

# Understanding Autism - Ageing

Ageing with Autistic Spectrum Conditions



Developed in partnership with



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## Purpose of this booklet

**T**his booklet has been written to support improvement in the level of understanding of autistic spectrum disorders.

The booklet provides information about the ageing process for people living with autism and some of the inequalities faced.

It is appreciated that there are many terms used to describe people living with conditions as defined on the autistic spectrum.

The terms autism, autistic people and people living with autism will be used in this document to encompass all Autistic Spectrum Conditions (including Asperger's Syndrome).



# What is Autism?

**Autism is a lifelong development disorder which affects how a person communicates with, and relates to, other people. It also affects how they make sense of the world around them – National Autistic Society**

**A**round 1% of population are believed to be autistic, which means that there are over 700,000 people living with autism in the UK.

It is estimated there may be around 7,800 people in Derbyshire County and 2,500 people in Derby City living with autism.

Everyone on the autistic spectrum is different and unique and the condition is not always apparent, but they all share three core social difficulties:

- social interaction
- social communication
- social imagination

As a result people on the autistic spectrum can struggle in social situations. For example they may:

- find it hard to begin or carry on a conversation
- not understand how far to stand from somebody else
- find it difficult to make friends.

People with autism may also display restricted and/or repetitive patterns of behaviour, interests, or activities. For example they may:

- develop an overwhelming interest in something
- follow inflexible routines or rituals
- make repetitive body movements
- be hypersensitive to certain smells, tastes or sounds.

Autism is not a mental health condition; however, due to the social difficulties that people living with autism face, many may suffer with mental ill health.

Autism is not a learning disability, however, around half of people with a learning disability are also diagnosed as having autism. People with autism that do not have a learning disability may experience learning difficulties

because of their autism, for example, they may find it harder to structure tasks.

Awareness of autism in society is good, but understanding of the condition and the way the condition affects communication, sensory experience and behaviour, is not as good.

Too many myths about autism still exist, including the belief autistic people lack empathy or that everyone with autism is the same.

There are neurological differences between people with autism and people who are viewed as 'normal'. Autism is an example of neurodiversity. People without autism are often referred to as 'neurotypical' by people within the autistic community. Some people with autism use these terms to explain and make sense of the neurological differences that exist between them.

## Social communication

**M**any people living with autism have problems with communication, both verbal and non-verbal. They may find it hard to process language and could find it difficult to follow long or complex sentences, or to follow instructions. People with autism can find it difficult to interpret a person's tone of voice, their body language or their facial expression. They may also find it difficult to maintain eye contact with others.

In some cases, autistic people may have no, or very limited speech, but can understand what people say to them. They may prefer to use a different form of communication, such as symbols or sign language.

People with autism often take information very literally and they may not be able to understand sarcasm, jokes, hidden meanings, and figures of speech that people use in every day life.

## Social interaction

**M**any people living with autism have difficulty in understanding social rules and interactions. They find it hard to recognise and understand the emotions that other people display, and find it difficult to communicate or explain their own emotions and feelings. They may also find it difficult to manage their emotions.

People with autism may appear to behave strangely or inappropriately due to the way they express feelings, emotions or needs. They, for example, stand too close to another person, accidentally invading their personal space.

Many people with autism prefer to spend time alone or isolate themselves from others, they may not seek comfort from other people and may not show any interest in other people's opinions or interests. This can come across as rudeness, withdrawal from, or disinterest in the people they meet, making it hard for them to keep friends.

## Social imagination

**P**eople with autism can find it difficult to understand other people's intentions and behaviour.

They may find it difficult to imagine situations that are outside their own routine. They might find it hard to predict what will, or may happen if they are faced with change, so often limit themselves to only a small, repetitive range of activities.

Some people with autism may also have difficulty in understanding the concept of danger.

A lack of social imagination should not be confused with a lack of imagination. Many people with autism are very creative.

## Sensory Differences

**M**any people with autism have sensory differences, including heightened sensitivity (hypersensitivity) or under-sensitivity (hyposensitivity), to one or more sensory stimuli - for example, sound, light, textures, smells and taste. These sensitivities can also make being touched difficult and can sometimes result in sensory overload and some people can switch between the two.

People with autism may also engage in stimming (self-stimulatory behaviours), as a means of helping them to feel less anxious. Examples of stimming are flapping hands and tapping fingers.

**A**utism is a spectrum condition, which means that people with autism have a wide range of ways in which they may communicate and interact with people. They also have differing abilities, interests and difficulties, which can vary dependent upon the environment and stressors they are currently dealing with. Autism is sometimes called a “hidden” disability because not every person with autism presents with the same or with obvious characteristics. For example, people with autism can have good eye contact, be sociable and share normal interests. This can be particularly true in women or girls who may attempt to engage in social activity more frequently than males and may try to mask their difficulties by copying the behaviour of others. Problems may only become apparent when individuals are expected to be highly flexible and tolerate a lot of environmental demands.

It is important not to generalise or stereotype the behaviours of people with autism, otherwise we may expect and/or try to predict certain behaviours, which could have a detrimental effect on people living with autism in a number of different ways.

Remember that:

**‘If you have met one person with autism you have met one person with autism’**

# Ageing with autism spectrum conditions

The first generation of people diagnosed with autism in childhood are now reaching old age, and mature adults are being diagnosed with autism for the first time. This means that there is a need to consider the impact of the ageing process on people with autistic spectrum conditions (ASC).

Evidence suggests some people with autism may experience age-related changes at an earlier age and higher rates of age-related conditions than the general population.

The research into learning disabilities and ageing, and dementia and its progression means that we understand more about the needs of people who are ageing with autism.

## Understanding Ageing

As people with autism get older, they will experience the same physical and mental changes that all older people may face, including arthritis, hearing loss, impaired vision, loss of mobility and dementia. As people with autism age, it is important that they are helped to understand these changes.

Each person will have different symptoms, some being more complex and severe than others. Some have sensory problems or difficulties with language and communication; some have additional intellectual disabilities. Others have average or higher than average intelligence but may have difficulty organising their everyday life. Many have anxiety, depression or other mental health problems.

Support staff working with older adults with ASC will find it helpful to learn as much as they can about the people they are supporting, and how they personally experience autism, so that they can identify age-related changes and provide the best possible support tailored to their individual needs. This knowledge will also help staff to identify changes in behaviour that indicate the person with autism is experiencing difficulties as they age.



## Ageing and social interaction

Older people are at greater risk of loneliness than the general population. Problems with Communication, personal interactions and behaviour can all lead to increased social isolation for people with autism. Older people ageing with autism are, therefore, doubly at risk of isolation and loneliness.

Many people with autism develop strong interests and age can make it



difficult for them to continue with these, leading to significant distress. Support to continue their chosen interests or to find alternative activities may help them to maintain their independence. This is essential to the overall wellbeing, healthier ageing and improved life expectancy in people with autism.

As change is an inevitable part of ageing, this can be a difficult time for people with autism. Ageing can limit activity and mobility making it harder to maintain activities relating to employment or sport that they may have previously participated in. The time may also come when the effects of ageing mean that they can no longer remain living in the place that has been their home for many years.

They may also face uncertain changes as their carers and other members of their social support network get older, this could include issues surrounding loss and bereavement. It is important that we help and encourage an autistic person to prepare for the changes they will face as they age.

## Communication

**M**any people with autism have problems with either, or both, verbal and non-verbal communication. Some may find it very easy to talk about a subject they find interesting, but may find it difficult to understand when someone is talking to them, or to follow instructions. Some people may have no or very limited language, but are able to communicate effectively by other means such as symbols or sign language.

Key points to consider are:

- Use clear and concise language in short sentences. Use visual tools and prompts as much as possible. Do not use slang, jargon, sarcasm or irony.
- Do not expect people to be able to interpret facial expressions or body language. Do not expect to keep eye contact. Keep hand gestures and other non-verbal communication to a minimum.
- Explain who you are and what you do; include specific examples of what your work involves.
- Make your language age appropriate, for example an older person probably would not understand modern abbreviations or “text speak”. If they do not understand what you are saying, they might not ask, either due to a lack of confidence, or because they would just not think to do so.
- It may be helpful to back up what you say by also providing the information in an easy read format and/or by using visual aids, pictures or a short DVD.
- Ask questions to check that you have been understood and repeat back the conversation if possible, so that the person has a chance to absorb the information and identify any questions they have.
- Allow time for people to process one piece of information before moving on to the next; this means that a conversation will take longer than might be expected. Be patient, and try not to interrupt as this may add to any confusion and cause anxiety. People with autism find it more difficult to concentrate and to remember information when they are anxious or frightened, or making changes in their routine, environment or staff.

- Be aware that people with autism frequently interpret what is said very literally. Failure to do something promised, or to arrive on time, may cause distress and anxiety. This may damage the relationship that you have built up. A person with autism may need time to form a relationship with you and it is important to invest the time to establish trust and confidence.
- Change can cause a lot of stress and anxiety for an autistic person so the more they can be prepared, the easier it will be for them; this is best done by someone who knows the person well.
- Plan visits (for example; to the dentist, optician, GP) or meetings in advance, using the person's preferred method of communication to make the arrangements (for example; text, letter, email, phone); make sure this is followed up by sending confirmation in writing. It may be helpful to include a photograph of any people they don't know who will be present at the appointment; this can reduce their anxiety and they will be more likely to attend.
- Be clear about the date, time and location as inconsistencies can be confusing for people with autism.
- Where meetings have to take place outside the person's home, make sure that the venue meets their needs. It should be quiet, without distractions and preferably somewhere they know. It may be necessary to remove items such as ticking clocks or telephones, and shiny or brightly coloured objects. Check whether they will be able to wait in an ordinary waiting room and make alternative arrangements for a quieter place with fewer stimuli if needed. Make staff aware of the person's communication needs and any sensory issues (for example bright lights, noise, smells).
- Explain to them what they will need to do when they arrive, for example to sit down in the waiting room and wait to be called. Make sure that they know where the toilet is. Tell them about any equipment that will be used, what it does and what it is like.
- Make sure that you are on time for the appointment and make sure the appointment finishes on time; being either late or early could cause great distress and may mean that the appointment cannot go ahead.

- Explain what will happen next clearly and concisely and write down what the person needs to do and in what order; text or email this information to them if that is their preferred means of communication. Consider whether they has any special interests that they can enjoy while they wait, such as listening to music, or can be accompanied by a family member, friend or carer who may be able to help the person to feel safe and calm.

## Health

**S**ome people with autism may experience age-related changes and higher rates of specific conditions earlier than others, so there is a greater need to monitor their health. Making sure that they receive their annual health check is important.

It is important to be aware that people with autism are more prone to side-effects from medication, particularly anti-psychotic medication, which they may have been taking for many years.

Supporting people with autism to maintain, or increase, their activity levels as they get older can improve their physical and mental health and wellbeing. Being physically active will help them to remain independent and in contact with their friends and the wider community. Physical activity can also help them manage their stress and anxiety levels and have a positive influence on their quality of life.

## Sensory Sensitivity

**P**eople with autism may be hypersensitive or hyposensitive to sounds, light, colours, touch, smells, tastes, temperature or pain. For example, they may find certain background sounds, which other people ignore or block out, unbearably loud or distracting, or even painful, or they may be fascinated by lights or shining objects.

Most people will experience changes in their senses as they grow older. For people with autism, these changes may make their pre-existing problems worse, and can impact on their quality of life, safety in their environment and their physical and mental wellbeing. It is important that people with autism are given the right support to help them manage these changes.

Age related sensory changes can occur earlier in people with autism, and

monitoring for these changes may need to begin as early as 40 years of age.

Key points to think about include:

**Sight** – changes to vision may impact on a person's mobility, making it harder to get around safely. This can result in them becoming more isolated. It is important to make sure that vision is tested regularly to minimise the risks and that any correctable sight loss is detected.

**Hearing** – sometimes, a lack of response does not mean an individual is deliberately ignoring the conversation; they may simply be unaware of it. Regular hearing tests may be required to make sure that older people with autism have any correctable hearing loss detected.

**Proprioception** - (this is about how the body moves, and special awareness) examples of proprioception can be people finding it increasingly hard to do up buttons or zips. People may appear more unsteady on their feet or trip or fall more often. They may become increasingly clumsy, repeatedly dropping or bumping into things. As the risk of falls increases with age, it is important to remove potential trip and other hazards from their environment as far as possible. A referral for physiotherapy may be helpful.

**Balance** – changes in balance are closely linked to proprioception, vision and hearing. Older people who develop problems with balance may appear very deliberate when moving or their movements may become uncoordinated. They may develop difficulties with activities of daily living, such as getting dressed and their usual physical activities such as sports, could become more challenging. As a result, individuals may appear fidgety and behaviours such as rocking may increase. It is important to understand that these behaviours may be a response to their sensory issues, and it does not necessarily mean they are agitated, ill or under the influence of drugs or alcohol. The movements may be something they enjoy or find calming.

**Touch** – Both hypersensitivity and hyposensitivity to touch are common issues in people with autism. Age related changes can lead to a decrease in sensitivity and it is important to be aware that this could lead to an increased risk of injury.

**Smell** - people with autism may be hypersensitive or hyposensitive to particular smells. Some smells could be overpowering and unpleasant so they may try and avoid them. If they like a particular smell they may actively seek it out. Sensitivity to smell can decrease with age and can have an impact on the taste and enjoyment of food. This can impact the amount of food they eat, and affect their overall health. Older people may need support to find ways to adapt to these changes, for example by increasing the stronger flavours in their diet.

It is important to be aware that people with autism may use smell to help them recognise different people. If a person changes the source of that odour, for example by changing their soap or shampoo, this can make recognition harder, and can cause anxiety or confusion for the person with autism.

**Taste** - a good, well balanced diet is an important part of keeping healthy. Older people often report changes to their sense of taste as they age, and it may therefore be helpful to monitor the diet of older people with autism. Monitoring oral hygiene may also be helpful.

**Pain** – some people with autism may not have the same pain thresholds as others, and pain can be a difficult sensation for many to describe. This can have serious consequences if their pain is due to a condition such as an infection, which may become life threatening if left untreated. It can also be serious in conditions that affect people when ageing, as an early diagnosis and treatment can have a positive effect on the symptoms of degenerative conditions.

Sometimes it can be difficult to identify if someone is in pain. Try to pay close attention to changes in behaviour that may be quite subtle. Staff who know their clients well are in a good position to spot if the behaviour changes may be related to pain. It is important to be aware that self-harming behaviours or other anxiety-related behaviours may in fact, be indicators of pain.

## Conclusions

As people with autism age and they face the challenges of physical, mental and environmental changes as well as of loss and bereavement, it is important that both they, and the people who work with them, understand the process of ageing and its impact. Learning as much as possible about the person you support as early as possible will be beneficial; knowledge about someone's past helps provide better support for their future.

Remember that all people with autism are unique. Adaptations that work for one person may not be necessary for another, and different approaches may be required. People with autism may show signs of age related symptoms early, and so the support and services need to be age appropriate for their needs. Involve the person with autism in all decision related to them.



## Further information

- Derbyshire County Council: [www.derbyshire.gov.uk/adultswithautism](http://www.derbyshire.gov.uk/adultswithautism)
- National Autistic Society: [www.autism.org.uk](http://www.autism.org.uk)
- Derbyshire Autism Services: [www.derbyshireautismservices.org](http://www.derbyshireautismservices.org)
- NHS Choices: [www.nhs.uk/conditions/Autistic-spectrum-disorder](http://www.nhs.uk/conditions/Autistic-spectrum-disorder)

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