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Autism Aware

Full Film

To view the full film please click on the link below.

https://vimeo.com/289080530
Welcome to this e-book resource, which has been designed to accompany the ‘Autism Alert – Help Us To Help You’ film, supported by NHS England and produced in partnership with North Cumbria Clinical Commissioning Group, Cumbria County Council and Triple A (All About Autism).

Whilst these resources cannot possibly cover all there is to know about autism, we hope they help to increase understanding of autism and how this can impact lives. Showing how communication, sensory and environment issues can cause difficulties and how we can help has the potential to make a significant difference for autistic individuals – very often trying to navigate through a world that does not always make sense.

The resources are designed to be concise, relevant and non-technical. Throughout the e-book there are links to relevant points in the film and at the end there are hyper-links to trusted sources used for more information.

The film and accompanying e-book have been co-produced in concept, design and content. Characters are authentically played, i.e. roles of autistic individuals and health professionals are played by autistic and health professionals respectively. There is a great deal of information available about autism which can be overwhelming and confusing. This e-book brings together practical advice and guidance collected from trusted sources.

By listening to each other and working together, I believe we can all do our bit to move autism from being a so-called ‘invisible disability’ to an empowered and respected community of people with ‘diffabilities’.

Helen Storey
Founder, Triple A (All About Autism)
Put quite simply what an amazing film and an invaluable e-book! All health professionals will benefit from the content and undoubtedly deliver more effective interventions for children, young people, adults and their families. The content is very thought provoking and highlights the need for everyone to make reasonable adjustments in their working environments. Thereby, enabling people with autism to access health provision equitably and to ensure that they are treated fairly and with ‘parity of esteem’.

Harry Harrison
Children’s & Families, Commissioning Manager
North Cumbria CCG

This amazing film and accompanying e-book represent an important step towards recognising and addressing the inequality that exists for autistic people and their families when trying to access health services. It gives Health and Care professionals the tools needed to assess their services and implement the changes needed to ensure they meet autistic people’s needs. In the formative years of the NHS, Autism was not acknowledged and yet here we are today with what can only be described as a truly innovative and ground-breaking resource. Autistic people have a huge amount to contribute. Better understanding and improved Health and Care services have the potential to change our lives for the better and this resource is a much-needed step in that direction.

Karen Quinn
Triple A (All About Autism), Chair of Trustees
Hello, my name is Kath. I am a children’s nurse by background and I work in NHS England improving experiences in care importantly for and with people.

I am really excited by this suite of films and supporting e-book resource that has been developed with people who have autism. It will help guide us as healthcare professionals about how we meet the needs of people with autism in the best way possible.

Our actions can make all the difference, whether it be ensuring that we have the right communication skills, ensuring that we consider environmental factors and whether it is about the timing and how we engage with people. There is information for us all here – please do share the films, have conversations with colleagues. Together we can make sure that people with autism have much better healthcare experiences.

Thank you.
Hello everyone, my name is David Gill and I am a Learning Disability and Autism Advisor at NHS England.

As I have a diagnosis of autism, I related to that film and what happened.

Making those reasonable adjustments is important. For example, the mother giving her daughter the chance to make a choice whether she wanted her to come and support her or not was important because it makes you feel like you are not being treated like a child—it makes you feel like you are in control of that situation. Also, having those reasonable adjustments in a Doctors setting, or in any setting is important as it helps the person to get the right support that they need to get the service that they need.

This is also important to be transferred in an A&E setting so every child or young person can get the right care and support at the right place at the right time by the right person.

I hope you enjoyed this film and that the information in this film will help your clinical practice on a day to day basis.
About the Film

The film shows two separate scenarios — the first in General Practice setting, the second depicts a situation that takes place in Accident & Emergency Department (A&E).

*It should be noted that due to the nature and function of the department, the production team simulated A&E within Cumberland Infirmary.*

The first scenario is about a young person attending a routine appointment for a blood test with the Healthcare Assistant. The scene highlights a few difficulties experienced, some of which are quite subtle, for example literal language.

This section also shows how the young person on the autism spectrum benefits from having someone accompany her to the appointment – in this instance, it’s Mum.

The scene shows Mum enabling her daughter to navigate the experience in a subtle, non-obtrusive way. A key point to note is that the medical staff communicate directly with the young person.

The second scenario takes place in A&E Department. The scenes involved in this scenario show a couple of the self-help actions someone on the autism spectrum may do in order to cope with the situation, for example noise reduction headphones, practicing what to say and how to answer questions.

As with the first situation, there are subtleties to look out for …

*We hope you find the film and this e-book interesting and informative.*
CONTEXT

National Autistic Society estimates that 11 in every 1,000 people (1.1% of the population) are on the autism spectrum. This means if you are a GP with a list size of 2,000 people, you're likely to have around 22 people on the autism spectrum on your list.

What is Autism?

- Autism is defined as a lifelong neurodevelopmental condition that affects a person’s ability to:
  - communicate and relate to other people
  - function in certain environments

- Autistic individuals often have sensory processing difficulties; they can be over or under-sensitive in some or all their senses.

- Features typically begin to appear during childhood as social demands exceed capabilities.

- Autism is not a learning disability or a mental health difficulty.

- However, some people with autism may also have learning disability mental health issues, dyslexia, dyspraxia, ADHD and other disabilities/conditions.

- People with autism may acquire mental health problems, for example through isolation.


- Autism is a hidden condition, which can make it difficult to identify a person on the autism spectrum.
• Interaction without awareness of autism can sometimes lead to misunderstandings between neurotypical people and those with autism.

• Appropriate support can greatly improve the quality of life for autistic people

• Autism is a spectrum condition which means that each person on the autism spectrum will have very different abilities and challenges from another. Processing information is one of the major challenges for most.

“… because every autism is different.”
- Harry

[View this segment on Vimeo]
Autism: Fundamental Features

Theory of mind differences –
the ability to understand other people’s beliefs, desires, intentions, imagination and emotions
The fundamental features of autism impact on social and emotional interactions, creating difficulties understanding others and problems communicating in almost all aspects of life. Consequently, this affects how someone on the autism spectrum presents and impacts on behaviour, for example, rituals, routines, mannerisms that may appear strange, talking a lot, interrupting, etc.

The impact of having difficulties with theory of mind may include:

- **Understanding or explaining own behavior and emotions**
- **Predicting or understanding the behavior or emotional state of others**
- **Understanding the perspectives of others**
- **Guessing the intentions of others**
- **Understanding the way behavior impacts how others think and/or feel**
- **Being able to tell fiction from fact**

“People think I’m odd and very often avoid me”

(Credit: pexels.com. Zero (CC0) License)
How can autism affect a person’s life?

<table>
<thead>
<tr>
<th>The difficulty ...</th>
<th>&gt;&gt; which can fast forward to...</th>
</tr>
</thead>
</table>
| Contact with people/strangers | ▪ Distress and anxiety  
▪ Contact with other people, especially strangers, might be distressing |
| Lack of understanding | ▪ Cause, offence, appear insensitive or egocentric  
▪ They may often cause offence without being aware and appear rude |
| Relationships and friendships | ▪ Difficulty in forming and maintaining throughout life  
▪ Forming and keeping friendships might be more difficult throughout their life |
| Broken routine | ▪ Anxiety  
▪ May become anxious if routines are broken or changed |
| Period of uncertainty | ▪ Lack of structure and predictability can lead to anxiety and distress  
▪ Difficulty handling period of uncertainty |
| Unmet expectations | ▪ Anxiety, distress, anger  
▪ Angry or anxious if expectations are not met |

*Royal College of General Practitioners & Autism Alliance*
Communication

National Autistic Society: Most people on the autism spectrum have difficulty interacting with others. They may have difficulty with initiating interactions, responding to others, or using interaction to show people things or to be sociable. Understanding and relating to other people, and taking part in everyday family, school, work and social life, can be harder.

Additionally, that other people appear to know, intuitively, how to communicate and interact with each other, yet can also struggle to build rapport with autistic people. A 2016 study found that neurotypical people often quickly develop a negative bias towards autistic people in face to face social situations. However, these biases were not present when the conversation took place without audio-visual cues.

An autistic person can find it difficult to filter out the less important information. If there is too much information, it can lead to ‘overload’, where no further information can be processed.

“... it would take me a long time to explain what’s wrong with me”
- Adam

[View this segment on Vimeo]
• Autistic people often have difficulties with interpreting both verbal and non-verbal language, such as gestures or tone of voice.

• May find it difficult to use or understand: facial expressions; tone of voice; jokes and sarcasm.

• To demonstrate the significance on the difficulties this presents, studies on non-verbal communication find that only 7% of any message is conveyed through words; 38% through vocal elements and 55% through non-verbal elements such as facial expressions, gestures, posture, etc.

• May have a very literal understanding of language, and think people always mean exactly what they say. They could misinterpret your questions or instructions: low understanding of metaphor.

*Examples include* –

**Question:** “Have you passed water today?”

**Answer:** “Yes, I went passed the River Eden on the way here.”

**Question:** “Have your bowels moved this week?”

**Answer:** “I don’t know – I suppose they must have because I’ve been moving about all the time.”

Something to watch out for is ‘statement’ questions, for example – stating, “You are not allergic to anything.” as opposed to asking, “Are you allergic to anything?”.
To demonstrate literal understanding, below are some examples that if taken literally, these comments could potentially cause problems through misinterpretation:

**Statement:**
“You’re not allergic to micro-pore or plasters.”

**Question:**
“Are you allergic to micro-pore or plasters.”

**Statement:**
“You’re not allergic to anything.”

**Question:**
“Are you allergic to anything?”

Did you notice what happened when the receptionist asked Hannah to ‘take a seat’?

[View this scene]

Additionally, some people may not understand humor or sarcasm.
- Perceived vagueness in questions may lead to confusion and create anxiety
- Will not ‘read between the lines’ or pick up on hints
- No filter – not trying to be hurtful, just verbalising thoughts
- Can sometimes look angry when not or may have learnt to smile despite their feelings

- Generally, avoid eye contact, although this is not always the case.
- Often have difficulty knowing when to start or finish conversations
- Can have problems picking up on the non-verbal clues in others
- Some people may not understand humour or sarcasm
- Body language can be mis-interpreted or misunderstood, so distracting habits should be avoided as much as possible.

Being specific when communicating with individuals on the autism spectrum is important.
Some individuals on the autism spectrum use tools and techniques to help themselves communicate. Some examples are:

**Script Writing**
Writing down a script – for example questions that they want to ask or things that they would like to say.

**Rehearsing**
Practice what they want to say & perhaps rehearse scenario beforehand including the questions they may be asked.

**Bringing Someone**
Take someone along to help navigate situations.

**Using Alert Cards**
Present something that says they are autistic, for example an alert card or a hospital passport.

“The use of the Health Passport would be helpful to me so it can cut out communication issues and it would make me feel like I was not repeating myself all the time.”
- Daniella
[View this segment on Vimeo]
Communication: Top Tips

1. Use **less words** and try not to speak fast.

2. Pause between words and phrases to give the person time to process what you’ve said, and to give the person chance to think about their response.

3. Don’t use too many questions.

4. Do not rely on non-verbal communication (e.g. eye contact, facial expressions, gestures, body language) and try to use less when a person is showing signs of anxiety.

5. **Use visual supports** (e.g. symbols, timetables, Social Stories™).

6. Be aware of the environment that you are in. Sensory input may be affecting how much they can concentrate on what you are saying, making it even harder process (e.g. noisy/crowded).
The Environment and Sensory Differences

Most people on the autism spectrum may be either over-sensitive or under-sensitive – sometimes both, which could be experienced at different times. This directly impacts on the behaviour of a person, consequently affecting a person’s life – particularly how they are perceived by others who are not familiar or aware how an environment can affect someone who is autistic.

It is quite normal to become stressed when experiencing sensory overload, but this happens far more regularly for those on the autism spectrum mainly because sensory processing is very often different in autism. Individuals can quickly enter a ‘fight or flight’ mode and need to escape the situation very suddenly. If someone is presenting with behaviour that seems unreasonable, look at the environment to see if it is creating difficulties. [link here to chapter on reasonable adjustments]

National Autistic Society (NAS) state that sometimes an autistic person may behave in a way that you wouldn't immediately link to sensory sensitivities. A person who struggles to deal with everyday sensory information can experience sensory overload, or information overload. Too much information can cause stress, anxiety, and possibly physical pain. This can result in withdrawal, so-called challenging behaviour or meltdowns. NAS has listed some of the effects of hypersensitivity or hyposensitivity to and ways we can help.

Sight

Under-Sensitive

- Objects appear quite dark or lose some of their features.
- Central vision is blurred but peripheral vision quite sharp.
- A central object is magnified but things on the periphery are blurred.
- Poor depth perception, problems with throwing and catching, clumsiness.
- Ways you might help include the use of visual supports or coloured lenses, although there is only very limited research evidence for such lenses.
**Over-Sensitive**

- Distorted vision - objects and bright lights can appear to jump around.
- Images may fragment.
- Easier and more pleasurable to focus on a detail rather than the whole object.
- Has difficulty getting to sleep as sensitive to the light.

**Sound**

**Over-Sensitive**

- Noise can be magnified, and sounds become distorted and muddled.
- May be able to hear conversations in the distance.
- Inability to block out sounds – notably background noise, leading to difficulties concentrating.

**We can help by:**

- Shutting doors and windows to reduce external sounds.
- Preparing the person before going to noisy or crowded places.
- Providing ear plugs, noise reduction headphones or music to listen to.

**Smell**

**Under-Sensitive**

Some people have no sense of smell and fail to notice extreme odours (this can include their own body odour).

**Over-Sensitive**

- Smells can be intense and overpowering. This can cause toileting problems.
- Dislikes people with distinctive perfumes, shampoos, etc.
We can help by:

- Using unscented detergents or shampoos
- Avoiding wearing perfume
- and making the environment as fragrance-free as possible are all actions that can help, where practical.

Touch

Under-Sensitive

- Holds others tightly - needs to do so before there is a sensation of having applied any pressure.
- Has a high pain threshold.
- May be unable to feel food in the mouth.
- May self-harm.
- Enjoys heavy objects (e.g. weighted blankets) on top of them.
- Smears faeces as enjoys the texture.
- Chews on everything, including clothing and inedible objects.

Over-Sensitive

Touch can be painful and uncomfortable - people may not like to be touched and this can affect their relationships with others.

We can help by:

- Warning the person if you are about to touch them - always approach from the front.
- Remembering that a hug or a handshake may be painful rather than comforting and welcoming.
- Allowing a person to complete activities themselves so that they can do what is comfortable for them.
- Turning clothes inside out so there is no seam, removing any tags or labels.
- Allowing the person to wear clothes they're comfortable in.
Balance (Vestibular)

**Under-Sensitive**
- A need to rock, swing or spin to get some sensory input.
- Stands too close to others, because they may not be able to measure their proximity to other people and judge personal space.
- Finds it hard to navigate rooms and avoid obstructions.
- May bump into people.

**Over-Sensitive**
- Body awareness (Proprioception)
- Our body awareness system tells us where our bodies are in space, and how different body parts are moving.

**We can help by:**
- Positioning furniture around the edge of a room to make navigation easier
- Putting coloured tape on the floor to indicate boundaries
- Using the 'arm's-length rule' to judge personal space - this means standing an arm's length away from other people.
The Royal College of General Practitioners and Autism Alliance consulted with 72 parents in North England about issues with contact with GP services for their children on the autism spectrum:
### Reasonable Adjustments

There are ways that a GP practice or hospital location (where applicable) can make it easier for someone on the autism spectrum to access their services. The following suggestions have been made by Royal College of General Practitioners and Autism Alliance on ways the surgery can help to make the most of a visit to the surgery:

<table>
<thead>
<tr>
<th>Suggestion</th>
<th>Details</th>
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<tbody>
<tr>
<td>Ensure their diagnosis is coded as a significant active problem on the records.</td>
<td></td>
</tr>
<tr>
<td>Ensure their carers are on the Carers Register if appropriate.</td>
<td></td>
</tr>
<tr>
<td>Highlight any reasonable adjustments that are needed to allow the patients or their carers to access services.</td>
<td></td>
</tr>
<tr>
<td>Ensure these adjustments are clearly “flagged” on the records.</td>
<td></td>
</tr>
<tr>
<td>If someone is registering at the practice and they are anxious about visits, arrange some time to visit without an appointment and when no interventions are needed.</td>
<td></td>
</tr>
<tr>
<td>Encourage them to use a hospital passport and take it to appointments in case they see a member of staff who does not know them.</td>
<td></td>
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<tr>
<td>If they do not understand something – encourage them to say so.</td>
<td></td>
</tr>
<tr>
<td>If you refer them to hospital or to another secondary service for tests or treatment write on the referral letter the reasonable adjustments they will need.</td>
<td></td>
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</table>
Very often, small changes to the environment can make a significant difference – or at least being aware of items in the environment that can create challenges, will also help understanding. The National Autistic Society produced the following guidance for designing spaces.

**Colour and patterns**

It is generally accepted that low arousal colours such as cream (not yellow or white) should be used for walls and patterned wallpaper should be avoided. Soft furnishings should also be kept plain. Single-colour, painted walls can also eliminate the possibility of wallpaper being removed.

Patterned floors can be confusing to walk across and may increase anxiety or cause people to become fixated.

**Lighting**

Fluorescent or harsh lighting can hurt the eyes of an autistic person. Many say that they can see these types of lights flickering or hear them hum, this can be distracting. Due to these difficulties, it is best to use soft lighting where possible. Adjustable lighting in some rooms can be calming.

**Curtains and blinds**

It has been suggested that it’s best to avoid using slatted blinds, particularly vertical ones, as these can be distracting. Curtains may be a better option, with blackout curtains helping someone who is particularly sensitive to light. If someone tends to pull on curtain rails, curtains can be held up with Velcro.

Plastic stick-on covering can also be placed on windows, giving privacy while letting some light in.

**Noise**

Some autistic people can’t filter out noises that other people simply block out or ignore. Furnishing can help to reduce noise levels. For example, carpet or soft flooring is quieter than laminated flooring which can be noisy. This type of furnishing can also create a feeling of cosiness and safety.

**Smells**

People on the autism spectrum can become overwhelmed by subtle smells that you may not notice, such as someone's deodorant or perfume, or the smells of fabrics. Creating a sensory profile may help you to work out what adjustments are needed (See Tools)
Anxiety in Autism

It is largely due to issues around communication or the environment that causes anxiety - *not knowing what to expect; unsure about what is going to happen next; what is expected of me; why does everyone else seem to know what to do; is nobody else affected by that distracting noise and whilst we are at it, that patterned carpet is making me feel really nauseous* ...

This section looks closer at some elements that cause anxiety and some of the ways that a GP practice or hospital location (where applicable) can make it easier for someone on the autism spectrum to access their services:

**POSSIBLE CAUSES OF ANXIETY**

- Calling to book an appointment and having to speak to a stranger
- **Appointments consistently being at a time of day that is not suitable for them**
- Travelling to the surgery, especially if they have not been before
- **Appointment at a busy time with too many people in the waiting area**
- Lighting and noises in the waiting area
- **If the doctor/nurse does not keep to the appointment time**
- Seeing a different doctor or nurse every time they visit
- **May have been referred numerous times to a wide range of services**

**SUGGESTED WAYS TO REDUCE ANXIETY**

- **Option to book appointments online or by email**
- Offer known patients with autism the option to choose their own appointments rather than allocated times
- **Written and visual guides**
- Choose own appointment time (for known patients)
- **Take to a quiet waiting space/room, or suggest waiting in their car and remember to call them in**
- Place information online and in writing about visiting the practice for e.g. what to expect, the services available, step-by-step guides to common processes, such as collecting medication from the chemist
- **Keep the person informed as much as practical particularly if running late.**
- All in-house staff receive autism awareness training
- **Allow the person to see the same clinician if possible** (recognising that in an emergency this may not be possible)
- Nominate a key named contact person who will navigate the system, this may be a receptionist, administrator or nurse and not necessarily the GP
Top Tips

- Let the individual **know you are talking to them**

- **Be very clear** about what you mean – be specific.

- **Speak calmly and clearly** in short sentences - reduce your language.

- **Allow** a period of time for a response to a question. - **Avoid** the temptation to re-phrase – this can often appear like a different question.

- **Do not** rely on tone of voice.

- **Do not insist** that they **look at you** – eye-contact can cause difficulties, for example may need look away so they can concentrate on what you are saying. In some cases, eye-contact can create other challenges, for example speech.

- One size **does not** fit all

- **Every individual is unique:** find out about the person – about their autism. This is the key to understanding the individual.

- The environment is **important**.

- **Be consistent**.

- **If in doubt, ask**.

- **Share** the information with others.

- **Provide** reassurance and support.

- **Say what you mean, mean what you say** - many will take you at your word.

- **Make sure** the person really understands what you have said.
Additionally, specifically for clinicians consulting, the Royal College of General Practitioners have the following advice (see external links):

- **Explain verbally and/or in writing the process of the consultation.**
- **Demonstrate an action or intended procedure before starting it.**
- **Recap and write down future plans. Try to give written information if possible.**
- **Avoid diagnostic overshadowing. Co-morbidity is common, and you should always consider a serious illness, particularly if the person’s behaviour changes.**
- **Consult family or carers, with permission, for more information and to establish if your patient has particular sensitivities, but do not assume the person with Autism must have a carer present – they should be offered the same confidentiality as all.**
- **Make sure the diagnosis is coded as a significant active problem on the computer.**
- **Ensure reasonable adjustments needed to access your services are clearly recorded.**
- **Referrals to other services should include clear instructions about any reasonable adjustments that may be needed.**
Helpful Tools

Health Passport

The passport is designed to help autistic people to communicate their needs to doctors, nurses and other healthcare professionals. It was developed by Baroness Angela Browning – a National Autistic Society Vice President – in collaboration with The National Autistic Society. It was independently reviewed in 2017 and updated following comments by autistic people and professionals about how they were using it or wanted to use it.

The passport and guidance is available at:

https://www.autism.org.uk/about/health/hospital-passport.aspx
# Sample Sensory Assessment Checklist

<table>
<thead>
<tr>
<th>Brief description</th>
<th>Regularly</th>
<th>Occasionally</th>
<th>Never</th>
<th>Don’t know</th>
<th>Action</th>
</tr>
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<tbody>
<tr>
<td>Dislikes bright lights</td>
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<tr>
<td>Dislikes fluorescent lights</td>
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<tr>
<td>Covers or closes eyes in bright light</td>
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<tr>
<td>Is attracted to lights</td>
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<td></td>
<td></td>
</tr>
<tr>
<td>Fascinated by shiny objects and bright colours</td>
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<tr>
<td>Touches walls of rooms</td>
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<tr>
<td>Resists/gets anxious about changes to familiar routines</td>
<td></td>
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<tr>
<td>Does not like shaking hands or being hugged</td>
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<tr>
<td>Likes a hug if chosen to do this</td>
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<tr>
<td>Hugs very tightly</td>
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<tr>
<td>Fascinated by patterns</td>
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</tr>
<tr>
<td>Dislikes the feel of certain fabrics</td>
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</tr>
<tr>
<td>Enjoys the feel of certain materials/objects</td>
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<td>Seems unaware of temperature</td>
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<td>Dislikes texture of certain foods and drinks</td>
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<td>Dislikes crunchy or chewy food</td>
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<td>Likes food presented in a certain way</td>
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<td>Bumps into objects and people</td>
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<td>Finds fine motor skills hard</td>
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<td>Does not seem to know where body is in space</td>
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<td>Difficulties with balancing</td>
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<td>Seeks pressure by crawling under heavy objects</td>
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<td>Gets lost easily</td>
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<td>Has a fear of heights, lifts, escalators</td>
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<td>Does not recognise familiar people in unfamiliar clothes or settings</td>
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<td>Is startled/gets anxious when approached by others</td>
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<tr>
<td>Smells, licks, taps objects and people</td>
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<td>Uses peripheral vision when doing a task</td>
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<td>Finds it easier to listen when not looking at person</td>
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<tr>
<td><strong>Remembers routes and places very well</strong></td>
<td><strong>Can memorise large amounts of information on certain topics</strong></td>
<td><strong>Finds crowded areas very difficult</strong></td>
<td><strong>Prefers to sit at back of a group</strong></td>
<td><strong>Prefers to sit at the front of a group</strong></td>
<td><strong>Covers ears at certain sounds (e.g. phone ringing, tannoy announcements)</strong></td>
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Autism Alert Card

The alert card enables those that carry it to identify themselves to workers in emergency services as being on the Autism Spectrum. It has been designed by Triple A Project with Cumbria Police to be recognised by their officers but can be used to show personnel from other emergency services such as fire officers and ambulance staff.

The card can be applied for on the Triple A website found at:

http://tripleaproject.org.uk/autism-alert-card/
Video Transcription

Adam

“I would ask the receptionist for a longer appointment because I have autism and it would take me a long time to explain what is wrong with me.

I need to see the same Doctor every time I go to the surgery because he knows my problems.

I would like to sit in a quiet room and then they could come and get me when it is my appointment. I feel impatient if I had to wait so long and feel upset. It is difficult to talk to the Doctor as I get struggled for words, so the Doctor needs to speak slowly.”

Daniella

“Giving me priority reduces the amount of time that I have to wait and can lessen my anxiety levels.”

“The use of the Health Passport would be helpful to me so it can cut out communication issues and it would make me feel like I was not repeating myself all the time.”

Harry

“Giving me appointments in the middle of the day, say half past two in the afternoon – that’s quite stressful for a person with autism. Maybe giving me the appointment at first in the morning or maybe last before you close – that would really help with just the stress levels. Also, may be giving me longer periods. I know a lot of the time that’s not possible, but just possibly just wherever possible. Also, maybe just give me someone that I am familiar with – someone that isn’t a stranger because people with autism are not really big fans of meeting new people who are strangers in an official environment like that.”

“When I am in the middle of an appointment you can’t really explain to me what is wrong by explaining loads of technical jargon, abbreviations and in this day and age, internet slang. When you’re talking to me, in my personal experience because everyone with autism is different, try and speak more slowly – just try and make it easy to understand in simple, basic English. Don’t cover it with loads of technical jargon. Thank you.”
Links for more information:

Royal College of General Practitioners:

National Autistic Society:
https://www.autism.org.uk/

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

Legal Framework Training and beyond basic awareness, Dr. Yo Dunn:
https://www.consultyo.com/

University accredited learning – University of Cumbria:
https://www.cumbria.ac.uk/

Links to legislation and guidelines:

2009 – Autism Act:

Think Autism strategy: governance refresh 2018:

NICE guidelines

2011 CG 128 assessment in children:

2012 CG 142 assessment and management adults:
https://www.nice.org.uk/guidance/cg142

2014 - NICE quality standards QS51:
https://www.nice.org.uk/guidance/qs51

2015 – statutory guidance for all health and social care staff on autism awareness training:
Acknowledgements

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Advice given by individuals on the autism spectrum, colleagues from NHS and Cumbria County Council has been invaluable and a great help in making sure the project is authentic and as accurate as possible.

We are particularly grateful to all the brave actors for taking part in the film – each one made it look like acting was their day job – very professional!

Special thanks are extended to the NHS colleagues supporting production team to use genuine NHS locations in Carlisle and Penrith. Special thanks also to contributors from NHS England and Triple A Team for sharing thoughts in the film.

Finally, thanks to the filming team for professionalism, guidance and sense of calm throughout.

**Harry Harrison, North Cumbria Clinical Commissioning Group; Helen Storey, Triple A**
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