



# Complex Child E-Magazine

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## Cultivating Relationships: Relating to Your "Typical" Friends

by Shannon Gonsalves

Relationships are fundamental for our emotional and physical well-being. This is especially true for parents who are raising a child with complex needs. Often, it is too easy to become isolated by the day-to-day struggles and parents need that connection with friends.

This is where it gets messy. How do you connect with others when their issues seem insignificant compared to what you're living with? How do you relate when parents are sweating the small stuff and you are up all night holding your child who is in pain? I am by no means an expert on this, nor do I think it is a simple answer. I am simply a mom who is working on herself and willing to share what has worked.

It starts with a commitment to challenge your own perspective of others and to cultivate relationships instead of letting them go.

### **The Emotional Roller Coaster**

We've all been here: a mom with a typically developing or healthy child dealing only with typical kid issues complains about something so insignificant that you can hardly respond. For me, I would go home and rant and rave about how they have no idea what "difficult" really is. Later, the guilt sets in for being angry over nothing and realizing it was really envy of how simple their lives seemed.

This roller coaster of emotions could be from simply watching a child meet milestones on time or listening to a mom rightfully share how proud she is of her child. A well-intended comment could be misconstrued as criticism or insensitivity.

I was going through life with a huge chip on my shoulder, but to be honest, it was more like a huge plank on my shoulder.

I didn't like who I was becoming. The cycle of anger and guilt had me feeling out of control, like being on a crazy, frightening roller coaster. I felt scared, worried, exhausted, and frustrated and began to isolate myself from others and pull back from friends who I didn't think I could relate to anymore.

## **An Amazing, Inspiring Woman**

It sounds almost trite to say that one person changed my life, but it's true. She inspired me to be a better person and to work through my emotions instead of staying on this roller coaster. K.J. didn't do this by spouting wisdom or telling me I was wrong. In fact, she has never come right out and told me that I was going about things the wrong way. Instead, she simply modeled what I wasn't capable of doing or understanding yet.

She lost her son at a very young age to cancer. In my mind, nothing could compare to the loss of a child or the very scary and serious surgeries and treatments that he had to endure. For four years, her son had the same feeding tube that my son was about to have placed.

During a casual discussion, she shared that she had experience with feeding tubes and offered to be there for me if I needed anything. As much as I appreciated the offer, I guarded what I would say and tried not to complain. She had been through so much more than I had.

By complete accident, I found myself complaining one day about how rough things were at home. Immediately, I felt awful for complaining about our situation when she had lost her son to cancer. I apologized and acknowledged that it was nothing like what she had experienced. How could I be so insensitive? Isn't this what angered me about other people?

I will never forget the conversation that followed. Mid-apology, she told me that she never wanted me to feel like I couldn't share what was going on in my life. My struggles were no less important than what she had gone through. She was very firm in telling me that everyone's issues are real and important in that moment and said it with such a reassuring smile. She truly meant what she was saying and didn't want me to feel insignificant or like I had to censor my conversations with her. I was amazed by this, but was so embarrassed that her message didn't quite sink in right away.

## **Perception is Vital**

It took me many weeks to really wrap my mind around our conversation, but I never forgot it. I began to realize that before my son, Caleb, was born with his complex issues, I felt frustration for my daughter's "typical" childhood struggles. There were many conversations with friends on the woes of teething, sleepless nights, nursing all the time and general baby crabbiness. Looking back, those complaints really don't hold a candle to all that many children with complex medical issues go through. However, it was an important part of our life, and in that moment, those issues were frustrating, difficult, and most importantly, they were real to us. I had forgotten this. I learned that comparisons aren't healthy.

My perspective is shifting once again. I have realized that in order to be in productive and healthy relationships, I need to be able to support my friends through any hiccups or hardships and not just when their lives are as hard as mine. Even more important is the realization that I need these connections with friends and family.

More and more, I started to pay attention to the people behind the stories on my parent support website, [www.parent-2-parent.com](http://www.parent-2-parent.com). I felt free to complain or celebrate there knowing that there are parents who are going through something similar and can relate. In the past, I thought it was great that we could even bash the parents who didn't have it as hard as we did. However, another shift occurred when I starting thinking about the fact that many of the parents there had life much harder than I did, yet they were always there for me without complaint.

I wanted--correction--*needed* to become a better friend. My perspective of what a friendship meant was shifting and I was quickly realizing that friendships must be cultivated or you lose them. Quality relationships take hard work and need on-going care.

### **Anger is Part of the Grieving Process (see addendum)**

In order to get to this point, I allowed myself to grieve for what could have, should have, and would have been if my son hadn't been born prematurely with his health problems. I used to think that "regular" families should feel grateful for what they have or felt that they needed to fix their thinking. Later, I realized that I was the one who needed the fix and that I needed to find things I was grateful for. Before I could do that, I acknowledged that it was okay to be angry without feeling guilt. I researched what the grieving process is to help me see that this is all natural and acceptable (see addendum at end of article).

Find an outlet for your anger, which will be different for every person. For me, it was joining an online support group. It was a safe place to whine, complain, rant, be angry, cry, or experience any emotion. Be honest with your friends instead of alienating them.

It is really important to get help if you need it. It is a challenge to know when you need help outside of your family. If your anger is getting in the way of relationships, it's becoming a problem. It's okay to talk to a religious leader, get counseling, join a support group, or include your spouse in these feelings. Most importantly, don't take it out on others in your life. It's the best thing you can do for your children.

### **Converting Negative Energy into Positive Actions**

The first step for me in changing how I interacted with friends and family was to turn negative energy into positive actions. Negative energy that isn't converted will eat at you and will alter your personality in negative ways.

This was and still is one of the hardest things that I did. I began to ask--yes ask--parents how their children were doing. I would force myself to say something kind when they shared celebrations or frustrations no matter how they responded. I'm being honest here; saying something kind was very forced at first. Over time and many opportunities to practice, it has become a very genuine thing and now I am truly interested in all of my friends' celebrations and frustrations.

Begin by really listening to your friends. When I really listened, I found that many of our conversations had comparison statements about our lives. Many times, the parents sharing would start out or end with saying something about how it's nothing like what I'm dealing with. When did that happen? When did I send the message that my issues were more important than theirs? These are people I care very deeply about and yet I had really no idea what was going on in their lives.

I started applying K.J.'s message to my conversations with friends. "Your issues are real and therefore important to me. You don't need to compare our children. They are all unique, wonderful, and frustrating gifts in their own ways. Please, never feel afraid to share what is going on in your life." It became my mantra.

Take a breath and assume that comments are well-intended before reacting or walking away hurt. Sometimes, I had to search for a positive message in a friend's comment instead of reacting with anger. If I couldn't immediately find the good intentions in the message, then I would actually ask for clarification rather than going home heavy with misunderstanding and hurt. I've found that by being open and assuming good intentions the insensitive comments are nonexistent. I'm not convinced that the comments aren't there, but more convinced that I'm not misinterpreting them or allowing them to bother me.

I also sought out situations where I could help or make a difference. It's one thing to want change, but another to put it in place. Change is an action-oriented word. Seek out opportunities to change. When a meal sign up sheet showed up in our staff lounge for a family in need, I signed up. A family member had a baby and I dropped off a meal for her. I tried to give back to my online support group of moms who had been so helpful to me by spending more time there supporting other moms. I even put myself out there and offered to be a host of some forums as a way of giving back and channeling that negative energy into something positive.

Basically, I didn't wait for opportunities to make a difference, but sought them out. I stayed very busy doing things for others even if it was difficult to fit it into my life. If you believe in the power of prayer, pray specifically that God will help you convert your negative energy into positive actions.

## **Expect Imperfection**

Please don't think that this makes me a saint, a perfect person, a "Pollyanna," or even the friend of the year! I am by no means perfect or even consistent in this process. This was a very self-serving plan that I desperately needed to follow to feel normal again. It was this or let the anger eat at me until I became a bitter person who couldn't function in any relationship, including the one with my husband. It turned out to be a mutually satisfying arrangement, but I went into it to heal me first.

There are many times that jealousy rears its ugly head and bites me in the behind. I am continually working on the process. However, working at this feels better than being angry and out of control. It is better for my soul and fits more closely with my own faith and beliefs.

In whatever method that you use to help yourself become a better friend or family member, allow yourself to be imperfect. Expect lapses in judgment and acceptance of those hiccups.

I still have my struggles with one particular topic: support and free time. My husband and I work opposite days of the week to provide care for our children, and it is very difficult to find someone who is willing to care for our son. Getting alone time with my daughter or reconnecting with my husband just doesn't happen. It's very easy to become jealous of parents who can drop their children off with grandparents and get away for dates or trips together. I am working on changing me yet again, but this one has been slow and definitely imperfect!

My work on me isn't done. I know that I need to be less jealous of moms who go on dates with their husbands or sleep most nights straight through without pump alarms going off or having to jump out of bed to sit up a choking/vomiting child. It is a different life that I live, but I can still support my friends through their struggles with much less pain than before. I have reconnected with friends, and I've gotten off the roller coaster.

## **The Grieving Process for Families with Children with Complex Needs**

There is a lot of research out there about how parents of children with complex needs will go through a grieving process very similar to the process you go through when you lose a family member.

I read a wonderful article written by Dr. Marlene Williams, PhD, at BYU, titled “Raising a Child with a Disability,” which helped me to understand that what I was going through was normal and to be expected.<sup>1</sup> In this article, she said it very well: “Adjusting to having a child with a disability is a process. It is not an event.” This is one of many articles you can find online with a similar message that you will go through a grieving process when your child has complex needs.

She has adapted the stages of grieving to more appropriately fit the process of adjusting your life to living with a child with complex needs. Being aware that there was a process that I was going through and seeing what I could do to progress through this process, helped me to become a better person and friend.

This is a little bit of what I learned from six of the stages of adjusting to having a child with complex medical needs.

### **1. Shock**

- Emotion: It is very scary and shocking to learn that your child’s life won’t be as you expected.
- Response: To help, begin researching your child’s situation. Seek answers!

### **2. Denial**

- Emotion: Feeling out of control, unprepared, overwhelmed, afraid and worried can all result in denial.
- Response: Continue seeking answers and information.

### **3. Anxiety**

- Emotion: Anxiety is the body’s way of responding to fear and mobilizing resources.
- Response: Her advice here was critical for me: seek out relationships and support with other parents who are living this life. Take care of yourself when you are feeling anxious. Look into respite care.

### **4. Guilt**

- Emotion: Moms are particularly good at this one! We blame ourselves pretty quickly and easily.
- Response: Sometimes, the guilt happens from unintended hurtful comments from others. Assume that all comments have good intentions until that person proves otherwise.

### **5. Depression and Grief**

- Emotion: Yes, your child is still alive, but it is okay to feel loss for the hopes and dreams that you had for your child and family.

- ❑ Response: Allow yourself to cry, grieve, rant, rave, be angry, pray, whatever you need to do to cleanse your mind, body and soul.

6. **Anger**

- ❑ Emotion: Your child struggling with his/her own situation isn't fair or just. It makes you angry! Life is not fair and fair isn't equal treatment.
- ❑ Response: Decide how you are going to show anger in a constructive way. Retaliation doesn't change the situation to a more fair or just situation. Search for your peace as you go through this process.

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<sup>1</sup> Williams, Marlene. "Raising a Child with a Disability."  
<http://ce.byu.edu/cw/fuf/archives/2001/WilliamsMarlene.pdf>