



# The Emotional Aspects of Having a Child With Disabilities

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**P**arents of children with special needs can find themselves on paths of many different emotions. Many parents talk about feeling great sorrow as well as great joy. These feelings can change who they are and their perspective on life.

I am a physical therapist, a teacher, and, most importantly, the mother of a child with cerebral palsy. I was a pediatric therapist and teacher long before my son was born. Having him has changed my life but ultimately for the better.

I have learned a lot through my experiences and those of other parents whom I have been blessed to know. I wish to share with you some of the things parents might go through. Each parent's experience is unique. As a unique person with a unique child, you might relate to some of this information.

Many parents describe their initial sense of being on a roller coaster. Their emotions move up and down quickly and unexpectedly, depending on how their child is doing. This is especially true of families whose babies have an extended stay in the hospital. There is a sense of being out of control. One minute the baby is doing well. The next minute, things are not going well. The parents feel helpless.

If a baby has to stay in the hospital, the parents become aware that there is a risk of later problems developing. In most cases, even when there is no extended hospitalization, it is the parent (usually the mother) who suspects something is wrong. She notices that her child is not doing the same things as other babies the same age. Or she might have had other children before and realizes that this baby is doing things differently. This is a very scary time. On the one hand, the parent has suspicions; on the other hand, she really doesn't want them confirmed.

When the doctors make a diagnosis, some parents go into shock. I remember going to have tests done on my son for a growth in his belly when he was about 3 weeks old. The doctor came out after the scan and said, "Well, when you're dealing with cancer..." I was devastated. The baby I had waited for so long had this terrible disease. I went into shock. I know that I continued to speak with the doctor and probably even appeared to be listening, but it was like being on automatic pilot. I didn't really hear anything more after the word *cancer*. In fact, I was so out of it that I couldn't even find the five-story garage where I had parked my car, much less find my car! I wandered around for quite a while.

Therapists and doctors wonder why parents don't listen to them. "Doesn't the parent know what's wrong with the child?" Well, if the information is new and emotionally upsetting, parents might not be able to listen because they have shut down inside.

After the diagnosis and the initial shock, parents might experience denial. Sometimes this takes the form of bargaining, thinking things like, "I can accept that my son has cerebral palsy if he walks funny, but please just let him walk." "I can deal with a physical disability, but don't let my daughter have any learning problems." These reactions are common and actually part of the normal process of acceptance.

Another form of denial is seeking other opinions. Some professionals criticize families who do this, but again it is part of the healing process. We might not be happy with the information we've been given, so we look for someone who will tell us that everything is okay.

Guilt is another common feeling that parents have. "Did I do everything I could?" "Did I do something wrong when I was pregnant?" "Could I have done something to prevent this from happening?" (My son's brain injury resulted when he stopped breathing after the surgery to remove his tumor.) We feel guilty over other things as well. Many parents say they feel that they aren't doing enough for their child, such as following the home therapy program more closely or spending more time with their child. They might feel guilty about the time they spend with their child with special needs, because they don't have enough time for their other children or their spouse.

Anger is another powerful emotion that parents sometimes experience. "Why me?" "Why my child?" We sometimes direct this anger at many people and in many places, even at those who are innocent bystanders! I took my son for professional photos when he was about 8 months old, and it didn't go very well. The photographer didn't know what to do with a baby this age who couldn't sit up or hold up his head. I decided to try again when he was about 12 months old. I went to the same studio for the appointment but was told that we weren't on the schedule. I became angry and fought with the woman at the counter, certain that I was right. I was furious. I got back into my car and cried. The anger I felt was strong, but was it really over a miscommunicated appointment time? No, my real issue was that nothing could be normal for me and my son, not even getting his picture taken.

Somehow, we need to help people understand that we are feeling great frustration and anger and are venting on whoever is in our path at that moment. Our anger is not really directed at that person whose words or actions are just "the straw that broke the camel's back." It might help to explain how we are feeling and ask the other person not to take it personally, but just to listen and be supportive.

Grief also is part of the process. We feel great sorrow about the loss of hopes and dreams that we had for this child. We feel sad when our child is sad. We also feel grief each time we receive a new piece of bad news. This can start the whole grieving process again.

We also might experience the loss of some friends. We might find that friends or family members withdraw because they don't know what to say or do, just like many situations in which people are diagnosed with cancer. This can be very hard for parents because it happens when we most need support.

Acceptance can be a long process but there are two parts to acceptance:

- Our acceptance of this child for who he or she is, because it is so important for us to bond with him or her, love that little person—that spirit that is our child—and build the parent-child relationship, which has a great effect on development.
- Our acceptance of the disability, which helps the child to accept and feel good about himself or herself.

For most parents, the acceptance of the disability takes much longer. Some parents say this will never happen completely for them. We need to realize that it's a different process for everyone. Parents come to terms with the disability in their own way and their own time. The *how* and the *when* are very individual. Remember that acceptance doesn't mean giving up hope.

Although all of these emotions sound hard, there also are many joyful moments and silver linings. The experience of living with your unique child can help put things into perspective. Parents come to realize what truly is important in life. We might be forced to slow down and take life one step at a time. We learn to appreciate the little things in life. Small steps become great joys. We find that we and others learn a lot about unconditional and pure love from our children. In fact, this particular child, no matter how disabled, can change the world and can affect the decisions others make just by being a part of their lives. For example, a cousin of such a child might decide to go into a medical field, a therapist might learn the meaning of patience, or a physician might learn about compassion. These are powerful lessons!

Therapists trained in Neuro-Developmental Treatment (NDT) have a principle that guides them in working with families. That principle is that parents and other family members are important team members. The parent is the expert in regard to the child.

Here are some suggestions that follow this basic principle and can help you through this life process:

- Live each day one at a time. Thinking too far into the future can be very frightening. It is impossible to predict anyone's future. No one knows for sure what any child's ultimate outcome will be. Enjoy your child today, in the moment.
- Ask your therapist to give you ideas for home activities that will help you bond with and enjoy your child as much as possible. Ask for this before you get a set of formal exercises. Do fun, playful things with your child. Don't do a home program when you or your child is not in the mood.
- Make friends with other families who have children with special needs, as well as families who have children without disabilities. Home visits from your therapist can be nice, but they are isolating. Go to the clinic for some of your therapy appointments. Ask your therapists for the names and phone numbers of other families in similar situations. There's nothing like having the support of friends who have been there and understand what you're going through. Create a network of other families for you and your family.
- When other people stare and ask questions, it's very tempting to get mad, but don't. It will be better if you stay relaxed and give a simple, matter-of-fact answer. My son had casts on his legs to stretch out his tight ankle muscles. People asked, "Oh dear, what happened? Did he break both of his legs?" I answered simply, "We're stretching out his muscles." That satisfied them. Everyone was happy. Don't feel that you must give a big explanation and the whole story. It isn't necessary. Now my son does the same thing. He's been asked, "What's wrong? Why do you have that walker?" He answers, "Nothing is wrong with me. I just have cerebral palsy, and I use my walker to walk." Bravo!
- Ask for and accept help. If you always seem to be the main person responsible for the child, ask your spouse to come to a medical appointment with you or to help by doing some of the home activities. Be specific and tell other members of your family exactly what you need. Sometimes a break is the best gift of all! Talk to your therapist about including your other children in therapy sessions. Therapists can design many home

programs to incorporate siblings. It doesn't always have to be you. Some of us are so used to doing everything! When strangers offer to help, accept it. For example, let them open the door for you or hold something while you're getting your child into the car.

- Surround yourself with team members who:
  - listen
  - are supportive, compassionate, and caring
  - don't pass judgment
  - answer your questions thoroughly and don't appear to be in a hurry
  - acknowledge you as the expert on your child
  - seem to look for opportunities to empower you
  - have a positive outlook for your child, believe in your child, and share your hope

When you ask a professional for an opinion, you should receive all the possible information. The professional should be honest and open without dashing your hopes. When you make your decision, the professional should respect you for making the decision that is best for your family and should support you even if you are not taking his or her advice. If that doesn't happen, you might want to look for someone else.

Have a sense of humor as you go on this journey. Humor can be very healing and healthy. Many times when we parents appear not to be doing well, it's because we are just trying to survive, doing the best we can at that moment. Be gentle with yourself and encourage others to do so. Be open to all of the possibilities that your unique child can bring to you and the world.

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*For more clarification of Neuro-Developmental Treatment (NDT) theory and how it influences therapy for children, see Article 1.2 by Judith Bierman, titled "Philosophy, Theory, and Principles: The What, Why, and How of NDT."*

A further note to parents:

Since I wrote this article I have had the lovely opportunity to share my story with many families in workshops, inservices & in my practice. Through my own continuing experience and through the words of other parents, I would like to add a bit more insight.

The article that you just read talks about the grief process & the road to acceptance. It can be a very challenging journey. However, especially if you are relatively new to this, I and other parents, want you to know that it is also a growth process. That growth can often lead to a new kind of inner joy.

Parents have described their growth in ways such as:

- the wisdom gained
- appreciation for the small things in life
- less materialism and more of what really matters
- the blessings that come with having a child with special needs instead of the burden
- a greater compassion for others
- finding out how strong one really is, and finding a voice
- the support of a community of other families, often leading to lifelong friendships with strong bonds

I hope this article and additional information brings to you a sense of peace and hope for the future. Our children often show us the most incredible unconditional love and joy despite their challenges. I am blessed by all the children and families that I have known, and I thank them for sharing their beautiful stories of resilience with me. I am forever grateful.