

Autism:

A Guide for Those Who Support Adults Following a Diagnosis



**Living with Autism
Byw gydag Awtistiaeth**

www.ASDinfoWales.co.uk

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Foreword

I am pleased to present you Autism: A Guide for Those Who Support Adults Following a Diagnosis.

The creation of this guide has been a lengthy project which was funded by the Welsh Government and hosted by Aneurin Bevan University Health Board.

This guide has been shaped and developed based on constructive feedback from the key stakeholders, this includes professionals, individuals with Autism and those who live with or support them.

Following the success of Autism: A Guide for Parents and Carers Following Diagnosis (written for parents and carers of children), and Autism: A Guide for Adults Following Diagnosis (written for adults with autism); this guide has been developed to provide information for those who are living with, caring for or supporting an adult with autism.

We hope that you will find this a useful resource, with the tips and personal stories leading to a common understanding of autism in adulthood.

We could not have achieved this without the help of those individuals who have contributed to the development of this guide especially the parents and carers of adults with Autism Spectrum Disorder.



Judith Paget

Chief Executive Aneurin Bevan University Health Board

Our Stories

I didn't get diagnosed until I asked, at 46, to be tested. I function, in my own quirky way, in society and do not need any more help than your average person. There are many people on the autistic spectrum who remain undiagnosed throughout their lives or whose diagnosis becomes irrelevant after they leave fulltime education. These people are a positive side of autism, a side, of which, most 'normal' people are unaware.

- Rubin Irvine

My name is Ian, and I am now 73. I have been married to Judy for 47 years, and we have two children, now grown-up and moved away. Five years ago I retired from a very satisfying career as a college lecturer, for 30 years full-time and then 15 years gradually diminishing part-time, with maths as my main subject (please don't stop reading at this point!!) We have both known for some time that I had mood swings and erratic behavioural problems. It was only seven years ago, however, as a "spin-off" from a colleague's lecture on "Autistic Savants", that we wondered whether there might be another cause. So we asked my GP whether I could be referred to a specialist for a diagnosis, since we felt that, if confirmed, knowing I had Asperger syndrome would answer a lot of questions about my unpredictable behavioural traits — which has indeed been the case. So he agreed, and nine months and two 90-minute interviews later the letter arrived, confirming that I did indeed have Asperger syndrome.

- Ian Walker

When I received my diagnosis on 10th May 2005 aged 38, I was so pleased to have the explanation for all the difficulties I had experienced up to this point. I had found the reason for the things I struggled with and it made sense of my life, as well as changing how I saw myself, so I was able to be more confident in my position as a person with Asperger syndrome. I was no longer someone who was awkward or stubborn. When I attended appointments where the people treated me badly, the diagnosis helped with managing these difficult situations. I found freedom in knowing that this is who I really am and that I can make the best of my life, as I learn and grow accustomed to this view of myself. The diagnosis was not just the end of not knowing about Asperger syndrome, it was the beginning of a long journey of discovery and learning about my life, and how to relate to the world around me in a new way, whilst remembering that as a person I had not changed, because I was born this way and I quite like myself anyway.

- Karen Thompson

Despite having difficulties; I still don't altogether see autism as a bad thing. There are a lot of good things about it. It gives me a unique way of looking at things, so I'll often think of things in an unusual way. I'll tend to think a lot deeper about certain things that other people do. I also feel proud all the things people with autism have achieved. A lot of the most famous people are thought to be on the autistic spectrum. Who do you think would be studying all the inventions and having big fixations on the stuff they're interested in? They likely wouldn't be the really sociable people would they? They would likely be the more withdrawn people. It's actually common in autism to have obsessions, and a lot of these famous people were really fixated on the stuff they were interested in. Truth be told, I don't really want to be normal. True: I want my difficulties to improve as much as they can, but I still like being a bit different from other people. I like having something, which makes me unique.

- *Alex Lowery*

I am proud of my autistic nature, my honesty, self-belief and autonomy. When I was told I had a disorder I felt insulted. I am not out of order, I am not wrong; I am just different. You and me are different in a similar way and one of the benefits of diagnosis is finding out that you are like other people. That said, diagnosis is a useful tool, helping you to understand yourself and others and for them to understand you better. Understanding people is vital to getting the best out of them.

- *Rubin Irvine*

Introduction

If you are related to, friends with, caring for or supporting an adult who has recently been diagnosed with an autism spectrum disorder (ASD), this guide is for you. It has been developed with the help of others who support adults with autism, and will:

- help you understand what autism is
- give you advice about what you and others can do to help
- tell you about support that may be available
- signpost you to other information sources

You may not want to read it all at once — you may find it more helpful to refer to different sections over time.

Throughout this booklet the terms autism, autism spectrum disorders and the abbreviation ASD are used to cover a range of developmental disorders and terms. These include Kanner's autism, autistic spectrum conditions (ASC) and Asperger syndrome.

We hope that this document gives you some useful information and points you to how and where you can access further information and help.

What is an Autism Spectrum Disorder (ASD)?

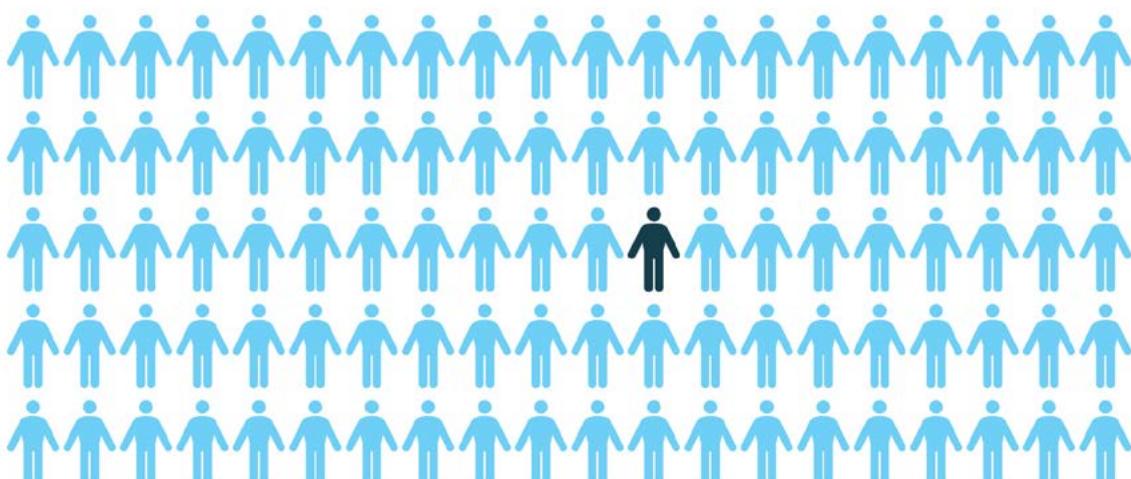
An autism spectrum disorder (ASD) is a developmental disorder which affects the way a person communicates with and relates to other people and the world around them. The way in which people are affected varies from one individual to another and by age and intellectual functioning.

Current estimates suggest that around **1 in 100** people have an Autistic Spectrum Disorder.

The causes of ASD are as yet unknown. What we do know for certain is that ASD is not caused by parenting or the way in which the individual is treated. It affects people from all walks of life and in all countries and cultures.

Nowadays, ASD is usually diagnosed in childhood. However, historically this has not always been the case and because of this many adults with ASD remain undiagnosed or are being diagnosed in adulthood. Some may have not received any diagnosis at all until adulthood and others may have been misdiagnosed.

Individuals with an ASD are affected in a variety of ways and to very different degrees. This may be due to other co-occurring conditions such as learning disability. This is why it's called 'the autism spectrum'. ASD can affect adults with any level of intellectual ability, from those who are profoundly learning disabled, to those with average or high intelligence. So, having an ASD doesn't necessarily mean that you have a learning disability. The more seriously affected individuals at one end of the spectrum have learning disability as well, and require high levels of support. At the other end of the spectrum, some people with Asperger syndrome, or high-functioning autism are very intelligent academically. They may be successful in their chosen field, or excel in a specific area. However, they still experience significant social and communication difficulties.



What are the Signs and Characteristics of Autism Spectrum Disorders?

Adults with ASD have significant difficulties relating to other people in a meaningful way. It is common for people with ASD to have sensory issues alongside their core problems. This, combined with the triad of impairments, means that adults with autism experience the world very differently. The ‘triad of impairments’ or ‘the three impairments’ are issues with:

Social interaction

Difficulty understanding social rules, social behaviours and relationships, for example, difficulty taking turns during a conversation, being unable to adapt behaviour to suit different situations.

Social communication

Difficulty with verbal and non-verbal communication, for example, not understanding the meaning of facial expressions or tone of voice, interpreting language literally.

Rigidity of thinking and difficulties with social imagination

A preference for consistency and sameness, difficulties with predicting outcomes to situations and planning ahead.

It is usual that all individuals with a diagnosis of autism have difficulties in all three of these areas. However, the ways in which they manifest themselves vary enormously. For example some people are very aloof, some passive and some may want interaction but may lack the expected social ‘norms’.

It is also common for people with an ASD to experience:

- issues with processing sensory information
- another condition such as ADHD, anxiety, depression or a learning difficulty
- repetitive behaviours
- a preoccupation with their special interests

We will explain these characteristics in more detail later in this guide.

Characteristics of ASD

This section will try to explain the characteristics of autism in more detail:

1. Social interaction
2. Social communication
3. Impairments in social imagination / Rigidity of thinking
4. Repetitive Behaviours
5. Special Interests
6. Sensory issues
7. ASD and other disorders

As we mentioned earlier in this guide, adults with ASD are affected in a variety of ways and to very different degrees, and this is why we refer to a spectrum. It is important to remember that the autism spectrum is broad, and therefore different individuals with ASD may display all or only some of the characteristics described in the following sections.

1. Social Interaction

From very young babies, most individuals appear to have an interest in other people. Most infants and children seek attention from others, look to others for comfort and appear to enjoy interacting on a social basis. As we reach adulthood, taking an interest in others, sharing, taking turns and enjoying chatting with friends are all examples of how most people engage in social interaction. Adults with an ASD find this social interaction very difficult, and will have struggled with it all their life. They may seem less interested in people, and find it hard to see things from another person's point of view. They often seem isolated, and struggle to make and maintain relationships. Some may like being sociable but don't seem to understand how to do these things and don't always get it right.

Individuals with an ASD may:

- show preference for activities that can be undertaken alone
- only tolerate approaches from very familiar people
- only be receptive to approaches from people they know well
- appear awkward in their social approaches
- not want to be comforted when in distress
- struggle to take turns in conversation
- have a poor understanding of social rules and conventions

2. Social Communication (Verbal and Non-Verbal Communication)

People usually use a variety of methods to communicate with others, from speech to body language. Adults with an ASD struggle with elements of this. The level of impairment varies from one individual to another, and those with a learning difficulty may have little or no verbal communication. An individual who does not have a learning difficulty may use good language, but may not be able to understand the same level of language, or may have difficulty with eye contact or facial expression. This can have a significant impact on learning and understanding, employment and the ability to make and maintain relationships.

An adult with an ASD may:

- have limited or no speech
- often use words and phrases out of context
- not respond when spoken to
- be better at using language than understanding it
- not understand or misunderstand figurative language
- talk at, rather than to others
- repeat words and phrases other people say (this is called echolalia)
- use too little or too much eye contact
- not appreciate the need to communicate information
- not communicate feelings using facial expressions or body language
- rarely understand or use gestures



3. Rigidity of Thinking and Difficulties with Social Imagination

Social imagination helps us understand the world. Most people use social imagination to predict responses and perspectives of other people. We use it to plan our days, to work out what we need to do and to solve problems. It enables us to vary our interaction with others to avoid conflict and to be polite and sociable.

Problems with social imagination can make the world feel like a very uncertain place, so people with an ASD find reassurance in setting up and adhering to routines and patterns that are predictable and they are in control of. They often have a preference for sameness and may be uncomfortable with change or unpredictable people and events.

Repetitive behaviours and routines are a common feature of ASD.

An adult with an ASD may:

- become distressed if a familiar routine changes
- not cope if things do not go to plan, e.g. if an appointment does not happen on time or the car breaks down
- have difficulty in planning and organising
- struggle to follow lengthy instructions or directions if they are not written down
- may try to impose routines on others
- often resist new experiences, for example trying different foods or visiting new places
- be reluctant to deviate from one way of doing things
- find it hard to work out what other people are going to do, and cannot make sense of why other people do what they do. They are unable to take someone else's perspective or point of view
- not be able to realise some things they say could offend others
- often pay particular attention to unusual details and struggle to see the bigger picture
- develop extreme behaviours to avoid some things/experiences
- often find it difficult to learn from experiences and make the same mistakes repeatedly

4. Repetitive Behaviours

The term repetitive behaviour is used to describe specific types of unusual or seemingly odd behaviours that are sometimes seen in adults with autism.

Repetitive behaviour is sometimes referred to as self-stimulating behaviour — also known as ‘stimming’. This behaviour may involve any or all of the senses in various degrees in different individuals.

Several examples are listed below:

Visual - staring at lights, blinking, gazing at fingers, staring at the corners of ceiling

Auditory - tapping fingers, snapping fingers, grunting, humming

Smell - smelling objects, sniffing people

Taste - licking objects, placing objects in mouth

Tactile - scratching, clapping, feeling objects, playing with strings, hair twisting, toe-walking

Vestibular - rocking, spinning, jumping, pacing

Proprioception - teeth grinding, pacing, jumping, banging against hard objects

Some repetitive behaviours are very obvious while others are more subtle and hard to detect such as blinking or eye rolling, tapping fingers and mild hair twisting.

We all engage in some of these behaviours occasionally, especially when we are stressed. However, the person may engage in these activities excessively to the point that they interfere with learning or daily living activities.

Why Repetitive Behaviour?

It's not completely clear why repetitive behaviour is often seen in people with autism but it has also been noticed in people with a learning disability without autism. Some of the possible reasons for repetitive behaviour are outlined below:

- self-regulation, which helps the individual become calm and overcome situations of stress or upset
- demonstrating excitement
- providing the person with an escape route when they are overworked or wound up
- enjoyment. Some people with ASD find the behaviour pleasurable even if causing injury to themselves
- a way of avoiding a task or activity

Some people eventually learn to monitor their behaviours so they can engage in them in ‘safe’ environments (at home rather than when out in the community).

No matter what repetitive behaviour the person engages in, you need to understand that this is something that they need to do in order to find peace in their autistic world. Do not force them to stop it unless it is dangerous to self or others.

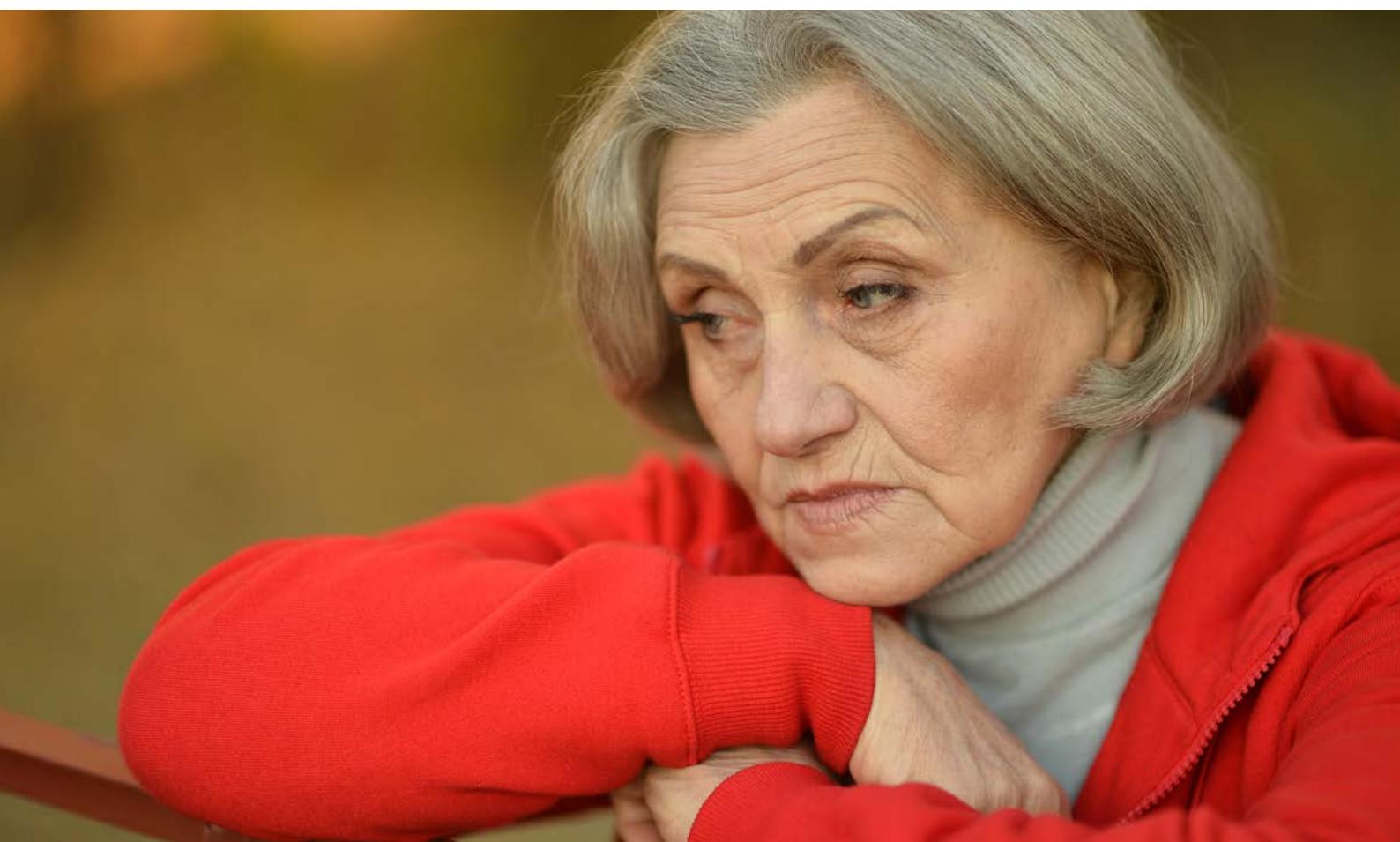
*“*My son taps repetitively on every surface. On the basis of ‘if you can’t beat them, join them’ we got him a drum kit. If he gets cross, angry or frustrated he goes and plays drums which helps him calm down and he is a grade six drummer now which gives him something to be proud of.

- Parent

”

Some top tips for managing the repetitive behaviours

- Try to be tolerant.
- If the behaviour is causing, or likely to cause, the person harm, ask to be referred to an Occupational Therapist, who might be able to help reduce or change these behaviours.
- Any increase in these behaviours is often an indication of raised anxiety levels.
- For acute increases in this behaviour, be a detective. Try and work out what may be causing anxiety and assist with the cause.
- Don’t reprimand the person for their behaviour — any attention is likely to increase the behaviour.
- Read the other sections in this guide. Implementing advice about managing anxiety and behaviours may reduce stimming behaviours.



5. Special Interests

It is not uncommon for autistic people to become fixated on past events, animals, places and people! This can be very interesting because they may feel comfortable sharing information and facts with you, which will give you a chance to bond with them in a way that they feel comfortable.

- *Sibling*

Everyone has their favourite pastime or activity that they enjoy and tend to engage in it frequently. But this interest does not interfere with their day-to-day life.

However, some people with ASD seem to develop interests in a way that impact on their daily lives. These interests are usually referred to as 'special interests' and to the individual with ASD they might be the most important thing in their life. These interests sometimes do not involve any other person and are often solitary activities. This can take up a lot of their free time to the exclusion of other activities of daily life. The activity can become repetitive and done in a rigid manner and may be difficult to break or change. These interests can change from time to time and are usually replaced by another similar interest.

These special interests have their beginning in childhood and evolve over time to more adult themes. These interests are different to repetitive behaviours but some of the reasons for the special interest can overlap, such as:

- reducing anxiety
- maintaining a sense of calm
- enjoyment
- a way of avoiding another task or activity

Special interests can be anything, ranging from typical to unusual interests. Some of the more common examples of special interests might include:

- transport (trains, planes and cars)
- collecting
- counting
- computer games and IT
- art and photography
- specific TV programmes / films (e.g. Dr Who, Twilight)
- specific subjects such as history, astronomy, palaeontology

As with repetitive behaviours adults can become engaged in their special interest if they are feeling anxious or scared, but the reality is that they have an uncontrollable desire to involve themselves in these things because their interest is real and their enjoyment and satisfaction is real.

Spending large amounts of time engaged in or talking about special interest activities can lead to social exclusion and isolation, but when utilised in a functional way can be used as a motivator or to develop a career.

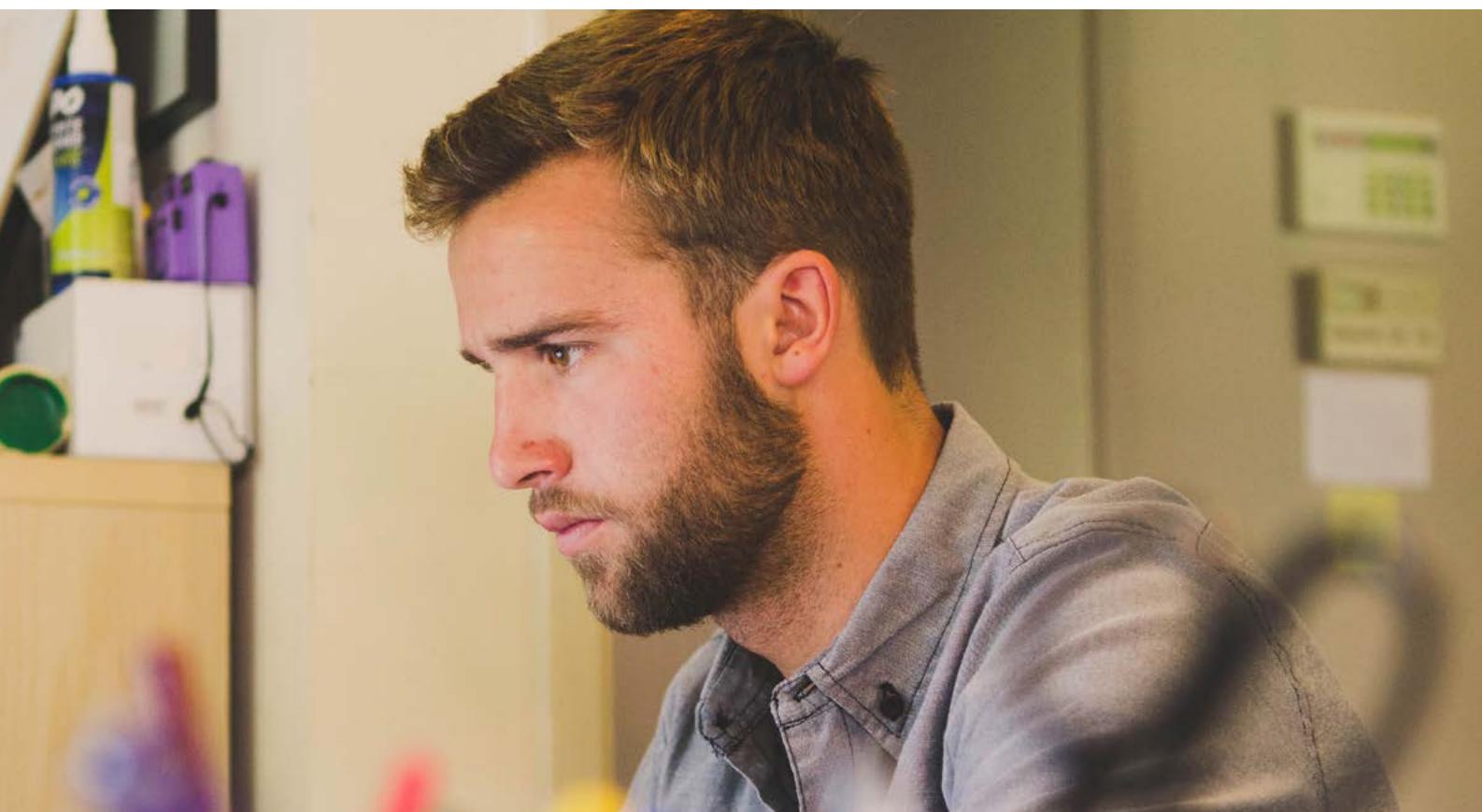
Some of the most famous autistic people have developed successful careers from their special interest.

Even though my son had great difficulties working in a group and turn taking, his keen interest in music allowed him to overcome his difficulties. We encouraged him to join in workshops and group music sessions, and this helped him to work on his social skills and team work, with like-minded people. He is now a valid member of a rock group and enjoys performing in gigs throughout the area.

- Parent

Some top tips for managing the person's Special Interests:

- Be tolerant.
- Support the person to use these as motivators or rewards when other activities are completed.
- Do not make fun of or criticise their interest.
- If the interest is interfering with learning or daily activities, encourage engagement in activity only at specific times.
- Look for ways to expand the special interest into an useful activity.
- Use the special interest as a focus when supporting the adult and to get more meaningful engagement.
- Remember, to you the special interest may seem pointless or unnecessary, but to the person with ASD, it might be the only thing that gives them pleasure or excitement.



6. Sensory Processing in People with Autism

Sensory processing refers to the way individuals experience their environment and surroundings. As well as the more commonly known sensations of sight, hearing smell and taste there are three more senses to include. They are balance (vestibular), body awareness (proprioceptive) and touch (tactile).

We all experience a large number of sensations at any one time and have 'sensory preferences'. These are not right or wrong, but affect the way we interpret the world around us (for example, some like hot curry others prefer blander food; some like rollercoasters other people avoid them).

For some people with ASD, the senses may work too well and the brain receives too much information (hypersensitive), or not well enough where the brain doesn't get enough information (hyposensitive).

Most people will consciously make choices and adapt their lifestyle according to their preferences, with a range of responses we consider to be 'normal' — and there will be no right or wrong response to those everyday sensations.

For people with an ASD, these different sensory perceptions can sometimes cause pain, distress, anxiety, fear or confusion and result in behaviours that can appear challenging as the individual tries to block out what is causing the problem.

Hypersensitive	Hyposensitive
Dislikes dark and bright lights	Moves fingers or objects in front of the eyes
Looks at minute particles, picks up smallest pieces of dust	Fascinated with reflections, brightly coloured objects
Covers ears	Makes loud rhythmic noises
Dislikes having their hair cut	Likes vibration
Resists touch	Likes pressure, tight clothes
Avoids people	Enjoys rough and tumble play
Runs from smells	Smells self, people and objects
Moves away from people	Seeks strong odours
Craves certain foods	Mouths and licks objects
Uses tip of tongue for tasting	Eats anything
Places body in strange positions	Rocks back and forth
Turns whole body to look at something	Lack of awareness of body position in space
Difficulty walking on uneven surfaces	Spins, runs round and round
Becomes anxious or distressed when feet leave the ground	Bumps into objects and people

Taken from 'Sensory Issues in Autism' by the Autism and Practice Group, East Sussex County Council

Special interests can be anything, ranging from typical to unusual interests. Some of the more common examples of special interests might include:

- The brain tries to process everything at once without filtering out unimportant things like background noise, wallpaper, people moving about and the feel of clothes on their skin. This results in sensory overload.
- Sometimes there is an inability to separate foreground and background information so that everything is seen as a whole. For example, when they look at a room they will see everything at once, so even when something small is changed they will notice. This will make the room look ‘wrong’ and can cause fear, stress and frustration.
- When there is too much information to be processed at the same time it may be difficult for people with autism to break a whole picture down into meaningful units. For example, when talking to someone we will see their whole face but some people with autism may see eyes, nose, mouth, etc. as individual things which all need to be processed separately. This makes it more complicated to process information and can lead to them focussing on only one aspect or not having enough memory to process everything.
- Sometimes it can take time to process information, particularly if there are distractions (for example, background noise, scratchy clothing), if there is a lot of information to process or if the context changes (eg they may learn to make a cup of tea in the kitchen but be unable to transfer that skill to a different kitchen).
- In some cases senses become distorted which may mean that the adult with autism sees, hears, smells, tastes or feels something different to everyone else.
- At times one of the senses may appear to ‘shut down’ as a way of the person coping with sensory overload. For example, when noises become unbearable they may appear to be deaf because this enables them to cope and to allow their other senses to work better.
- Due to the difficulties outlined above, some people will use some senses to compensate for others. For example, they may smell, lick or touch objects, or watch their feet whilst walking.

When my son was older he explained to me ‘When I was a baby I remember having a strange object thrust into my mouth which I found quite annoying. It had a very strange taste and an even stranger texture. Also, when I sucked on it, it made the most awful squeaking noise.’ I now realise the reason why my son got so distressed when a rubber teat on a bottle or dummy was put into his mouth.

- Parent

It is important to remember that when people are tired, unwell, in pain or stressed their tolerance levels are affected. This is also true of someone with autism and their ability to tolerate sensory stimuli may be impaired. Therefore, try to learn what sensory issues the person may have and the ways in which they cope with these so that you can understand and support them. On the next page is a list of things that may be helpful, and things that may challenge them. Through observation, you may be able to tell if suggestions on the list, or something similar, are relevant.

These things might help me...	These things might challenge me...
Look to the side of my face or over my shoulder when you are interacting with me	Direct eye contact
Address what you are saying to a nearby wall rather than directly to me	Direct communication
One person talking to me at a time	More than one person talking to me, other people's conversations
Neutral odours	Perfume, aftershave or other scents
Plain clothes	Patterned clothing
Dull coloured clothing	Bright coloured clothing
Uplighters	Strip lights
Red or green bulbs	Bright or white light, bright sunshine
A quiet environment	Kettles, engines, traffic sounds, phones
Quiet personal care	The toilet flushing, running water, fans, phones
Consistency	Different people responding to me in different ways
One thing at a time	Being bombarded by a lot of information
Knowing what is happening next	Unpredictability and chaos

Taken from 'Sensory Issues in Autism' by the Autism and Practice Group, East Sussex County Council

Some top tips relating to sensory issues:

- Observe the person and try to learn which sensory issues they may have — the more you can learn and understand, the easier it will be to support them.
- If they are upset, distressed or behaving in a challenging way, consider whether this is being caused by sensory issues. Dim lights, reduce noise levels to see if there is improvement.
- Be aware that they may only be able to utilise one sense at a time. For example, not looking at you does not mean not listening to you.
- When you've identified issues which trigger sensory problems, try to avoid these where possible and advise others where appropriate.
- Have a quiet time / space so that they can relax and regain their composure.
- Sometimes ear defenders, sunglasses and other sensory reducing equipment can help.

I discovered that we could have longer and deeper conversations over a cup of hot chocolate by candle light or with the dimmer switch turned down.

- Carer

7. ASD and Other Disorders

Some people with ASD may also have additional difficulties or disorders, which are not directly part of their ASD. These may be other neuro-developmental disorders that have been present from childhood (and may have been missed) or may be issues that have developed in adulthood.

Some conditions appear to affect individuals with ASD more frequently, although it is sometimes difficult for professionals to ascertain whether symptoms are part of the ASD or another condition. Some of these disorders are:

- Dyspraxia
- Dyslexia
- Anxiety
- Epilepsy
- Obsessive Compulsive Disorder (OCD)
- Attention Deficit Hyperactivity Disorder (ADHD)

It is important to recognise that individuals with ASD are not excluded from other mental health and physiological conditions, and professional advice should be sought if possible symptoms of another disorder occur.



Communication

As we mentioned earlier the way in which the person with ASD's communication is impaired can vary greatly. Communication issues may be more obvious in those who also have a learning difficulty, but those people who have a higher functioning ASD will also have impairments in communication and their apparent level of language can sometimes be misleading.

These impairments in communication can cause problems in giving information to and gaining information from them. Being aware of these difficulties and adapting your own communication style will go some way to ensuring that individuals understand what you are asking them and ensuring you get the most accurate response. They may require support to understand and express language.

Language

People with autism will often have a very literal understanding of language. This means that figurative language may be interpreted literally, and this can cause anxiety, confusion or misunderstandings. A simple example of this is the phrase 'hop on the scales'. To those who can interpret figurative language this means that they are being asked to stand on the scales but when interpreted literally, it means that they are being asked to stand on one leg and jump up and down on the scales. Therefore figurative language including idioms, metaphors and similes should be avoided when interacting with someone with an ASD. Here are some examples of other everyday sayings that can cause confusion for an individual with autism.

Idioms:

- "Make up your mind"
- "You're barking up the wrong tree"
- "Pull your socks up"
- "Don't make a mountain out of a molehill"
- "That's the pot calling the kettle black"

Metaphors:

- "She's an old flame"
- "Dad is a rock"
- "You are an angel"
- "Bill is a snake"
- "My head was spinning"

Similes:

- "He is as rich as a king"
- "She is as cool as a cucumber"
- "As bright as a button"
- "You are as cold as ice"

Don't be misled by the individual using metaphors themselves. They may be repeating them but not understanding them, or they may have learned the meaning of some of them over the years. This does not necessarily mean they will understand your use of them, especially if they are not familiar with them.

Many people with an ASD have a higher level of expressive language (the language they use) than receptive language (understanding the language you use). Therefore do not assume that they can understand the same level of complex language as they use.

Long, complex instructions and statements can often be confusing, as can adding in phrases that are not needed (for example, 'if you know what I mean', 'I couldn't believe it', or 'you know what she's like').

Tone, Pitch, Volume and Speed of Voice

Most people alter the tone, pitch, volume and speed of voice in response to the social situation we are in or in order to convey emotion to the people we are talking to. If we say "I can't believe it" in a high pitched, fast, varied tone of voice most people will assume that we are excited about something, whereas if this is said in a low, monotone, slow voice the assumption will be that we have had bad news. Some people with an ASD find it difficult to do this. For example, they may talk loudly in situations that require a quiet voice, or may talk in a monotone voice all the time.

They also find it difficult to interpret the changes in your voice and guess what they mean. For some, changes in voice patterns can provoke anxiety as it is often unexpected and can cause sensory issues. Be calm and consistent when addressing individuals with an ASD, and use language or pictures to explain things, rather than relying on changes in your voice patterns.

Eye Contact

People with autism often have an unusual way of using eye contact and some describe feeling uncomfortable with maintaining eye contact. As mentioned previously, sometimes sensory issues mean that in order to pay attention to words that are said the person with ASD has to avoid looking at you. Forcing eye contact can make the person very distressed.

We often use eye contact to indicate to another person that we are addressing them, if the person with an ASD has issues with eye contact, say their name first to let them know instead.

Facial Expressions

Many people with an ASD have difficulties in conveying and interpreting facial expressions. They may not communicate their feelings using facial expressions and may appear flat or unaffected by news you have delivered even if this may not actually be the case.

They may not be able to accurately read or interpret your facial expressions. We often rely on others reading our expressions in our communication and this is often how others work out if you are annoyed, happy or being sarcastic. Remember that individuals with an ASD cannot interpret this, so say what you mean and don't use sarcasm.

Body Language and Gestures

We often communicate our intentions, wishes and feelings using body language. Crossed arms often mean annoyance, open arms often signal affection. Individuals with an ASD may interpret these incorrectly or not notice them at all. This can lead to social mistakes or the presumption of aloofness. Don't rely on these when interacting with someone with an ASD.

Gestures are often used to explain or emphasise a point, and can often be misinterpreted or missed. Avoid using where possible.

Other Issues

If the individual has sensory problems or difficulties, it may be difficult for them to focus on what you are saying if the area around them is busy or chaotic. Try and reduce sensory information (noise, smells, bright lights) before talking to them.

People with an ASD may need longer to process information. Allow time for this and check they have understood.

Using generalised questions that may produce misleading answers, for example, "How are you feeling?" may get a learned response of "Very well, thank you", but asking "Have you got a headache?" may get a "Yes", because it is a more specific question.

People with Autism often do not offer any more information than they are asked for. For example, if asked "Can you reach the milk out of the fridge?" they may answer "Yes", but may not offer additional information such as "But only if I stand on tiptoes on a box", or they may not carry out the task based on the question posed.

Many adults may have a preference for communicating via email, text or in writing.

Individuals with autism often benefit from the use of visual support to aid communication. Objects, pictures and symbols are often used to support communication, and can help individuals to understand language, information and routines and also to express themselves.

Some examples of a visual support include:

- Photographs of meals to choose what they would like for tea.
- Visual schedule of activities so individuals can see what is planned for the day.

Some top tips for supporting communication:

- Ensure you have their attention, say their name before beginning.
- Minimise sensory distractions such as noise, bright lights and busy rooms.
- Use a clear, calm voice.
- Keep things short and straightforward.
- Allow the person some time to process information and check that they've understood.
- Avoid using idioms, metaphors and similes.
- Use facts to explain things, avoid analogies and never use sarcasm.
- Don't rely on body language, gestures and tone of voice.
- Ask specific questions.
- Use pictures to help explain things.
- Always check you have been understood.
- Do not overload the person with lots of verbal information.
- Allow time to express their view and be patient. Increased anxiety may reduce the ability to communicate verbally.

Anxiety

One of the most debilitating issues experienced by the person with ASD is anxiety. Most people with an ASD experience anxiety at one time or another. For some this is a chronic issue that affects every aspect of their lives. For others, it may occur in relation to specific events or activities and for others, it may come and go throughout their lives.

Anxiety is often the cause or trigger of other behaviours that might be impacting on daily life.

Some people with an ASD may not be able to verbalise their anxiety or may not be able to understand that the physical symptoms they are experiencing are related to anxiety. They may engage in behaviours that are a way of communicating their anxiety. Behaviours may also be caused by them avoiding anxiety provoking situations or people, or by eliminating anything that is not predictable.

Some of the behaviours you might see are:

- aggressive behaviour
- becoming withdrawn and resisting any interaction with others
- avoidance
- increase in repetitive behaviours
- self injurious behaviours
- restlessness and over activity
- limited attention span
- low mood
- using alcohol to cope with anxiety
- becoming distressed

“One thing autistic people are often particularly good at is worrying.”

- Marc Segar

Being aware that someone is anxious is the first step in trying to help.

Causes of anxiety are numerous, some obvious and some not, which makes it very difficult to eliminate it. We all experience anxiety. It is part of our everyday life, and we all react to stressful situations in a way which is personal to us, but the symptoms of anxiety are often similar. We cope because we are able to recognise what anxiety is and more often than not, we can recognise why. This is difficult for people with an ASD.

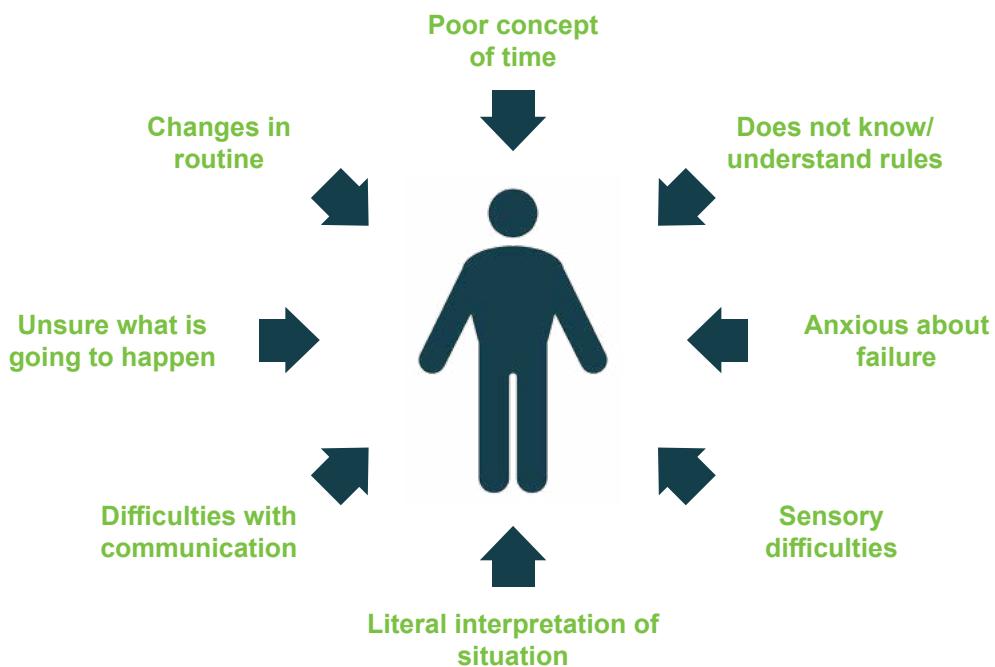
People with ASD experience anxiety for a variety of reasons, which can include:

- lack of structure to the day
- meeting strangers
- being given too many choices
- not being able to communicate their needs/lack of understanding
- changes in routine
- new activities or places
- experiencing unpleasant sensations, eg dog barking, flashing lights, crowded and noisy environments, overpowering smells
- transition from one activity to another — even small transitions
- trauma - remembering unpleasant events, for example, having a haircut, seeing the dentist or doctor, which when being asked to repeat makes them anxious
- physical causes such as pain, itching or discomfort

Reality to an autistic person is a confusing, interacting mass of events, people, places, sounds and sights. There seem to be no clear boundaries, order or meaning to anything. A large part of my life is spent just trying to work out the pattern behind everything. Set routines, times, particular routes, and rituals all help to get order into an unbearably chaotic life.

- Joliffe, 1992, p.16

Frequently, somebody with an ASD can be anxious about more than one thing at a time which can lead to high levels of anxiety and associated behaviours.



In order to decrease their anxiety, the person's quest in life can become one of routine and predictability. Some individuals may want to control situations or take part in things only on their terms.

Tips that might help

- Consider if anxiety could be the cause of behaviours, keep a record.
- Reduce sensory triggers in the environment.
- Adapt your communication appropriately.
- Encourage the person to use planners to help predict the day.
- Use lists and encourage person to mark what has been completed.
- Undertake things as planned, be on time for meetings don't make last minute changes where possible.
- Ask the person with ASD to tell you about recent events or write them down, you may be able to help them realise what has caused them anxiety.
- Give warnings before activities are about to end or something is about to start.
- Encourage some exercise, even running on the spot can help to reduce physical symptoms of anxiety.
- Seek professional help, sometimes therapies or medication are appropriate.

Long before any diagnosis of Asperger syndrome, my family found out that lists helped me remember to do things, so there were lists for everything. Notes from Mum about what she is doing in the day, such as when she goes shopping without me. Cooking, chores for the day, to do list, phone numbers, Timetables listing when I have to be somewhere, worked out the night before (and the list could go on). Lists are good if they help you organise your life. I love lists and they really help me.

- Karen Thompson

Social Skills and Relationships

Most of us learn how to interact with others and initiate and maintain relationships as we grow up. Some elements are learned through being taught by others, for example, eating with a knife and fork; whereas some just appear to come naturally as we develop, for example, maintaining space between us and the people we are talking to. Many of our social behaviours develop from our thoughts about how we expect others to interact with us, for example, we say nice things to people because we like it when people say nice things to us.

Individuals with an ASD do not develop these skills in the same way, and frequently struggle to understand social rules and the nuances of social interaction.

Impairments in social imagination often mean that someone with an ASD struggles to predict how others think or feel, for example, they may point out that someone is overweight without realising that this can cause offence.

Issues with interpreting social communication may mean that they miss cues, for example, when somebody is annoyed or bored. Most people would assume that someone is bored if they are yawning and checking their watch. Someone with an ASD may not notice this, and will keep talking about the same subject, which can lead to people avoiding them in the future.

As with other impairments, the level of social skills varies from one person to another, — but impairments have a significant impact on the ability to maintain friendships, secure employment and engage in leisure activities.

Some social rules and knowledge of social expectations can be developed through training. Many people with an ASD tell us that they would like to understand what is expected of them, as this is often unclear in a social situation and training can help with this. Other elements are more difficult to explain, for example, why is it OK to lie at times (for example, 'I'll be there in a minute') and not at others (for example 'I didn't do it').

There are many structured programmes that address social skills. Some are run as group interventions and others can be purchased as work books or DVDs.

However some social skills can be taught by anyone supporting someone with an ASD. Improving social skills can help people with an ASD to access social relationships and activities and feeling confident about what is expected of them can reduce anxiety.

Some tips:

- Teach social skills as 'rules'.
- Use short explanations.
- Use language that has a clear meaning.
- For social rules that vary in relation to situation, be clear about the situation you are talking about.
- Practice in a variety of situations.
- Explain legal issues clearly, e.g. it is illegal to take things that don't belong to you.
- Make sure you explain social interaction in relation to age, social rules change as people get older and in relation to whether we are interacting with children or adults.
- Plan your approach, and go slow. Choose two or three items and work on these first.



What about Family and Friends?

For Family and Friends

Receiving a diagnosis in adulthood maybe a shock for some people, whilst for others it is a relief to have an explanation for the difficulties they may be experiencing. Each person will react differently to the diagnosis, as will those who are close to the individual with an ASD.

There is no right or wrong way to feel when someone close to you is diagnosed with an ASD. People may experience a variety of emotions around this, and these can often change on a daily basis.

It is quite normal to experience feelings such as:

- Sadness
- Anger
- Relief
- Denial
- Guilt
- Frustration
- Fear
- Grief

It is important to remember that the person you support is still the same person they were before they received their diagnosis; they have not changed. The positive change is that now that they have a diagnosis you will be better able to understand them and their needs.

For those Supporting Family and Friends

Living with someone with an ASD can be stressful due to their needs or behaviours. This will more than likely have been the case for a long time before the diagnosis is received. This may have caused a lot of tension in the family home from childhood and in the current home, this may have had a negative impact on relatives and the individuals their selves.

The diagnosis may also make a difference to relationships with wider family members and family friends. Any behaviours that may have been previously interpreted as 'odd' or 'rude' are now explained and this can help to heal relationships that may have broken down.

For those who support from outside the family / friendship circle it is important to consider the emotional and learning needs of family members, siblings, parents, partners and children following diagnosis.

Having the diagnosis changed relationships with family, especially with my Mum and continues to do so every day. We still have misunderstandings from time to time and we are still learning about how each other sees the world, in these things we are no different from a lot of other people. I see the world quite differently than my Mum does and this is alright, but life is a lot, lot better knowing that I have Asperger syndrome because we now know the truth and life can move along as we learn together.

- Karen Thompson

Some top tips for family and friends:

- Consider contacting / joining a support group.
- Talk to someone you trust and feel comfortable with about how you are feeling.
- Make time for yourself and time to relax.
- Learn about Autism — this guide is a good starting point.
- Talk to professionals, write down any questions you have ahead of any meetings.
- Remember you are not alone.

Understandably, when a person is diagnosed the thoughts and advice flow to the parents, but people do have a tendency to forget about the siblings and how it can impact upon them too. There are many difficulties that can be encountered, however these are equally measured with the good times and memories that can be created.

- Sibling

The realisation that there is an underlying neurological reason has been an enormous relief for my wife, Judy. The realisation that marriage of an Aspie and a neurotypical will encounter considerable difficulties has been of great help in enabling us to work at tackling the problems.

- Ian Walker



Further Information

www.ASDinfoWales.co.uk is the National website hosted by the National ASD Development Team within the WLGA in partnership with Public Health Wales and funded by Welsh Government.

Visit the website to view further information and resources for individuals with ASD and those supporting them.



Notes