

## The Parent Journey: Post Diagnosis:

### Dealing with the diagnosis?

It's not easy to hear the news that your child has autism, and realise that your life will be utterly different from that day forward. Daily life with a special-needs child presents many unique challenges. How do you come to terms with the fact that your child has autism? How do you cope once you get over the initial phase after diagnosis?

You are never prepared for a diagnosis of autism. It is likely that you will experience a range of emotions. It is painful to love so much but you must take a practical approach as you would in overcoming other challenges in your life although you may feel some of the stages commonly associated with grieving. You may "revisit" these feelings from time to time in the future. Part of moving forward, is dealing with your own needs and emotions along the way.

### Shock:

Immediately after the diagnosis you may feel stunned or confused. The reality of the diagnosis may be so overwhelming that you're not ready to accept it or you initially ignore it. You may also question the diagnosis or search for another doctor who will tell you something different.

### Sadness:

Many parents must mourn some of the hopes and dreams they held for their child before they can move on. There will probably be many times when you feel extremely sad. Friends may refer to this as being "depressed," which can sound frightening. There is, however, a difference between sadness and depression. Depression often stands in the way of moving forward. Allowing yourself to feel sadness can help you grow. You have every right to feel sad and to express it in ways that are comfortable. Crying can help release some of the tension that builds up when you try to hold in sadness. A good cry can get you over one hurdle and help you face the next challenge.

### Anger:

With time, your sadness may give way to anger. Although anger is a natural part of the process, you may find that it's directed at those closest to you – your child, your spouse, your friend or at the world in general. You may also feel resentment toward parents of typical children. Your anger may come out in different ways – snapping at people, overreacting at small things, even screaming and

yelling. Anger is normal. It is a healthy and expected reaction to feelings of loss and stress that come with this diagnosis. Expressing your anger releases tension. It's an attempt to tell the people around you that you hurt, that you are outraged that this diagnosis has happened to your child.

### **Denial:**

You may go through periods of refusing to believe what is happening to your child. You don't consciously choose this reaction; like anger, it just happens. During this time, you may not be able to hear the facts as they related to your child's diagnosis. Don't be critical of yourself for reacting this way. Denial is a way of coping. It may be what gets you through a particularly difficult period. You must, however, be aware of that you may be experiencing denial so that it doesn't cause you to lose focus on your child's treatment.

Try not to "shoot the messenger." When someone, a professional, a therapist or a teacher, tells you something that is hard to hear about your child, consider that they are trying to help you so that you can address the problem. It is important not to alienate people who can give you helpful feedback and monitoring of your child's progress. Whether you agree or not, try to thank them for the information. If you are upset, try considering their information when you have had a chance to calm down.

### **Loneliness:**

You may feel isolated and lonely. These feelings may have many causes. Loneliness may also come from the fact that in your new situation you simply don't feel you have the time to contact friends or family for company or that, if you did reach out, they wouldn't understand or be supportive. In the items that follow, we have some suggestions for taking care of yourself and for getting the support you need.

### **Acceptance:**

Ultimately, you may feel a sense of acceptance. It's helpful to distinguish between accepting that your child has been diagnosed with autism and accepting autism. Accepting the diagnosis simply means that you are ready to advocate for your child. The period following an autism diagnosis can be very challenging, even for the most harmonious families. Although the child affected by autism may never experience the negative emotions associated with the diagnosis, parents, siblings and extended family members may each process the diagnosis in different ways, and at different rates.

## Dealing with the Judgements of Others:

The parents of children with autism find the negative judgements of others to be extremely hurtful and upsetting. All parents with autism have or will experience situations where their child has displayed challenging behaviours or had an emotional meltdown in a public place like the supermarket or school yard. As a parent you are extremely vulnerable to the reactions and comments of others and these remarks can arrive when you are already struggling to cope with your child's issue at that time. A simple look of disdain or throwaway comment from another person can be extremely hurtful and further undermine your feelings of self esteem and self worth as a parent. In these situations it's best to focus exclusively on your child and try to block out everything else.

## Ongoing Issues: (As identified by the parents of children with autism)

### Physical Exhaustion:

1. Sleep deprivation (exhaustion, irritability)
2. Physical assaults - challenging behaviours.
3. Physical symptoms of anxiety & stress (panic attacks, palpitations)
4. Constant vigilance (state of alert) to ensure the child's safety (anxiety).
5. Performance issues in the workplace (absence).

### Mental Exhaustion:

Stress, anxiety, low self esteem, impact on family functioning and relationships

### Stressors:

1. Challenging behaviours & Self Injurious behaviours.
2. Judgements of others - negative reactions of others.
3. Education – negative feedback, behavioural issues, suspension, exclusion.
4. Ongoing impact on family functioning
5. Lack of quality parenting time with other children.
6. Guilt - self, child with autism, siblings.
7. Lack of state support and services.
8. Delays in accessing services and interventions.
9. Perceived stigma of having a special needs child.
10. Social exclusion – Child – exclusion from social events, parties etc.
11. Social isolation – Parents – self exclusion based on the needs of the child.
12. Seeing no end in sight – lack of support & respite services.

13. Financial pressures associated with funding private therapeutic interventions.
14. Relationship difficulties – spouse, partner, family and friends.
15. Planning for the future – education and adult services, financial security.
16. What happens when I'm gone – life without the parent.

### **Practical challenges faced by the parents of children with ASD:**

1. Stress pre-diagnosis: Constant worry, researching online to compare the symptoms the child is demonstrating to symptoms of autism.
2. Waiting times for a diagnosis are very long with waiting times of 18 months to 2 years. Services are only available to children who have a diagnosis of autism.
3. Many parents feel pressured to take the private diagnostic route and this can put financial strain on parents that are already worried and under pressure.
4. Having received the diagnosis waiting times for services are again very lengthy. Services are also very sporadic which leads some parents paying for private intervention such as occupational therapy, speech and language therapy and physiotherapy. Those who cannot afford to pay for such services often feel guilty as they cannot provide crucial intervention for their child.
5. Trying to find a suitable education placement, be it in an early intervention centre or with a home tutor is again very stressful as there simply are not enough places available.
6. The affect on the family can be enormous. Shock, confusion, anger, sadness, feeling of being overwhelmed and loneliness are all common emotions that are experienced by the parents and wider family members of the child with autism.
7. Relationships often struggle or break down. Tensions within the wider family.
8. Siblings can often feel helpless as they are not fully aware of what is going on and they may suffer from deferred anger from parents. Siblings often feel left out as all of the focus is on the child with ASD.
9. Lack of respite and support services.
10. Parents are very often left in a very negative state of mind following a diagnosis. The clinical diagnosis focuses on disability and not the ability of the child.