



Guidance
for Parents/
Carers with
a Recent
Diagnosis

Autism Diagnosis

Your child has just been diagnosed with autism. You may have had concerns for a while and the assessment process may have prepared you to some extent for the confirmation you have just received. You will probably be experiencing many different feelings, reactions and thoughts.

No matter how prepared you are the chances are you are worrying about the future and 'what next?' This fact sheet is designed to help you begin to understand your family's journey with autism. You may be trying to find new ways for everyone to move forward together and feel supported.

Many parents will say 'What am I supposed to do now? Some would say 'find everything you can out about autism'. While others might say 'how on earth can you begin to manage to help your child?' There is no right or wrong way to react. We are all different and how we deal with a diagnosis differs from family to family and person to person. Other people in your family may well react completely differently to you. Autism NI provide a confidential Helpline, this offers advice and support. You can telephone Monday – Friday (9am – 5pm) on 02890 401729 (Opt 1).

Why?

When a child receives a diagnosis of autism many parents want to know why, why their child and why their family? It is likely that there is not one specific reason why your child has autism.

What next?

Your child is the same person they have always been. Now that you know they are on the autism spectrum, you can better understand their needs, arrange supports and help them fulfil their full potential. Trust your own judgement – you know your child best!

Autistic children can benefit from appropriate early supports. Yes, you will need to find out more information on autism, strategies, education and future planning. Getting a diagnosis is part of the

journey that began when your child was born and will continue during their lifetime – 'the journey with autism'. At times this is an interesting and fascinating journey and at other times it can be challenging. But it is a journey and not a race. Cramping your head full of autism information from any and every source right now, is not always helpful. It may be information that you are not able to judge or that you may find inaccurate or frustrating.

So, where do you start?

Begin with understanding how your child's autism affects them. Think back to when your child was born, what were the signals that you misunderstood, what behaviours and reactions does your child have to situations and external stimuli. How have you adapted strategies to lessen these reactions so far? Often post diagnosis parents say 'But I don't know how to help my child' or 'I don't know anything about autism' when in fact they have been living with and working with autism in the family without realising it.

So, the need at this point is not to start from scratch in your journey with autism but to enhance what you already know.

The uniqueness of autism

Every individual who gets a diagnosis of autism is unique because we are all different. Autism affects the way an individual relates to people, situations and the immediate environment. Many autistic children have difficulty processing everyday sensory information like sight, smells, touch, tastes and sounds.

Not every autistic child reacts in the same way to the same situation. So, helping your child starts with understanding how they experience the world and its effect on them. Sometimes asking others what they have noticed about your child can be useful. They may be able to help you identify strengths and areas that will support your child. Understanding why your child is reacting the way they do means you can look at their environment and try to change the cause of the reaction.

Learning about diagnosis, increasing knowledge and maximizing supports will enable you to develop strategies. These will assist your child to gradually develop confidence with reasonable adjustments that promote independence and strengthen their skills. Acknowledging that you are doing your best, will make a difference and empower you to advocate for your child.

Dual diagnosis

When you received your child's diagnosis or prior to receiving it, your child may have been diagnosed with another condition. Often when autism spectrum is present other conditions may be present also. Conditions such as ADHD, Dyslexia, Dyspraxia, Obsessive Compulsive Disorder, Tourettes Syndrome etc. The same advice applies, don't overload yourself but do find out more about your child's other conditions and learn strategies to help them. Check out the 'Contact a Family' website www.contact.org.uk for their online directory of conditions.

Sibling and Carer support

Often when a child is diagnosed you spend a lot of time attending appointments and making sure they get the best support. It is important to recognise that you need a balance in your life, as at times it can feel as though you can't spread yourself across everyone's needs. Of course, last on the list may be you.

You can ask for an assessment of your needs as a carer. You might be able to access a variety of support such as short breaks. See what if any respite might be available. Register with the carers co-ordinator in your area to see what is on offer to help. Contact your local Health and Social Care Trust for details or check with local advice services.

You can find out about local Support Groups, Sibling Groups or Young Carer Groups in your area.

Interventions

A diagnosis can help your child get autism specific support; autistic children can benefit from appropriate early interventions. Talk to the professionals who know your child, ask for advice and information. Also do your homework ensuring any early supports fit with your child's needs and what your family can manage.

Isolation

It is important to link with other parent/carers as their knowledge is often invaluable. They can offer advice or hints and tips about what worked or didn't work for them along with knowledge on services available. If possible, join a local support group, log onto www.autismni.org to locate your nearest group. Just knowing you are not alone can be supportive. Celebrate your child's place in the world and how you navigate your journey together.

The Future

Every autistic child has potential. Many parents/carers worry about achievement in areas such as speech and academia etc. What is certain is that autistic children will surprise us, as they grow and develop. We should never underestimate their potential, look back on how much your child has already accomplished. Tapping into their potential is key to helping them achieve in the future. Celebrate what they can do!

Training

Autism NI run accredited training courses across Northern Ireland, many of these are free for parents/carers. We pride ourselves on providing training and advice that is evidence based, practical and to the highest standard of accuracy to ensure it is effective in supporting autistic people and their families.



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Quick Tip

Throughout the assessment and diagnostic process, you will have received appointment letters and copies of reports. Now is the time to set up an information system to keep all this information together. As your child grows and develops you may well see different professionals for different needs, and it can be confusing. It's important to remember who's who and how to contact them. All the information is relevant, maybe not straight away but in the future.

Useful Resources

Autism NI Helpline - 02890 401729 (Option 1)
Amazing Things Happen - Autism (Youtube)
Rainbow Resource Kit - (Downloadable from Autism NI website)

Useful Websites

www.autismni.org
www.contact.org.uk
www.autism.org.uk
www.carersuk.org