



After Diagnosis

The Umbrella Pathway

Introduction:

If you have recently found out that your child has a diagnosis of autism, you may be experiencing a variety of emotions and may well have lots of questions. We hope that the following information will help you understand what autism is and things you may wish to consider. It contains some tips on how to support your child and suggests some possible avenues of support.

What is the Autism Spectrum:

Autism is diagnosed when a child meets certain medical criteria - autism is in the category of Pervasive Developmental Disorders and your child may have received a differential diagnosis of any of the following:

- Autism Spectrum Disorder
- Asperger syndrome
- PDA (Pathological Demand Avoidance)

Although there are subtle differences between these conditions, there are many overlaps – hence, the term ‘autism spectrum’ is often used.

‘Difference’ not ‘Deficit’:

Autism is sometimes referred to as a different way of thinking so rather than focusing on what children cannot do, it can be more helpful for people working with a child on the autism spectrum, to think of how they do things differently.

The 4 Key Areas of Difference:

Previously children with autism were described as having a ‘triad of impairment’ in the areas of socialisation, communication and imagination. Current research and information from young people and adults with autism, has moved this thinking on and it is now believed that people on the autism spectrum experience and perceive the world differently to people of typical neuro-development - that they have a difference in the way they develop in key areas.

Although each child or young person possesses a unique profile of strengths and differences, their differences can be grouped into four areas:

- **Social understanding** – differences in understanding social behaviour and the feelings of others. This informs how we interact with each other and how we form and maintain friendships/relationships.
- **Social communication** – differences in understanding and expressing communication and language, both verbal and non-verbal. Good language skills can sometimes mask misunderstanding.
- **Information processing** – differences in perception, focusing attention, shifting attention, planning, understanding concepts, generalising, managing transitions, special interests, and ability to absorb information.
- **Sensory processing** – differences in perceiving information via the senses. This could mean low (hypo) or high (hyper) sensitivity to touch, smell, sight, sound, taste, balance and body awareness, as well as lesser known senses such as proprioception and vestibular.

A Spectrum Condition:

Spectrum means ‘range’. This means it affects children in different ways. Each will have an individual profile of strengths and differences – this is what makes your child unique. It is possible to do well in one area but face challenges in another and so children can be described as having an array of abilities.

Some Statistics:

1 in 100 children within the UK have autism. Currently there are three times as many boys as girls who receive a diagnosis but this is changing as the understanding of how autism affects girls is improving. Most children with autism (70%) are educated within mainstream schools. Lifelong Condition:

Autism is a lifelong condition which means that children do not grow out of it. A child with autism becomes an adult with autism. Many people with autism develop to have independent and fulfilling lives. This is why it is so important to put strategies in place as early as possible because they will become tools for life. Receiving the diagnosis can be a positive step along that path.

Causes

The fact that your child has a diagnosis has nothing to do with the way they have been looked after. It is not a mental illness, nor is it caused by emotional deprivation. The specific causes are as yet unknown but evidence suggests there may be environmental, physical or genetic factors.

Autism affects children from all walks of life and across all countries and cultures.

Co-occurring conditions

A child with autism can sometimes have another condition or conditions alongside it. Such conditions might include epilepsy, attention deficit disorder, hearing or visual impairments, or problems with anxiety. It is important to understand the impact of these combined conditions as a whole.

Anxiety

Many children with autism find coping with everyday life extremely stressful. This can be because the world is a more bewildering place for them than it is for most people and they need to work extra hard to understand what is going on around them. A useful comparison is the idea of a stress bucket, whereby everyday situations, both large and small gradually fill up the bucket. Sometimes the bucket gets full and overflows - this explains why some children experience 'melt-downs', need time alone or are over-tired.

Strengths

Children and young people with autism often have areas where they demonstrate a high level of skill. These include:

- Attention to detail
- Special interests or passions
- Honesty
- A good memory
- Good at visual processing
- A tendency to be logical
- A clear sense of right and wrong
- Adherence to rules
- Typically punctual and able to follow a schedule

The longer term

With the right support, children can learn, develop and can achieve a life style that they choose. Children with autism are able to reach their full educational potential with the right understanding of how their autism affects them and with the most appropriate strategies in place.

Ways Forward

There is no right or wrong way to feel when your child receives a diagnosis of autism spectrum. Parents tell us they feel a variety of emotions, many of which may be new or unexpected. Time can help to come to terms with or fully understand the implications of the diagnosis. It is important to remember that the child is still the same child that they were before they received a diagnosis and parent/carers are their best advocate. Parents tell us it helps to think of the diagnosis as a signpost, not a label – it helps to point people in the right direction.

Talking to Friends and Family

You may wish to consider telling other members of the family and friends. Different people react in different ways. They may have noticed that your child behaves differently from others. They may have questions. Providing them with appropriate information about autism may help.

Talking to Siblings

Explaining your child's diagnosis to siblings will depend on their age and level of understanding. There are also different ways to give that information and in the way they will understand it best, e.g. through a book, a DVD or face to face. A successful way of sharing this information has been to focus on the fact that everyone is different and each has their own set of strengths and challenges.

Talking to School

It is your choice whether or not to tell school about your child's diagnosis. However, schools can do a lot to support your child if they know and it is important that they understand how your child's autism affects them. You know your child best and can help school develop their understanding so that they can put effective strategies in place - consistency of approach between home and school is crucial.

Talking to your Child

Ultimately your child will need to know that they have a diagnosis. The timing of this will depend on when they are ready and you, as parents, are in the best position to determine when this is. A successful way of introducing this is to base it around the fact that everyone is different and each child has their own set of strengths and challenges. It is important to focus on the positives, the things they do well and what makes them unique.

Supporting your Child within their Peer Group

Children with autism often have difficulty with understanding social situations. It can help them to make friends by encouraging them to share their special interests. Encourage them to be able to see things from another person's point of view.

Tips for Parents

Here are some ideas that other parents have found helpful. It is not an exhaustive list:

- **Learn about the autism spectrum.** The more you know, the more you can help your child.

- **Help your child to remain calm and to help them to de-stress.** Try not to add to the child's anxiety through the things you say or do e.g., by showing your own concerns or over talking about your worries.
- **Structure is important** for children with autism. Have clear 'rules' and expectations at home. It is often helpful to have these written down as a visual reminder. Be consistent. Warn your child of any changes.
- **Use positive direction.** Tell them what to do rather than what not to do. Break instructions into small chunks. Avoid negative criticism.
- **Celebrate success and build self-esteem.** Be explicit and give praise using vocabulary that is meaningful to them. Remember that they may have to work very hard at things that others find easy.
- **Your child may not be aware of social trends and this can sometimes lead other children to make unkind remarks.** Try to ensure that haircuts and clothing do not make him/her stand out in this way. Encourage the middle ground.
- **Prepare for new or anxiety provoking situations.** Give them a visual run through of what will happen, try role play, or practise key phrases.
- **Capitalise on your child's strengths and interests.** Plan activities, particularly social ones, based around the things he/she likes to do or the things that he/she is good at, e.g. LEGO or trains.
- **Manage the sensory environment.** Be mindful of your child's sensitivities and whenever possible try to minimize triggers that are likely to cause overload. If unsettling sensory experiences cannot be avoided, ensure your child has a place to where they can regain equilibrium.
- **Use a visual timetable to help your child understand what he/she is going to be doing** – you can use photographs, symbols, or words (depending on which your child understands the best). This will help them to prepare for what is coming next.
- **Have a 'days of the week' calendar** up in the house - which can show your child at a glance what they are doing each day, e.g., colour code so that a 'yellow' day is a school day and a 'red' day is a home day.
- **Use photos or symbols to help them make a choice** of food/toys/activities etc. The use of visual prompts really helps any child with communication difficulties.
- **Work with professionals** to put in place strategies that reflect your child's needs. Seek advice and keep the channels of communication open.

Your child will have much to offer the world and a whole life time to grow and learn.

Finding Support

The following agencies support children with a diagnosis in various ways; some work with schools, some work with parents. Some have websites or publish information. The kind of support available depends on your child's specific needs.

- Clinical Psychology
- Community Paediatrician
- Occupational Therapy Service
- Specialist Teachers for Autism/Complex Communication Needs (CCN)
- Speech and Language Therapy Service
- Special Educational Needs and Disabilities Information Advice and Support Service (SENDIASS)

The professional who discusses the outcome of the assessment with you will provide information about local groups which offer a range of support and activities.

Do you have a concern, complaint or comment?

We always value feedback from you about the care you receive and you may be contacted to comment on the service. However, if you wish to make a compliment, comment or complaint please contact:

Patient Relations Team, Worcestershire Health and Care Trust
Isaac Maddox House, Shrub Hill Road, Worcester, WR4 9RW

Tel: 01905 681517 Email: Whcnhs.pals@nhs.net

Do you have a communication or information support need?

If so please contact the person who gave you this leaflet so that those needs can be recorded and responded to.



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