

I've just been told my child is autistic, where do I start?

When parents are first told that their child may be on the autistic spectrum it is usually a highly anxious time. Many people know very little about autism and are unaware of what to expect, or what they should do. Some parents may have already suspected that their child was different in some way, or that they did not reach normal milestones, but it is still a shock.

After you have been given a diagnosis, you may want to request a second opinion. This is your right, and you should not be persuaded otherwise. It is important that you have a diagnosis from a suitable qualified professional such as a paediatrician.

What next?

So what is the first thing to do? Well firstly, don't panic!! Your child is still your child and although they may be behaving a little differently you can still have loving and fulfilling relationship together. Your immediate focus should be your child and what you can do to help them. You are also not alone, there are many parents out there who have been through exactly what you are feeling right now.

To start with, look for information to understand the nature of autism. Reliable information can be sought from books, the websites of Autism Associations and from local autism support groups, (see our website www.icommunicatetherapy.com for lots of information about Autistic Spectrum Disorders). There is a wealth of information on autism, so try and get a good background knowledge of the disorder before enquiring about any programs. You will find a lot of information about treatments for autism, some making wild claims. Talk to other parents with autistic children before embarking on any treatment options or therapies.

Once the diagnosis is made it is a great idea to contact local support networks or groups. These groups should be able to give you information about services that can help, and you can speak to other people in similar situations that will give you invaluable advice. Your paediatrician, doctor, school, pre-school and local education department should all have information about where to get professional help such as speech and language therapy.

It is important to know that there is a lot of support available when your child is diagnosed with autism. There are many simple strategies you can use to make life easier for yourself and your child. There are also many professionals available to help you with all aspects of your child's development.



Professional Involvement

The next step is to contact relevant professionals that can help your child. The paediatrician may have given you advice and/or referred you to some relevant agencies. Schools and kindergartens often have contact with specialist professionals to help with special needs. Not all children will need lots of specialist attention, and some may just require some minor input from a couple of professionals.

A suitably trained Speech and Language Therapist /Pathologist will be able to advise on communication, social skills and alternative communication options. They will also have lots strategies that can help with day to day things like helping the child understand commands, using visuals, following visual schedules, and expressing themselves.



An <u>Educational Psychologist</u> will observe and assess behaviour and behaviour difficulties, and implement a management program if necessary. They may also introduce strategies in the home and at school.

An <u>Occupational Therapist</u> will focus on skills of daily living (shirt buttoning, handwriting, cooking etc), but they also focus on play skills, sensory integration (helping children deal appropriately with sensory sensitivities) or finding appropriate sensory stimuli to help engage the child.

A Physiotherapist will focus on motor and physical difficulties.

A <u>Dietician</u> may be involved with an autistic child because many children have a very narrow range of food that they like to eat. A dietician can provide advice and information on nutrition and diet. Some studies are showing that certain diets may be beneficial for children with autism, but it is important that you check with a professional before implementing a specific type of diet.

A <u>Paediatrician</u> will have expert knowledge in child development and developmental disorders. Paediatricians are also able to give a diagnosis of autism.



Dealing with professionals

Depending on the nature of your child's autism, there may be several professionals involved in his habilitation. Take on board what they tell you and be patient and persistent with therapy tasks. If you feel that all the involvement is getting too much, or that nothing is being achieved, ask for a team meeting and get everyone to outline their responsibilities and their goals. However, be patient with professionals and try and maintain a good relationship with them. Progress can sometimes be slow and the people working with your child are there to help him/her.

If you are unhappy or disagree with what you are being told by a professional, ask questions and ask for a rationale to what they are saying. Remember you are the expert when it comes to knowing your child.

Funding and waiting lists

Depending on which area you live in, another issue may be waiting lists for specialist professional involvement and/or funding for extra specialist help. Unfortunately, this is a fact of life and if you cannot afford private therapy, you have to try and make the best of what you can get. If you are in this position, try and get some tips from relevant professionals or other parents about some things you can do with your child at home. For instance, ask the speech therapist about strategies for enhancing communication, or about using visuals to help with understanding. Doing some therapy yourself while your child is on a waiting list can facilitate his progress.

If you are unhappy about the professional help you are getting (or lack of help), be persistent and polite, but not unpleasant. Being unpleasant and pushy will more likely make you enemies than friends.

Dealing with your own grief

Following a diagnosis of autism some parents go through a period of grief. The grief process may cause a number of different emotions over a period of time including denial, guilt, depression and anger. Acceptance can take longer for some people, and some remain angry for a long time. This anger is often aimed at other members of the family or at the professionals working with the child. It is important to look after your own mental health and if you feel you cannot cope see your doctor about counselling or medication.

www.icommunicatetherapy.com provides many ideas and programs to help with communication and behaviour, as well as links to relevant support groups and associations.



For more information on communication approaches with individuals with an autistic spectrum disorder, and the use of visuals and social stories go to www.icommunicatetherapy.com

To learn more about Autism, language and communication click this link to see our **Book Shop** to look at, and purchase books.

Suggested Reading:

Ten Things Every Child with Autism Wishes You Knew by Ellen Notbohm and Veronica Zysk

Autism Spectrum Disorders: The Complete Guide to Understanding Autism, Asperger's Syndrome, Pervasive Developmental Disorder, and Other ASDs by Chantal Sicile-Kira and Temple Grandin

Playing, Laughing and Learning With Children on the Autism Spectrum: A Practical Resource of Play Ideas for Parents and Carers by Julia Moor

Look Me in the Eye: My Life with Asperger's by John Elder Robison

Overcoming Autism: Finding the Answers, Strategies, and Hope That Can Transform a Child's life by Lynn Kern Koegel and Claire LaZebnik

Changing the Course of Autism: A Scientific Approach for Parents and Physicians by Bryan Jepson, Katie Wright, and Jane Johnson

Louder Than Words: A Mother's Journey in Healing Autism by Jenny McCarthy

Self-Help Skills for People With Autism: A Systematic Teaching Approach by Stephen R. Anderson, Amy L. Jablonski, Vicki Madaus Knapp, and Marcus L Thomeer

Helping Children with Autism Learn: Treatment Approaches for Parents and **Professionals** by Bryna Siegel

Adolescents on the Autism Spectrum: A Parent's Guide to the Cognitive, Social, Physical, and Transition Needs of Teenagers with Autism Spectrum Disorders by Chantal Sicile-Kira and Temple Grandin