?

How a child copes with a disability is dependent on a number of things:

- The severity of the disability
- The child's age when diagnosed
- The outward appearance of the child including facial or body deformity and/or dependence on a medical device
- The child's personality and upbringing and ability to handle stress
- The family dynamics

Over time, the child's reactions might change and the child often feels loss anew when their peers are attaining new abilities or developmental milestones that they do not.

## How Do Parents of a Disabled Child React?

Part of the psychological preparation during pregnancy involves the dreaming and visualization of a perfect, beautiful baby. Parents often have many expectations for the "idealized" child. The birth of a child with a chronic illness or the discovery that a child has a disability has profound effects on a family.

When parents learn that their child has a disability or special health care need, they begin a process of continuous, lifelong adjustment. Adjustment is characterized by periods of stress. During this time, family members' individual feelings of loss can be overwhelming, shutting out almost all other feelings. Coping with uncertainty about the child's development may interfere with the parents' ability to provide support to each other and to other family members. Even when the diagnosis is clear, there are still many uncertainties – health, programmatic, and financial.

## **Parents' Grieving**

Following the diagnosis or birth of the child, parents often go through a period of mourning the loss of the anticipated, perfect child. All their dreams and expectations for their child will have to change to match the reality of the new situation. Parents will experience a range of emotions, most notably, shock, denial, magical thinking, sadness, guilt, anger, disappointment, lack of control and resentment related to the chronic illness or disability of their child. These feelings usually lessen over time, though critical events, as when their child is missing a developmental milestone, may bring them up again.

## **What Do Parents Worry About?**

Seeing their child be disabled is very hard on parents as well as all other family members. There are a number of things that parents worry about: not being in control, not being able to help their child, and concern over not making the right treatment decisions. Some specific issues include:

- The struggle with their own emotions – anger, guilt – physical and mental exhaustion
- Stress on the marriage
- Figuring out how to support their child; feeling alone in fighting every resource (schools, agencies, the health care team, insurance or Medi-Cal, social worker) for the care they deem their child needs
- Stress over making medical decisions for their child and not understanding what is going on
- Fear of medical treatments and their outcome
- Hoping with every new encounter that it was a misdiagnosis or that a new treatment might be the “magic pill”
- Worrying that everyone is evaluating how they deal with their child
- Fear of an emergency situation and knowing when to get help
- Not having access to a doctor who is knowledgeable about their child's condition
- Knowing how to parent a chronically ill child
- What to tell friends and family
- Monitoring their child's symptoms and knowing a condition may be worsening
- Learning how to meet a child's needs at home
- Meeting the needs of the entire family while caring for a sick child
- Trying to define a "new normal"

## **Some advice you can give the parents of a child with a disability:**

- Take care of yourself so you can take care of your child – It is important for the parents to have the personal energy and emotional stamina in order to take care of his/her child.
- Balance – It is common for parents to focus nearly all attention on the disabled child at the expense of that child's siblings and the parents' relationship. Parents should be encouraged to get the help they need so that the family system can thrive. This can take the form of a family outing with the non-disabled child, leaving the disabled child with a family member or a relief provider. Praise should be given to the siblings for jobs well done. Siblings are at the risk of losing their childhood because of the needs of the disabled child; the siblings' role in the family and in sharing caretaking of the disabled child should be appropriate to the age of the sibling.
- Reach out and seek information – Parents should be encouraged to learn what they can so they can be an advocate for their child's needs. If they have information from good sources, they will be credible when discussing their child's needs. They should be encouraged to reach out to friends and family for support.
- Be realistic about meeting everyone's needs – Personal expectations may need to be altered with the need to deal with care issues of their child. Understand that control of the situation is not possible and that everything will constantly shift. This will help decrease the stress of trying to make things 'perfect.'
- Build a support system – If not family then in the community (friends, church, formal support groups, neighbors). If the parent finds that it is getting increasingly difficult to manage her sick child at home, she should arrange for some respite care.
- Focus on the big picture – Parents should be encouraged to look for progress and accomplishments one day at a time. Seeing the overview of the situation may help decrease frustration with the day-to-day challenges.
- Focus on the child as a person and not the illness – Even children with a chronic illness or disability needs support and discipline. The parent should be encouraged to keep perspective on what to expect from the child and his/her personal needs without only looking at their healthcare

needs. If the parent needs help in setting appropriate boundaries for the child with a disability, he/she might benefit from parenting classes or assistance from the regional center; ignored inappropriate behavior from a toddler will only become a more significant behavior problem as the child grows.

### **How do Parents Cope when their Child is Disabled?**

The parents' lives change dramatically once a child is diagnosed with a chronic condition. They will learn a new vocabulary and develop a new way of living. Many parents indicate that while discovering their child may have a lifelong condition is a bit like the "loss of a dream," it also provides the opportunity to see life in a new light and focus on the other good things that can be valued. Focusing on the child as a person and not the illness and being as positive as possible helps the parent, the child with the disability, and the family cope.

It is very helpful for the parent to talk to people who are supportive and reliable, and who will be there for them now and in the future. This can be a family member, friend, or support group. Some friends or family members might not cope well with the news, but it is important to find those who can be an effective support for the parents. Parents should also be encouraged to learn as much as they can about the condition.

Speaking with other parents whose children have gone through something similar can also be beneficial, because they can share their experience. There are support groups dealing with most disabling conditions. Often the health care team makes referrals to such support groups. Support groups can also be located on the internet. This is a great venue for asking questions, expressing concerns, and learning from the experiences of others. Health care professionals associated with the hospital who are trained in counseling, such as child life specialists and social workers, can often provide some support.

Through all this, it is important for the parents to look after themselves by managing their emotions, eating well, and finding some time to exercise and relax. And it is equally important to stay engaged with the rest of the family. They should be encouraged to continue to nurture their relationship with each other and any other children they have.

## **How to Raise a Child with Chronic Illness**

Raise them the same way you would another child. They need boundaries, opportunities, encouragement, and support. Overprotecting and spoiling them does not instill confidence and will not prepare them well for the future. Cultivating independence and having expectations of a child as he grows speaks to future wellness and the child's overall capability. Having structure also contributes to a sense of security. Also, by giving the child opportunities to make decisions, the parents give him a sense of being in control of his life when so much of it is beyond his control.

## **How Can Parents Support their Child with a Disability?**

It is critical to explain to the child, as best and as simply as possible, the origins of the illness or disability. Many children feel guilty, believing that they are sick because they did something "bad." They also feel angry that they may not be able to do all the things their peers can do or not being able to "get well."

Parents can support their child by letting them know what is going on and what lies ahead in terms of treatment. They should help provide as many opportunities for choice as possible. By staying calm, the parents model calmness to their child. If the child is young, the parent should make sure he has a favorite toy to comfort him.

Parents should communicate often so the child has a chance to express his emotions about the disability. If he is young, he should be encouraged to express himself through play. If he is old enough, he should be taught problem solving skills and deep breathing techniques to cope with the effects of the condition on his life. He should be encouraged to develop special interests that take the focus off the condition and give him something to be proud of. Above all, parents need to express love and make their child a key player in the family's activities.

## **How Can Parents Help the Child Get Used to Being Different?**

Parents should talk with their child about the issues that are important to him/her. Communication will help ease stress. It will also serve to dispel misinformation that the parent or his/her child may be focused on. Parents should encourage the child to live life to the fullest within the context of his illness. They should help him/her develop strengths and areas of interest, things he/she can be proud of. Helping him grow as a person will build his self-esteem. Sometimes self-esteem takes a hit in a child with chronic illness if they feel they did something to deserve being sick or if the disability stops them from doing certain things. Building self-esteem can

have beneficial effects in all areas of life, including making friends, fitting in, and doing well at school. On top of that, people with good self-esteem and a positive outlook also tend to be healthier and take better care of themselves.

It also helps for parents to prepare their child for questions from peers and others about his/her condition, as well as possible teasing or bullying, which affects children who stand out as being "different." The child will also need to be prepared to encounter ignorance from people who do not understand their condition. They may think, for example, that the child's condition is contagious. It helps if parents educate the child and inform others as necessary.

There are also health care professionals who can help the child adjust. These include social workers, child life specialists, and doctors who specialize in pediatric or adolescent medicine. There may also be support groups or camps for kids with the disability that connect children with common illnesses. In addition, there are lots of wonderful books for children that reinforce the positives of being different.

### **How Can Parent Help the Child Deal with Teasing or Bullying?**

Children often tease if they feel threatened by or are misinformed about someone. They also feel stronger themselves if they can pick on someone who seems weaker or different in some way. Often they pick up this attitude at home. Strategies for dealing with confrontation include:

- Ignoring it
- Refusing to express distress
- Meeting it head on, looking the person in the eye and saying "I refuse to be treated like this," and forcing the confronter to respond
- Defusing the situation with humor
- If in a public place, simply walking away
- If there is threat of assault, alerting people nearby by yelling "fire!" which gets more attention than "help!"

### **How Do Parents Help Siblings Cope?**

When a child is disabled, it affects everyone in a family – parents, siblings, grandparents. Often, siblings get lost in the shuffle. All the attention is focused on the sick brother or sister. Everything seems to be about them: they get the visitors and the toys. Sometimes special occasions are forgotten when medical emergencies arise. All this can make siblings feel isolated and ignored. When parents are sad and frightened about a child, this can also affect the family dynamic.

Siblings may not get a chance to discuss their feelings and what they think about their sibling's illness. As a result, they may act out or be very dramatic (sometimes even faking illness or acting younger than they are, for example) to get their parent's attention. They can also be very emotional – angry, jealous, sad, fearful, guilty. There may also be some embarrassment when their peers start making comments about their sick sibling.

Studies show that without proper attention, these children are at increased risk of health problems, as well as psychosocial difficulties. They may suffer depression, anxiety, or other disorders. This can stem from the pressure of the uncertainty of the sibling's condition, the fact that life may be upside down, and the realization that responsibilities will increase in order to manage the household.

There are things that can be done however, and the good news is that sometimes illness brings families closer together. One key thing parents can do is explain to their other children the condition that the disabled child has and explain why it requires so much time away from home at appointments are in the hospital.

Parents should maintain structure at home, while also being flexible. They should be as organized as possible, and have a schedule so siblings know who is at the hospital and when, and who is fixing dinner, picking the kids up from school. Parents should strive to be flexible but strive to maintain a sense of balance in the family.

Parents should schedule special "family time" together and make a conscious effort not to focus on the sick child's condition during family time. They should communicate often and meaningfully to reinforce the family relationship. In terms of attention, the disabled child should be taught to share his toys with his siblings, and relatives should be asked to focus equally on all the children in the family.

Parents should try to be hopeful and encourage their kids to have positive thoughts. If they are old enough, they should be taught stress management. If a child really seems to not be coping well with their sibling's disability, get them some help by way of a counselor. This is particularly important if they are demonstrating destructive or self-destructive behaviors.

## How Can Parents and Siblings of a Child with a Disability Decrease Stress?

Parents of a chronically disabled child and the child's siblings need to learn how to lessen the stress they are feeling. The following are things that can be done to decrease stress:

1. **Do not ignore stress you are experiencing** – eliminate stressors, pay attention to stress and do not let it take control of you.
2. **Keep stressful situations in perspective** – look at the big picture, weigh the importance of a situation, do not over-react.
3. **Work at controlling your expectations** – keep expectations within reality, give up control of outcomes, do not look at things as black and white.
4. **Do not be a perfectionist** – learn to go with the flow, do not be so hard on yourself, and respect hard work even if it is not perfect.
5. **Develop problem solving skills** – look for ways to take control of problems, do not let problems run your life and learn to make decisions.
6. **Watch how you spend your time** – prioritize how you spend your time; use time to meet your needs and learn to say 'no'.
7. **Do not procrastinate** – letting things pile up just makes stress worse; do not waste energy worrying about something – just do it!
8. **Get organized** – set realistic goals for yourself and keep to them; disorganization wastes energy and time and increases stress.
9. **Learn to relax** – learn relaxation techniques and find time to be quiet and focus on yourself; find time to have fun.
10. **Get enough sleep or rest** – find ways to get help so you can sleep, take naps during the day to re-energize; fatigue decreases your ability to cope with stressful situations.
11. **Eat a healthy diet** – good nutrition will help you feel better and give you the energy to deal with the stress in your daily life.
12. **Get regular exercise** – exercise helps by increasing energy, allowing time to regenerate and helps clear the mind to make it easier to relax.
13. **Focus on the positive** – a negative attitude will only reinforce the stress and create a negative environment; focusing on the positive will help you see the good in things you may otherwise see as negative.
14. **Develop a support system** – you cannot do it alone; find friends, family or a support group of others dealing with similar issues.
15. **Keep a sense of humor** – everything is easier to handle with a good sense of humor and a laugh.