

# Putting the Pieces Together

By Sue Sokoff

In the initial days and weeks after your child has been diagnosed with ASD, you may experience:

## **SHOCK**

- You may feel like you are going through the motions of everyday living, but may feel numb or unable to focus on daily tasks.

Some parents say getting the diagnosis of autism feels like getting hit with a hammer. The initial shock will subside. This is the time to reach out and connect with family and friends who are supportive and care.

## **DENIAL**

- You may believe your child will grow out of the symptoms or that it really isn't autism.

You may want to get a second opinion or try to convince yourself that somehow the experts got it wrong. By all means, get a second opinion if you do not believe the initial diagnosis is correct. If the diagnosis is correct, remember, living with autism means change and adjustment, but it is not the end of the world.

## **FEAR AND ANXIETY**

- You may experience the fear of an uncertain future and the unknown. "How can I parent a child with autism? I don't even know what autism is."

Empower yourself by finding out all you can about autism. Do your homework by researching credible studies. Thousands of others have been where you are. Tap into your natural resources; get involved in a support group, talk to other parents, find out what kinds of support are available in your community. Becoming an expert on autism will minimize your fears and anxiety.

## **ISOLATION**

- You may feel isolated because it may take some time for your friends and extended family members to learn how to offer support. They may not understand what your family is going through initially.

Although parenting a child with autism requires much time and energy, fight the isolation at all cost! While friends and family members may not understand why you can't do what you used to, you must keep them as a priority. They are your best resource. Learn to build autism into your family rather than build your family around autism.

## **HOPELESSNESS**

- You may wonder if researchers will ever find a cure for autism.

The medical community is becoming more aware of autism with each passing year. As a result, more research and funding allocated towards finding the cause of autism are available. Early interventions for autism can help a great deal. With increased awareness comes more hope for a cure. Choose to be hopeful!

## **FRUSTRATION**

- You may feel frustrated while trying to gain access to community services, respite, and during various transitions in your child's life.

While we are aware of the need for increased services, funding for ASD and other developmental disorders is not a priority for some lawmakers. Learn what resources are available through the state and take the steps to begin the process of accessing what is available.

## **STRESS**

- Moms, Dads, and siblings must learn new ways of interacting and working together to help your child with autism. Both parents may not be able to hold jobs outside the home. The financial strain on the family can compound the stress.

Financial planning is important. There are financial services that can provide sound advice and relief to parents. Honest communication about autism and how it affects your family is also important. Sometimes seeking professional help can assist with learning how to better communicate as a family. Be ready to laugh when the opportunity presents itself. In time you will find that funny things happen all around you, and while autism is not funny, it does help to be open to the other parts of life and focus on the positives.

## OVERWHELMED

- The physical, emotional, and spiritual toll on the family can leave all members feeling overwhelmed and exhausted. Some sources cite that 80-90% of families affected by autism experience divorce.

When your relationships become strained, make time for breaks so you can get away and nurture them. If you have family members or close friends that can help, don't be afraid to ask. You can't be everything for everybody. Caring for a child with autism is important, but caring for yourself is crucial to being able to care for your child. Also, try to focus on what is most important in your life. Not sweating the small stuff can help buffer feeling overwhelmed.

## ANGER

- You may feel anger towards people in the community because of attitudes and negative behaviors shown towards your child. Remember these people are often uneducated or insensitive to the unbelievable challenges your family faces.

Anger is a problem solving emotion. It can propel you to take action and become a proponent for your child. Journal each *miracle in the moment* as your child makes advances. You will find that anger quickly turns into positive energy focused on educating and advocating for your child.

## SADNESS OR LOSS

- You may feel sadness if parents of children without autism openly compare their child to your child. The unfair comparison is a reminder of your child's limitations.

Grieving is necessary to move forward. There will be times when others seem cruel or indifferent to your situation. The sense of loss you may feel, now, will eventually turn into a celebration of your child and will help your whole family become more sensitive to the fact that *everyone* is unique.

## GUILT

- You may wonder if you are to blame for your child's autism. You may ask yourself over and over, "What did I do that caused my child to be autistic?" or "Why did I not seek help sooner?"

There are some things in life that we have no control over, and autism is one of those things. You are not a bad parent! You may not understand all the reasons

why your child has autism, but ASD is not something you could have foreseen or prevented.

You may experience some or all of these emotions at some point. Emotions are complex and multi-layered. These are just a few samples of how these emotions have evolved in the lives of parents touched by autism. Be assured these feelings are all very normal! And while there may be times when you feel overwhelmed with life's competing pressures, you do not have to face them alone. There is a wealth of resources available with the single purpose of helping you. Being empowered with knowledge about autism and how other parents cope is a key to developing a more positive outlook about the future.

*Hope is the bedrock  
belief  
that the pieces will  
all  
eventually fit  
without force or struggle  
and the result  
will  
become something  
beautifully whole  
and good*