

Chapter 2

Visit 1: Part 2

After the Diagnosis: Grief, Guilt, Hope, and Action

A Profound Sadness

I turn off the tape recording of our session and give the Grants time to feel. Another wave of sadness wells up for Judy and she begins to tear up again. Jim scoots his chair close to hers and gently holds her hand. I offer another tissue and need one myself. We sit there together in a long, sad silence. I have done this too many times to count and it never gets easier.

Charlie, sensing the tension in the room, toddles over to his mom who lifts him into her lap, gives him a sippy cup and he sips away contentedly. Jacob entertains himself with the toys and seems oblivious to all the feelings going on in the room.

Mom (recovering a little): “I’m sorry Dr. Solomon. I just feel so sad for Jacob. He doesn’t deserve this.”

Me: “You have nothing to be sorry about, Julie. It’s so important to feel your feelings. And it *doesn’t* seem fair.”

Dad: “I have to admit I didn’t see it at first but Julie kept telling me: *Something is wrong, something is wrong.*”

Me: “Even when parents suspect the diagnosis, it’s still so hard to hear. No parent wants to hear that *anything* could be wrong with their child let alone a diagnosis of autism. That’s what denial is all about, protecting your heart.”

Dad: “I still don’t want to believe it.”

Me: “That’s what grief is—the sadness you feel when you stop denying and start accepting that your child has a condition. In other words, in order to accept your child for who he or she is you must grieve. And don’t get me wrong. I know you *love* your child but love is different than accepting their condition. *First you must grieve for the loss of the child you expected and then fall in love with the child you have.*”

The Grieving Process

These feelings of profound sadness are the immediate reaction to a grieving process that will go through many phases over time. Good grieving begins a healing process that leads to action and acceptance. Pathologic grieving including not grieving—called denial—can lead to inaction with calamitous results for the child and family.

Denial. Forms of *denial* include angry or defensive thoughts like: ‘Solomon doesn’t know what he’s talking about.’ Shock: ‘I don’t believe it. It’s not really autism. We need to get a second opinion.’ Rationalization: ‘I didn’t talk until I was four and I turned out all right.’ Straight denial: ‘There’s nothing wrong. He’ll be fine; he’ll outgrow it.’

There are two big risks to denial. The first is that it divides spouses. One spouse *knows* something is wrong and the other *denies* that there is a problem. The one who ‘knows’ feels isolated, not ‘heard’. This causes a rift in the marriage and if it continues for a long time, the rift can lead to estrangement and ultimately even to separation and divorce.

The second danger here of course is that denial leads to waiting and waiting leads to a delay in intervention at a critical time in the child's life. *I warn parents that there is a worse feeling than grief and that is the guilt of looking back on what you should have done.* I have some parents who waited years before they could accept the diagnosis of autism. By then precious time had been lost for effective early intervention.

Depression. On the other hand, being overwhelmed by feelings of grief is not good either. The reason for denying feelings is that these feelings are so *painful*. And some psychological self-protection is necessary. If you feel too much you can become overwhelmed with feelings, become seriously depressed, and not function to help your child.

I have some parents who just can't let the grief out. They hide the diagnosis from the grandparents and close friends. They feel upset when their child shows 'autistic' behavior in public (e.g. hand flapping) so they avoid going out. They won't talk about their feelings with their spouse and cry in isolation. They put on a stoic face and act as if everything is OK but, inside, they feel miserable. I advise parents who are overwhelmed with such grief, anger, and/or upset to get counseling and work through their feelings so they can get closer to *acceptance*.

Acceptance. The ultimate goal of grieving, according to Elizabeth Kubler-Ross, the famous grief researcher, is 'acceptance'. When parents begin to accept their child for *exactly* who he or she is, then paradoxically, this is the fastest and best way to help their child become what the parents want them to be—a functioning member of society. This cannot happen if there is too much denial or too much sadness.

My initial goal, then, is to help the family accept their child's condition in order to engage the child in interactions that are fun. This will make the child truly happy. It is my opinion that happiness, while related to success, is more important than 'success' especially early on and especially for children with autism. Playing and having fun is more important than teaching and learning. Fun, play-based social interactions lead to emotional intelligence, EQ. And EQ is more predictive of societal success than IQ. So my formula is this: acceptance leads to better interactions and more fun with people. Fun with people leads to happiness, functional skills, and emotional intelligence. Emotional intelligence leads to success.

Action. In my experience usually one parent is more feeling oriented (often the mother but not necessarily) and one parent is more action oriented and wants to get going. One parent might feel too sad and not ready to act, making the action oriented parent angry. It's important to acknowledge all feelings that come up and hold/support/love the one who feel sadness. On the other hand, it is important to realize that an action orientation is very helpful for the family to cope with the grief process. It's important not to be immobilized. *Feel your sadness but act. Act but feel your sadness.*

Finally, some parents are actually *relieved* to get the diagnosis. They *knew* something was wrong and they wanted to be confirmed. By the time they see me they've already done a lot of grieving and are past the deep initial sadness and just want to get going.

Guilt. Jim Grant was ready to get going but Julie still had one more set of feelings to work through. . .

Dad: “So what do we do next? (Getting emotional, his voice rising) Dr. Solomon, is Jaky going to be one of those kids who grows off the spectrum? Will he go to regular kindergarten? Will he. . .”

Me: “. . .get married, be happy? You’re such a dad! (We all laugh which breaks the tension.) I have high hopes for Jacob too dad. He’s got a lot of good prognostic signs. Given my experience with so many kids like Jacob I would be surprised if he didn’t do well. But it’s going to be a long road ahead.”

Mom: “I can’t even go there yet. I’m sorry Dr. Solomon but I feel like maybe we should have brought Jacob in sooner. Are you sure we didn’t do anything to cause this? He got the symptoms after I got him his shots. Is that what caused his autism?”

Me (lifting the tape recorder): “OK if I start taping again? (They nod.) I want you to hear this. Erma Bombach, the comedian, once said: ‘Guilt is the gift that keeps on giving.’ (We all laugh.) and I hear lots of guilt in your questions.”

Mom: “I had a feeling that something was wrong with Jacob’s development a lot earlier. I should have trusted myself.”

Me: “As far as bringing Jacob in sooner, sure you could have, but you got him in before the age of three, which is good. We have a lot time to work with him. Besides, you have to depend on your pediatric professionals to guide you and they weren’t worried until Jacob was over two so don’t blame yourself?”

Dad: “What about the shots?”

Me: “The MMR immunization is given around 15 months and autism’s first symptoms usually begin between 15 to 18 months. It’s the difference between *cause* and *coincidence*. In this case it’s coincidence, not cause. There are now over 20 articles that clearly indicate that immunizations do NOT cause autism. And, there are no articles to the contrary.” (see *Links: Autism is Not Caused by Immunizations*)

Mom: “And you’re sure it’s nothing I did during pregnancy?”

Me (Half jokingly): “Look me in the eyes Julie. (She looks.) I’m sure.”

Dad: “And my folks were blaming daycare because every time they went to pick Jacob up, he was playing alone. My mom said the day care ‘neglected Jacob’ and that’s why he was behind.”

Mom: “That’s why I stopped working; to be home more with Jacob.”

Me: “Being home for Jacob is a good thing as you’ll see when we talk about intervention but it wasn’t daycare that caused Jacob’s autism and it’s not related to parenting. (I raise my voice and speak loudly into the tape recorder.) *Listen to me you guys. I hereby relieve you of all guilt!*” (We all have a good laugh.)

Like the Grant family, most families worry that they caused the autism. Often I have to repeatedly reassure the parents that autism is not their fault. Sure, there are risk factors (see Chapter 1) but it’s worth mentioning again that autism spectrum disorders (ASD) are not caused by neglect or family conflicts; not caused by something moms ate or did during pregnancy (though certain medications that a pregnant woman takes can increase the risk of autism). All forms of autism are largely genetic conditions, out of parents’ control, that cause neurological changes in the brain.

Dad: “What am I going to tell my folks? They’re old school and say *He’s just a boy and he’ll grow out of it.*”

Me: I would tell them that you need them to ‘hear’ you. Use guilt! Tell them that if they don’t accept the diagnosis you won’t be able to talk to them about your feelings. Tell them you love them and want to share your life with them.”

Mom (toward Jim with an accusatory tone in her voice): “They’re one of the main reasons we didn’t get in sooner.”

Me: “Mom, let it go.”

Mom: “I’m sorry Dr. Solomon but they are in denial. And they do a lot of babysitting for the boys.”

Me: “How are *your* folks about this, mom?”

Mom: “My mom and dad are more on the same page but they live farther away.”

Me: “Well, we’ll have to bring Grandma and Grandpa Grant along. (Into the tape) It’s very important that all close family members are on the same page about the diagnosis and the intervention plan.”

Julie Grant smiled.

Extended Family

Early in the diagnostic process, it's very important for both parents *and* extended family to understand what autism is and to accept that the child has this condition. Sometimes grandparents add to the denial and guilt because they too would be so sad and overwhelmed if they let the diagnosis in. But not to accept the diagnosis is to deny what parents know and feel and this can really tear families apart. It is so important to support each other during this period of finding your way to acceptance.

Hope

Though grief must run its course, hope will shorten the distance it has to run. And for all my families I can offer true hope. Children with autism can make remarkable improvements in their development. I have seen so many children get better from intensive intervention that I can be honestly optimistic. Even the most severely affected children make progress with appropriate intervention. Hope leads to action.

Dad: “So what do we do next?”

Me: “Let’s talk about that. . .”

Summary:

- I list the basic reactions to the diagnosis of autism: sadness, grief, denial, guilt, and acceptance.
- The importance that all family members accept the accuracy of the diagnosis.
- ‘We must mourn the loss of the child we wished for; and fall in love with the child we have.’
- Acceptance leads to better interactions and more fun with people. Fun with people leads to happiness and emotional intelligence. Emotional intelligence leads to success.

Coming Up Next:

We'll get The Grant family on the road to hope by talking about the definition of 'intensive intervention', which therapies NOT to do, and intervention programs that work.