

## Receiving an Autism Diagnosis: (Ireland)

### 1. Pre- diagnosis:

Arguably the most traumatic time associated with Autism is the initial diagnosis. The period before diagnosis can be extremely stressful as you worry constantly if your child has autism. Most parents would have been on the internet checking for the signs and markers for autism and then comparing their child's behaviours for similarities. This is useful to a point but to get a confirmed diagnosis of autism you need to get a professional assessment. Generally, parents with concerns about their child's condition are referred by their GP or Paediatrician or to their local Autism Service Provider for an assessment. The majority of Service Providers have a waiting list so in some areas of the country it can take up to a year or more for the diagnostic process to begin. Normally you will be added to a waiting list. The assessment team will normally comprise of some or all of the following professionals – Speech & Language Therapist, Psychologist, Occupational Therapist and a Social Worker.

Due to the waiting times and the importance of the Early Intervention window for young children some parents who are not prepared to wait for long periods of time for a diagnosis choose the private route. A private registered Psychiatrist or Psychologist can diagnose autism but this route is expensive and you should always agree a full cost for the diagnosis prior to proceeding. If a child is already in the educational system a confirmed diagnosis of autism will allow you to access resource teaching hours and apply for an SNA (Special Needs Assistant) if one is required. A private diagnosis will also allow the parent(s) of the child to apply for such allowances as Domiciliary Care Allowance, Carers Allowance and the Incapacitated Child Tax Credit.

It is important to check that the private diagnosing professional is recognised by the HSE and other overlapping Government Departments so that you can begin to access services such as an appropriate educational placement or the Home Tuition Grant from the Department of Education. Even if you have a private diagnosis you will still need to be seen, assessed and diagnosed by the state service provider. The reason for this is that normally the service provider will provide the services such as speech & language therapy and occupational therapy for your child post diagnosis. Again there is normally a waiting list for these services. Once you have received a confirmed diagnosis of autism things will change on a practical level as well, your child now needs additional help so you need to focus on getting that help as quickly as possible.

## **2. Post - diagnosis:**

### **Initial affects on family:**

Suddenly, with a confirmed diagnosis of autism, everything changes. Parents and family members can react differently to the diagnosis. Some may start a grieving process while the other may go through an angry phase or non acceptance that their child has autism. This can create tension within the home so it's important that the issue is discussed as openly as possible and that you focus on the child's needs. If you need additional help in coping with the diagnosis in the early stages it is important that you get it as quickly as possible. There are many autism support groups throughout the country and it can help to talk to other parents who are a little further down the road than you are. There are professional councilors who can help you to deal with the issues that you are facing and assist you in navigating what is a very emotional time. We at Shine will be happy to help or put you in touch with a support group in your area.

### **Impact on Siblings:**

A diagnosis of Autism can have a huge affect on siblings also. The main focus at home, following a diagnosis, is the child with Autism and this can create a "left out" feeling for brothers and sisters. It is understandable that once a diagnosis is received families tend to spend most of their time and energy trying to deal with this issue. However, this can affect the family unit, particularly other siblings so try where possible to address this issue. Make time for your other children where it is your "special time" together. Older children and adolescents are very tuned in to what is happening in the home and can be equally affected by their sibling's diagnosis. It is important that they understand what is happening and often a simple brief explanation of their brother/sister's diagnosis of autism will help them deal with the upheaval in the home. If possible involve them in helping in some way (tidying up toys or playing with their sibling) so that they feel that they are making a positive contribution. Do not focus your anger and frustration on your other children as they can often suffer from deferred anger from parents who are tired and struggling emotionally.

### **Say the "A" Word:**

Autism affects an entire family and once an initial diagnosis is received, it is recommended to speak to somebody who has been through this situation. It's important that you talk to somebody just to say the words out loud and speak to somebody you are comfortable with a family member, a friend, a professional councillor.

### **How will I deal with this diagnosis?**

It's not easy to hear the news that your child has autism, and realise that your life will be utterly different than you had expected it to be. 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, to want something so much but you must take a practical approach as you would in overcoming other challenges in your life. You want your child to get better so much 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.

### **3. Emotions post diagnosis:**

#### **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.

#### **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.

#### 4. Some practical steps you can take:

##### **Give yourself time to adjust:**

Be patient with yourself. It will take some time to understand your child's diagnosis and the impact it has on you and your family. Difficult emotions may resurface from time to time. There may be times when you feel helpless and angry that autism has resulted in a life that is much different than you had planned. But you will also experience feelings of hope as your child begins to make progress.

Caring for the Caregiver:

Changing the course of your child's life with autism can be a very rewarding experience. You are making an enormous difference in his or her life. To make it happen, you need to take care of yourself. Take a moment to answer these questions: Where does your support and strength come from? How are you really doing? Do you need complain to someone? Scream? Would you like some help but don't know who to ask?

"Remember that if you want to take the best possible care of your child, you must first take the best possible care of yourself."

Parents often fail to evaluate their own sources of strength, coping skills, or emotional attitudes. You may be so busy meeting the needs of your child that you don't allow yourself time to relax or simply think. You may wait until you are so exhausted or stressed out that you can barely carry on before you consider your own needs. Reaching this point is bad for you and for your family. You may feel that your child needs you right now, more than ever. A "to do" list may be what is driving you forward right now. Or, you may feel completely overwhelmed and not know where to start.

There is no single way to cope. Each family is unique and deals with stressful situations differently. Getting your child started in treatment will help you feel better. Acknowledging the emotional impact of autism and taking care of yourself during this stressful period will help prepare you for the challenges ahead. Autism is a pervasive, multi-faceted disorder. It will not only change the way that you look at your child, it will change the way you look at the world. As some parents may tell you, you may be a better person for it. The love and hope that you have for your child is probably stronger than you realise.

## **5. Some tips from parents who have experienced what you are going through:**

### **Get Going:**

Getting your child started in treatment will help. There are many details you will be managing in an intensive treatment program, especially if it is based in your home. If you know your child is engaged in meaningful activities, you will be more able to focus on moving forward. It may also free up some of your time so you can educate yourself, advocate for your child, and take care of yourself so that you can keep going.

### **Ask for Help:**

Asking for help can be very difficult, especially at first. Don't hesitate to use whatever support is available to you.

### **Talk to Someone:**

Everyone needs someone to talk to. Let someone know what you are going through and how you feel. Someone who just listens can be a great source of strength. If you can't get out of the house, use the phone to call a friend, support line or other services.

### **Consider joining a Support Group:**

It may be helpful to listen or talk to people who have been or are going through a similar experience. Support groups can be great sources for information about what services are available in your area and who provides them. You may find you aren't a "support group kind of person." For many parents in your situation, support groups provide valuable hope, comfort and encouragement.

"At my support group I met a group of people who were juggling the same things I am. It felt so good not to feel like I was from another planet!"

### **Try to take a break:**

If you can, allow yourself to take some time away, even if it is only a few minutes to take a walk. If it's possible, go out or visiting a friend, it can make a world of difference to normalise your life for a few hours.

If you feel guilty about taking a break, try to remind yourself that it will help you to be renewed for the things you need to do when you get back. Consider keeping a journal as it allows you to get your thoughts down on paper. Some parents have found journaling a helpful tool for keeping track of their children's progress, what's working and what isn't. You can also log your emotions and how you feel at the time of writing, this can act as a release as you have cleared your mind and can refocus on the task in hand.

### **Be mindful of the time you spend online:**

The Internet will be one of the most important tools you have for learning what you need to know about autism and how to help your child. Unfortunately, there is more information on the web than any of us have time to read in a lifetime. There may also be a lot of misinformation. Right now, while you are trying to make the most of every minute, keep an eye on the clock and frequently ask yourself these important questions:

- Is what I'm reading right now very likely to be relevant to my child?
- Is it new information?
- Is it helpful?
- Is it from a reliable source?

Sometimes, the time you spend on the Internet will be incredibly valuable. Other times, it may be better for you and your child if you use that time to take a break from autism and do other things.

## **6. Tips for Parent, Siblings & Extended Families:**

As a result of her work with many families who deal so gracefully with the challenges of autism, Family Therapist, Kathryn Smerling, Ph.D., has provided the above five tips for parents, five for siblings and five for extended family members.

Learn to be the best advocate you can be for your child.

### **Don't push your feelings away:**

Talk about them. You may feel both ambivalent and angry. Those are emotions to be expected. It's OK to feel conflicting emotions. Try to direct your anger towards the disorder and not towards your loved ones. When you find yourself arguing with your spouse over an autism related issue, try to remember that this topic is painful for both of you; and be careful not to get mad at each other when it really is autism that has you so upset and angry.

**Get involved with the Autism community:**

Don't underestimate the power of "community". You may be the captain of your team, but you can't do everything yourself. Make friends with other parents who have children with autism. By meeting other parents you will have the support of families who understand your day to day challenges. Getting involved with autism advocacy is empowering and productive. You will be doing something for yourself as well as your child by being proactive.

**Be informed:**

Take advantage of all the services that are available to you in your community. You will meet practitioners and providers who can educate you and help you. You will gather great strength from the people you meet.

**Try to have some semblance of an adult life:**

Be careful to not let autism consume every waking hour of your life. Spend quality time with your typically developing children and your spouse, and refrain from constantly talking about autism. Everyone in your family needs support, and to be happy despite the circumstances.

**Appreciate the small victories your child may achieve:**

Love your child and take great pride in each small accomplishment. Focus on what they can do instead of making comparisons with a typically developing child. Love them for who they are rather than what they could be.

**Tips for Siblings:**

Remember that you are not alone! Every family is confronted with life's challenges... and yes, autism is challenging... but, if you look closely, nearly everyone has something difficult to face in their families.

**Be proud of your brother or sister:**

Learn to talk about autism and be open and comfortable describing the disorder to others. If you are comfortable with the topic...they will be comfortable too. If you are embarrassed by your brother or sister, your friends will sense this and it will make it awkward for them. If you talk openly to your friends about autism, they will become comfortable. But, like everyone else, sometimes you will love your brother or sister, and sometimes you will hate them. It's okay to feel your feelings.



**Love your brother or sister the way they are:**

While it is OK to be sad that you have a brother or sister affected by autism it doesn't help to be upset and angry for extended periods of time. Your anger doesn't change the situation; it only makes you unhappier. Remember your Mom and Dad may have those feelings too.

**Spend some time with your Mum and Dad alone:**

Doing things together as a family with and without your brother or sister strengthens your family bond. It's OK for you to want alone time. Having a family member with autism can often be very time consuming, and attention grabbing. You need to feel important too. Remember, even if your brother or sister didn't have autism, you would still need alone time with Mom and Dad.

**Find an activity you can do with your brother or sister:**

You will find it rewarding to connect with your brother or sister, even if it is just putting a simple puzzle together. No matter how impaired they may be, doing something together creates a closeness. They will look forward to these shared activities and greet you with a special smile.

**Tips for Grandparents and Extended Family:**

Family members have a lot to offer. Each family member is able to offer the things they have learned to do best over time. Ask how you can be helpful to your family. Your efforts will be appreciated whether it means taking care of the child so that the parents can go out to dinner, or raising money for the special school that helps your family's child. It will warm your family's hearts to know that you are pitching in to create support and closeness.

**Seek out your own support:**

If you find yourself having a difficult time accepting and dealing with the fact that your loved one has autism, seek out your own support. Your family may not be able to provide you with that kind of support so you must be considerate and look elsewhere. In this way you can be stronger for them, helping with the many challenges they face.

**Be open and honest about the disorder:**

The more you talk about the matter, the better you will feel. Your friends and family can become your support system...but only if you share your thoughts with them. It may be hard to talk about it at first, but as time goes on it will be easier. In the end your experience with autism will end up teaching you and your family profound life lessons.

**Put judgment aside:**

Consider your family's feelings and be supportive. Respect the decisions they make for their child with autism. They are working very hard to explore and research all options, and are typically coming to well thought out conclusions. Try not to compare children (this goes for typically developing kids as well). Children with autism can be brought up to achieve their personal best.

**Carve out special time for each child:**

You can enjoy special moments with both typically developing family members and the family member with autism. Yes, they may be different but both children look forward to spending time with you. Children with autism thrive on routines, so find one thing that you can do together that is structured, even if it is simply going to a park for fifteen minutes. If you go to the same park every week, chances are over time that activity will become easier and easier...it just takes time and patience. If you are having a difficult time trying to determine what you can do, ask your family. They will sincerely appreciate that you are making.