



**Supporting Parents and Carers:
Understanding Autism**

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Introduction

Many parents and carers of children who are showing early signs and symptoms of autism often wonder what are the causes, how it can be diagnosed at an early age, and what sort of help is available.

If you suspect your child might be autistic or if they have received a diagnosis, there is a variety of help and support available. This article will take you through a range of resources for understanding and supporting your child's needs as well as providing answers to commonly asked questions and practical advice and support. It is also important to note, whilst Autism Spectrum Disorder (ASD) is a medically recognised term that some people choose to term differently, the most important thing is developing an understanding and respect for the individual.

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1.0 What is Autism?

Autism (also called autism spectrum disorder) is a complex spectrum of neurodevelopment that affect children, adolescents, and adults. It is identified by a set of behaviours and symptoms that include difficulties with social interaction and communication, repetitive behaviours, narrow, obsessive interests, and sensory processing differences. The severity of symptoms varies greatly from person to person and ranges from mild social awkwardness to profound disability.

Autism is one of the most common neurodevelopmental conditions. It tends to affect boys more often than girls. The cause of autism remains unknown but the condition is believed to occur at approximately 1:100 worldwide. The identification, recognition and understanding of which has been rising since the 1980s.

It is important to stress that autism is not caused by parental neglect or poor parenting. Autism does affect the way people think, process, interact, communicate and behave but it does not change who they are as individuals. With appropriate support and maturation symptoms and behaviour patterns change and alter. Symptoms are sometimes said to be more noticeable in children than in adults but autism is a lifelong developmental difference.

2.0 What is life like for young autistic people

Young people with autism will experience differences in their sensory processing, they may be over or under-sensitive to sounds, touch, smells, taste, light, pain, balance; their sensory processing reflects a spectrum and is likely to differ greatly from that of their neuro-typical peers. Often described to be more detailed or not detailed enough, this results in some instances of a feeling of being overwhelmed but in others may be actively sensory seeking.

There will be differences in social development; de-coding the social world can be very challenging; often finding it hard to read the body language of others or understand how their actions affect those around them. This can make coping with the demands of everyday life difficult. Social stories are often suggested as a helpful means of explaining the expectations of the social world. It is important that those developing social stories have a sound understanding of them, as explained by carolgraysocialstories.com because the aim is to assist an autistic person in understanding a likely social experience.

Meaningful, expressive, and reciprocal communication are all areas that develop differently for autistic people. This impacts on interaction with family, friends and professionals involved in their care. These areas can often be supported, by a carefully selected and taught range of strategies, including augmentative, visual communication, to support both understanding and expression. This can help equip a young person with the means to communicate, seek help and support when they feel they need it.

Young people with an autism spectrum disorder often find comfort and experience a reduction in anxiety, from areas of special interest and routine. Coping with change can feel extremely stressful. It is likely activities are frequently repetitive and even behaviours may be repeated over and over. Favourite songs, phrases, programmes, or characters are also very usual. A preference for sameness is often apparent. Placing belongings or setting out activities in a routine and repetitive way is common. Lining up objects and repeating the same play patterns can foster a reassuring predictability that can help to diminish some of the anxiety associated with managing change.

As a result of these differing areas of development people with autism spectrum disorders may feel isolated, frustrated and lonely. Communication may be interpreted very literally which can add to anxiety and confusion. Sarcasm and socially founded jokes, interpreting body language and facial expressions can all escalate anxiety and trigger stressed behaviours. They may be very literal in the way they interpret what others say, so jokes and sarcasm can cause confusion. They may also have problems with interpreting facial expressions, which may make other people seem unfriendly.

3.0 Practical Advice

3.1 Social Interactions

Forming appropriate friendships is based on a two-way understanding. Empathy and communication are areas that autistic people usually require a substantial amount of support with. The more parents, carers and professionals understand the individual needs of their child, the better equipped they are to select appropriate strategies that will help to build social skills.

Supporting your child in understanding themselves and their preferences and teaching them how to share/communicate this information is important, for example, some people with autism may not like to be touched, they may prefer to be left alone. Teaching strategies, perhaps an outstretched arm accompanied by a verbal or visual request; “please don’t touch me”, can support more positive interactions and lead to establishing mutual respect and friendships.

Even the most intelligent, academically able autistic person can experience difficulties in interpreting other people's behaviour and intention. This can lead to them becoming very vulnerable in relationships. A high percentage of autistic children have experienced bullying.

Expressive language may never happen in words but can be successful in pictures. Physical contact / comforting an autistic child can be positive provided it is child-led, motivation and reward systems need to be established for specific reasons and on an individual basis.

Here are some steps you can take to help your child:

- Teach what peers may 'just know' about a given social situation
- Use visuals to encourage the child to look towards the speaker
- Help your child to see what we are saying through visual clues, gesture and demonstration
- Ensure your child has a means of sharing their distress and seeking comfort; this may be a practical approach; perhaps a soft toy, a blanket even a key ring they can show or give to communicate they are upset and need some comfort.

Like most children, motivation and reward can support desired behaviour. However, for autistic young people, it may be unlikely that social rewards; well done, great, are particularly helpful. It may be a more tangible system that is effective. Some families report simple visual systems, that can reward appropriate social behaviour; pom-poms in a jar every time a family member sits at the table, uses a fork etc. Once the jar is full a family treat can be agreed upon, perhaps pizza or extra time on their favourite game. Using a whole family approach can work more successfully than singling out an individual child. This is especially the case for autistic children who are perhaps very socially sensitive and reluctant to engage with personal schedules or directive approaches. Whatever reward systems or visuals are decided upon it is important to maintain a personalised, simple and consistent approach.

Social skills are often described as the 'hard labour' equivalent for an autistic person. It is important that they can access relaxing and enjoyable activities and interests. Autistic people often benefit from support in 'seeing the bigger picture; just because they enter a room full of toys does not suggest they will know what to choose. Making a choice is a complex social skill that may need support. A schedule or a choice basket, and a parent modelling / demonstrating its purpose can reassure them of the availability and opportunity for enjoying their special interests or activities and some relaxation time.

3.2 Making friendships

As with all parenting, there are occasions when it is difficult to allow young people to expand their interests and develop friendships. Supervised, organised groups or activities that offer some structure and predictability can often be a more appropriate and successful way of encouraging friendship. Ensuring basic skills in turn-taking, waiting, have been mastered through practice and experience at home can help achieve a good starting point. Teaching these skills through everyday activities even setting the table, taking socks out of the laundry basket or playing simple 1-1 turn-taking games can all help develop important skills required for successful friendships.

Many autistic children play alongside their peers unsure of how to participate in a social 'hanging out' scenario. They may seek older friends who are more predictable in their behaviour. A higher level of supervision and support may be required. A number of families report 'play dates' are more successful if a plan of what to play with has been agreed upon; any very special or particularly positioned toys or games are covered over or put away. A dolls house that has been poured over for hours and gets reorganised by the visiting school pal is not going to foster positive friendships!

3.3 Developing communication

Processing language and understanding social communication is an area that can create anxiety and confusion for autistic people. It is important that as the communicator we help children see what we say whenever possible. Using an accompanying object, photograph or picture can be hugely helpful in getting a message across.

Communication is a complex social process that requires teaching, patience and understanding. Even the most verbally able autistic child is likely to experience some challenges in processing and understanding the many elements of communication; the tone of voice, body language, facial expression all require a good level of social development and understanding.

Teaching these skills through role-play and modelling can be helpful. Drawing on a child's own experiences to explain a certain scenario; remember when you left Danny bear at school and you couldn't remember where he was? You were so upset, that's how Daddy felt when you took the car key to your room!

It is important to remember that everyone has different ways of thinking, and this is especially true for autistic young people. Some autistic people describe their thinking as in pictures or colour even patterns and numbers. As a result, processing language and responding to questions can take time. Allow longer for a response and explore with pictures or drawings to explain things rather than using too many words.

3.4 Building Confidence

Developing self-confidence is particularly important for autistic children. They may have experienced many occasions where they have 'failed' or not finished something. These experiences have a very negative impact on emotional well-being.

You can help your child build confidence by encouraging them to take part in activities that are fun and enjoyable.

Here are some ideas for things you can do with your child to help them build their self-confidence:

1. Offer opportunities at home where they can practice common scenarios; perhaps role play going to buy a ticket for the cinema or shopping before actually going through the process in real life. Role-playing is an excellent way for children to experience normal day-to-day activities safely and make the transition from one situation to another. This can help your child feel less anxious and more confident overall.
2. Teach your child some skills such as cooking, and give them time to try these out. Learning to cook is a great way for children to learn practical skills and take an active role in their lives. The sense of achievement they gain from this will help them to build confidence in themselves and their abilities.
3. Encourage your child to join clubs or other activities and participate, but if possible, let them choose what they want to do. Much of a child's confidence comes from being able to make choices on their own. Letting them make decisions about where they spend their time will help them feel good about themselves.
4. Allow your child to help around the house. If you want your child to clean for themselves or put away their toys, giving them the responsibility of cleaning could help boost self-confidence. Developing independence helps to develop self-confidence.

5. Encourage them to join you for a walk by making a plan, perhaps drawing a map or creating a treasure hunt. Remember to communicate the duration of time you may be out and that you will be returning home again. These important elements of social information can be the difference in your child joining in or refusing to. Being outside can be an excellent way for children with autism to clear their minds and make them feel relaxed and calm. This will help them to feel more confident overall.
6. Extended family, friends and their pets can all support your child's confidence. Expanding their social experiences; perhaps helping to wash a friend's car, gardening together, participating in pet care offers a chance to succeed and receive praise. Success and praise are foundations in building confidence.

3.5 Transitioning to college or employment

The move from school to college or employment is an exciting one for many, but for most people creates some levels of anxiety. Change is challenging and because of the elements of social differences, sensory processing and desire for sameness, associated with autism, transitional experiences can be more challenging. With the right support, planning and preparation they can also be successful and positive. It is helpful to have pre visited and shared information about any changes or adjustments that may be helpful.

Practising the route or drive to the new place of study or employment. Role-playing some scenarios e.g. what if the road is closed, the bus is late. Making reminder crib cards can reduce anxiety and have a support mechanism to hand.

Offering continued emotional support is important; reassuring and highlighting that all young people feel worried or anxious when dealing with change and in time changes become familiar. Remind the young person of all that will remain the same and of the things they can make a decision about; whether to eat in the dining hall or cafeteria.

Supporting successful transitions builds on life skills and can assist in developing into more confident adults. Here are some things to consider:

1. **Communication:** ensuring from the outset colleagues and peers are aware of how a young person communicates and any additional time, visual support, concise consistent language, they may require, can ensure a more successful start. Sharing information about autism and the implications of social communication differences will build everyone's confidence and support a more comfortable welcome.

2. **Anxiety:** Parents often understand the causes of stress in their child and can help them cope better with stressors throughout life. Examples include daily pressure at school or work, relationship problems such as conflicts with siblings or parents, or peer pressure while making friendships. It is helpful to share any information regarding helpful strategies; perhaps deep breathing, a tactile stress ball, movement, a quiet space that has been helpful in the past. The young person themselves will benefit from being shown where they can access quiet spaces or outdoors and teaching at a new workplace or environment, appropriateness and timings for accessing these.
3. **Transition programmes:** Support transition into college and/or employment by enrolling your child into a transition program for college or work, to help them learn new skills to assist them in their journey.
4. **Support systems:** Make sure your child is aware of any support systems that are available and how they may need to access these services throughout their time at college or work. It is essential that parents stay in contact with the transition program staff for their child to have continued support from others.

Some additional options to consider include:

1. Support groups or clubs for people in the local area. This can help your child get into a social routine and meet other people who understand them and the challenges they may encounter.
2. Educational and recreational activities such as occupational therapy, animal therapy, or music therapy. These can reduce anxiety, build confidence and help in regulating emotions.

3.6 Managing anxiety and stress

Teaching your child to manage stress is important for both their physical health and emotional well-being. The following may be of help;

1. Try and identify triggers. Try to minimise or reduce the likelihood of these.
2. Remember the cause of feeling overwhelmed may not always be apparent. Sometimes too many instructions or being too directive may be a trigger for anxiety. Misinterpreting communication can all be situations that trigger defensive behaviour. The more we can do in communicating clearly, allowing time to process and avoiding children feeling under pressure, the less likely it is that these behaviours occur.

3. If anxiety has triggered behaviour it is important to keep the child safe and allow them to calm down. Be aware of sensory needs... are they comforted by a hug or do they prefer a space? Try and reassure them in a non-invasive manner.
4. Teach your child some relaxation techniques for stress. Children can learn to relax just like everyone else, and relaxation techniques will help them learn how to do so. Teaching them yoga or meditation might work well for your child, but you can also try self hand massage, breathing up and over a window frame, blowing out and counting are all tips that other families have found helpful. There are a number of aromatherapy or some other self-care techniques that may be worth exploring.
5. Encourage your child to participate in activities that they find relaxing or calming. It can be hard for children to find activities that they enjoy that can also help them relax. They may need to try a few different things before they find something that works. And don't forget physical activity - many children with autism are drawn to exercise and finding ways to keep active is one of the simplest ways you can reduce your child's stress levels.
6. Set up a special place where your child can go if they feel stressed out. One of the best ways to reduce stress is by giving them somewhere quiet and comfortable where they can relax. Make sure it's somewhere where you know it's okay for them to be upset if they need to, and make sure that they know as well. You may want to create a safe space for your child, and make sure that they have a consistent way of getting there.
7. Avoid exposing your child to stressful situations if you can. Sometimes it's impossible to avoid having your child experience something that will be stressful, but if you can avoid placing them in those situations then it may be best for them. If your child is struggling with their stress levels, then know when it's okay for them to stop an activity or situation - and recognise that some activities might be too big of a challenge for them right now in terms of their stress level.
8. Give yourself some time out. It can be hard for parents to remove themselves from the situation when they are helping their child. However, if you're struggling and exhausting yourself, think about taking a break. Avoid trying to manage too many things on your own too - let other people help you out as well. Encourage your child to do the same when you're both coping with stress.

9. Take care of your own health as well. Stress and anxiety can seriously affect your health, so try to take care of yourself first and foremost if you are struggling while dealing with your child's stress levels. And of course, if you're a parent and you're struggling, talk to someone about it. There are lots of people who can help and support you - whether that's friends, family members or professionals.

If you are having problems with your child's stress levels, do not hesitate to get help for them. All parenting can feel overwhelming at times but particularly for parents of autistic children where working out what is causing anxiety can take a great deal of detective work.

4.0 Looking after yourself and your family

It is easy for parents and carers to become exhausted with all the responsibilities they have for their child. It is important for parents who feel this way not only to keep a balance in their own lives but also not to see the child as 'difficult'. Remember that your child cannot always understand what other people expect of him/her or how they feel. If you are feeling overwhelmed, it might help to try to make time for yourself or your partner.

Try getting together with other parents or carers who have a child with similar conditions so that you can share experiences and support each other. You can try to get in touch with other parents of children with autism, either through your child's school or a parent/child support group.

The support that families of young people with SEN require for themselves as well as each other is often unappreciated. Everyone can feel isolated and lonely at times. However, families need to help each other through this by sharing their own experiences and feelings.

It is important that parents who feel isolated talk to someone they trust about how they feel so that they don't blame themselves for the things that happen and also so that they know that there is support and advice that can directly help them and their family.

The **Events and Support** section on our website has a range of live, pre-recorded and digital events that can help you to support you and your family. By participating in our in-person or online events, you'll also get a chance to meet other parents and carers, and engage with some of our expert speakers.

5.0 Support organisations

The following is a list of websites and organisations that can help you. While we have done our best to list the most up to date and relevant information on this subject, please be advised that all the sources are constantly changing and new information will be added regularly so it is important to call back again if you need updated advice. Websites are listed alphabetically by name or narrow subject category.

Autism Alliance - <https://www.autism-alliance.org.uk/>

Autism Awareness Centre - <https://autismawarenesscentre.com/resource-regions/united-kingdom/>

Autism Education Trust - <https://www.autismeducationtrust.org.uk/resources/early-years-resources/>

Autism Toolbox - <http://www.autismtoolbox.co.uk/home>

Beyond Autism - <https://www.beyondautism.org.uk/professionals/resources/>

Child Autism - <https://www.childautism.org.uk/>

National Autistic Society (UK) - <https://www.autism.org.uk/>

NHS England Resources - <https://www.england.nhs.uk/learning-disabilities/about/useful-autism-resources-and-training/>

NHS Support - <https://www.nhs.uk/conditions/autism/support/>

Resources for Autism - <https://resourcesforautism.org.uk/>

About Witherslack Group

We are committed to sharing advice and support to parents, carers and professionals. Our webinars and online resources provide expert knowledge and practical support. If you would like to find out more information you can email webinars@witherslackgroup.co.uk or visit www.witherslackgroup.co.uk.

