



# Complex Child E-Magazine

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## Acceptance is a Rollercoaster

by Susan Agrawal

You've probably read at one time or another how accepting your child with special needs is like going through the typical stages of grief, such as shock, denial, guilt, bargaining, anger, depression, and acceptance. While we can all identify with some of these emotions, acceptance really seems to be much more of a rollercoaster for many caregivers.

Acceptance, at least for most parents, is a never-ending journey. There is no obvious end-point as you would experience with death. Instead, it is a process, and one that is different for every individual. You may accept certain things about your child while still having difficulty with others. One day you may be angry and the next day hopeful. Acceptance is a rollercoaster, complete with slow ascents, rapid and frightening descents, days when you are barely hanging on upside down by a tiny little harness, and both thrilling and frightening loop-de-loops.

### **What is Acceptance?**

Before we tackle the importance of acceptance, it is imperative to state up front that there is no clear relationship between the love you have for your child and your ability to accept or not accept his special needs. Love does not necessarily require full acceptance. Nor does having hope for your child's future—even hope for a cure—mean that you do not accept your child as she is.

Some of the most loving parents I have ever met actually have the greatest difficulty accepting their children. In fact, in some cases, there seems to be a direct correlation between a mother who loves her child intensely and her refusal to accept his current condition. At the same time, other families fully accept their children and love them just as much, feeling no need to change their special needs. These are both variants of normal, and one is not necessarily any better than the other. Both are part of the acceptance process.

Similarly, there are no set time limits on acceptance. There is no grand plan that says you need to accept your child's physical disabilities by age one, her behavioral issues by age three, or her medical condition by age five. Some parents will reach a remarkable place of acceptance and hope very early on, while others take many years and may never get there completely. Other caregivers may reach a point of acceptance, only to be faced

with a new challenge or issue and regress back into denial or sadness. In general, most caregivers move toward a greater acceptance of their children over time, but there are definitely periods when we easily fall backwards.

While it is fine to be at any place along the steps to acceptance, I do think it is important to ultimately aim to accept your child and her disability or medical condition.

We all have known the mother who bankrupts her family, puts her child through unsafe or invasive medical procedures, and forces her child to endure torturous therapies, all in the name of making the child into a better person. This, obviously, is not good for the child, her family, or the parent. We also probably recognize the father who takes his child to ten different specialists a month in search of a cure, inadvertently denying the child any sort of normal quality of life. Then there is the grandparent who insists that praying all day long will bring about a miracle cure, and spends so much time praying that she does not bother to ever visit her grandson. And I am sure we have seen the caregiver who simply denies there is anything wrong, year after year, as her child suffers from a complete lack of treatment.

All of these caricatures are reflections of a parent's inability to accept a child's condition, and can actually be grievously harmful to the child in some cases. They are, of course, extreme cases, but most of us probably see at least a little bit of ourselves in some of those caricatures. We definitely need to take a look at ourselves and think about what is truly best for our child and family.

What actions are we taking simply because we cannot or will not reach a point of acceptance?

This is the main reason acceptance is important. True acceptance will allow you, your child, and your entire family to live happily and maximize the quality of your lives. True acceptance also allows you to make appropriate and rational decisions about your child's care without your emotions getting in the way. It permits you to enjoy your child as he is while still being hopeful or at least realistic about his future.

### **The Rollercoaster of Emotions toward Acceptance**

Beginning on the first day of diagnosis, and oftentimes even before, you will go through a million emotions. I'll cover some of the common ones below. Yours may be similar or completely different. You'll notice that there are often both positive and negative aspects of each emotion. At times, these emotions are a necessary and important part of your coping and acceptance process.

#### **Shock and Emotional Shut-down**

Shock and emotional shut-down is a really common early emotion for many parents of children with special needs. For me, it started the day my daughter was born, when we knew things were going to be rough, if she even survived. I remember everyone telling

me how calm and accepting I was of everything those first few days. In reality, the calm was nothing more than shock. I was so shocked at everything going around me that I reverted into a state of what appeared to be inner calmness, but was actually me shutting my emotions down out of necessity.

Others experience shock in different ways. Shock can often be thought of as a fog. You are still able to function and do what needs to be done, often quite proficiently, but you feel utter numbness as you go through your day.

Shock can actually be a really useful emotion at times. There will be days when you simply need to get all of your child's procedures done, and sometimes the only way to cope is to completely shut down your emotions. That's OK, as long as you don't get stuck there permanently.

### **Denial**

Denial is a big one for many parents of children with special needs. For me, denial started early, within my daughter's first few weeks. Every time my daughter would make any progress, even lifting her head just a little bit, the denial would kick back in and I would think to myself that she would be fine with a few years of therapy. As she got older, I accepted her physical limitations with ease, but often denied that she had any sort of cognitive impairment. While we still don't know the exact level of her cognitive abilities, she surely does have some limitations in this area.

It is very common to accept certain aspects of your child's condition while denying others. Some things you may accept very early on, while others may take years or even decades to fully accept.

Denial can also be a productive emotion at times. If we all just accepted our children unconditionally at birth, we would never provide them with therapy or medical treatments. Our denial may help us to push them a little bit more, maximizing their development and health. This is great, as long as you don't take it too far.

Denial, on the other hand, can also be toxic for your child. If you neglect to get your child therapy or medical treatment because you are too stuck in denial to reach out for help, your child may suffer terribly. Similarly, if you push your child excessively or force him into risky treatments, your child may be negatively affected.

### **Guilt**

Guilt is one of those emotions that tend to plague us quite a bit. We all have those thoughts, the "if only" thoughts, that certain actions might have made things different for our children. If only I had taken every last prenatal vitamin. If only I had not waited so long when I knew something was wrong.

Guilt can also take other forms. You may feel guilty for passing on a genetic disease to your child, even if you had no idea you were a carrier. You may think that your past

actions have caused the present situation. You may also feel like your child is a punishment for your own behavior.

Even worse is the guilt that others thrust upon you. I really did not feel any guilt regarding my daughter's condition until my in-laws accused me of causing her problems because the feng shui in my bedroom was not quite right. This was heartbreaking, as well as just plain crazy!

Sometimes guilt can make you change your life for the better, which will always affect your child. Guilt may help you to stop drinking or smoking, or to get in better shape. It may push you a little bit to get your child better therapies or treatments. But for the most part, guilt is not a productive emotion when it comes to caring for your child, because it ultimately makes you feel negative toward yourself.

### **Spiritual Matters, Bargaining, and "Why Me?"**

Bargaining was never an emotion I experienced on my process to acceptance, but it is definitely important for some people. Both bargaining and asking the inevitable "why me?" questions are closely linked to your spiritual beliefs and your feelings about God or forces in the universe. We are reaching out to a higher being, asking why he or she has created this situation, and asking what we can do to make it better.

Sometimes parents bargain with God that they will never again commit a certain sin if only God lets their child get better. Others take the opposite approach and question their religious beliefs, not believing that God would inflict the situation upon them. Still others punish themselves, imploring God with "why me" questions.

Remember that even the most pious, such as Mother Theresa, have questioned their faith at one time or another. This is natural. Your spiritual outlook will definitely be impacted by your child's condition. You may undergo a spiritual journey that will eventually make your beliefs stronger or even change them. This journey is clearly part of acceptance, learning how you and your child fit within your own spiritual realm.

### **Anger**

Anger is another emotion that probably all of us have experienced at one time or another. You may be angry with yourself, at God, your partner, or even your child. You may also be angry at the situation, your child's doctors, the insurance company, and pretty much everybody around you, including the mailman!

We all have anger from time to time, and in many cases, anger is an appropriate response to a given situation. What is important about anger is not that you are experiencing the emotion, but how you handle it.

I have never been a particularly angry person, and anger is not an emotion I experience all too much, with the exception of some appropriately placed emotions toward my in-laws and the insurance company. But I have seen other parents and my husband

experience feelings of anger and know they are a definite part of the healing and acceptance process for many people.

Anger is rarely a productive emotion. While it can spur you to get things done, the problem with anger is that it is usually inflicted on others around you. If you are angry and just hitting your pillow or writing out the things that make you angry, that is just fine, and a good way to get rid of the emotion. But if you are raging against your spouse, your doctors, your child, and everyone around you, ultimately you will only succeed in alienating yourself. This kind of anger is toxic.

We have all probably seen anger used effectively, such as when a mother gets her child in to see a specialist after screaming at the office staff, or when a father convinces the insurance company to cover a charge by yelling at them. While this may work to get what you want at times, eventually anger will come back and bite you. I have found again and again that being kind to others, treating them respectfully, and assuming their motives are positive will get me much further than lashing out, degrading, and criticizing everyone out of anger.

The thing about anger is that it needs to be targeted and handled appropriately. If you let it take over your life and you live in a constant state of anger, you will never be a happy person and your child will sense this. But if you can target your anger, expressing it in productive ways like writing, music, or other activities, you can rid it from your body and move on without blaming or torturing all the people around you.

### **Depression, Sadness, and Loneliness**

The emotions of depression, sadness, and loneliness can be common companions for many parents of children with special needs. We feel a great depth of emotion, especially when our children are suffering or struggling. Similarly, we may feel as if we are the only people fighting this battle, alone with our thoughts, and isolated from those around us.

It is fine to be sad. It is fine to cry. What is not fine is being stuck there, unable to climb your way out. Spiraling into that level of sadness can be devastating, not only for you, but also for your child. It can lead you to neglect yourself, your family, and even your child.

It is important to fight your way out, using whatever supports, including family, friends, and medical professionals, you need. Reach out to families in similar situations. Get out of the house. Focus on the positive aspects of your child and situation. Try writing, praying, or a support group. Pamper yourself with a hot bath or a day out alone. Find some respite care.

The realm of sadness or loneliness is a terrible place to be. But it is also an emotion that most all of us experience at one time or another. As long as it is temporary and you are able to get past it, sadness is fine and to be expected.

## **Achieving Acceptance**

There is no single path to acceptance, just as there is no time limit on acceptance. Acceptance may come and go. Acceptance may easily be achieved for some aspects of your child's condition, and nearly impossible for others. Some days it may be simple, while other days painfully difficult. That's all part of the rollercoaster ride that is parenting a child with special needs. Give yourself permission to experience the wide range of emotions that are inevitable through the acceptance process.

Acceptance is important, nonetheless. Children are extremely intuitive and can easily sense a parent's feelings toward them. How can you expect your child to develop self-esteem or handle teasing at school if she does not feel accepted by her own family?

If you are having difficulty achieving acceptance or struggling with serious emotions such as anger or depression, it may be time to reach out. Friends and family may be helpful. Online and local support groups can also help dramatically. Visit your doctor or a mental health professional if you need to. Feel free to take medication when appropriate. Spend some time relaxing and don't forget to take care of yourself.

It is wonderful to have a loving and fully accepting relationship with your child. Keep working through the process, and enjoy the rollercoaster ride.