

# Patients with an Autism Spectrum Disorder: information for health professionals

By Christine Deudney

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## INTRODUCTION

This booklet is aimed at all health professionals who may come into contact with an adult or child with autism for reasons other than their autism. Doctors, nurses, paramedics, dentists and opticians will find this useful. Much of the advice in this leaflet will also be of use to hospital staff who are caring for an in-patient with an autistic spectrum disorder.

## WHAT IS AN AUTISM SPECTRUM DISORDER?

Autism Spectrum Disorder (ASD) is a term used to describe a lifelong developmental disorder that is characterised by impairments in social interaction, communication, and imagination. There is a 'spectrum' or range of disorders with these features, including autism and Asperger syndrome. Some people with an autism spectrum disorder have severe learning disabilities, and some may never speak. People with Asperger syndrome, on the other hand, usually have an average or above average IQ and acquire spoken language at the same age as typically developing children.

All people with an ASD experience three main areas of difficulty, known as the 'triad of impairments':

**Social interaction** – difficulty with social relationships, e.g. appearing aloof and indifferent to other people and difficulty with understanding others' viewpoints and intentions

**Social communication** – difficulty with verbal and non-verbal communication

**Imagination** – difficulty with interpersonal play and imagination, eg having a limited range of imaginative activities, possibly copied and pursued rigidly and repetitively.

In addition to this triad, repetitive behaviour patterns and resistance to change in routine are common.

They may also be hyper- or hyposensitive to sound, touch, pain, lights etc.

Children and adults with an ASD have illnesses and physical or emotional problems just the same as everybody else. There are over 300 000 people with an ASD in the UK so it is likely you will come across people with an ASD during your career.

Autism and Asperger syndrome are far commoner in men than in women. Because of this and for ease of reference 'he' will be used throughout to mean both he and she.



*Social interaction – difficulty with social relationships, e.g. appearing aloof and indifferent to other people and difficulty with understanding others' viewpoints and intentions.*

## APPOINTMENTS

Try to give the patient the first or last appointment of the day. People with an ASD find waiting around for an appointment extremely stressful.

Waiting in busy hospital corridors will increase the stress levels of an already anxious child or adult.

If possible find a small side room the family can wait in.

Alternatively, they may prefer to wait outside or in the car. A member of staff should be identified to collect them when the health professional is ready. If the appointment is likely to be delayed, the family may wish to leave the building completely and return at a later agreed time.



## TALKING TO PATIENTS WITH AN ASD

### MEDICAL PROCEDURES

Always explain what you are going to do before starting any procedure or examination.

If at all possible, show a picture of what is going to happen or use a doll if appropriate to explain what you are going to do.

### YOUR LANGUAGE

Use clear simple language with short sentences.

People with an ASD tend to take everything literally. Thus, if you say "It will only hurt for a minute" they will expect the pain to have gone within a minute.

Make your language concrete and avoid using idioms, irony, metaphors and words with double meanings, eg 'It's raining cats and dogs out there.' This could cause the patient to look outside for cats and dogs.

Give direct requests, eg 'Please stand up.' If you say, 'Can you stand up?' this may result in the person staying seated or the answer 'yes,' as the person with an ASD may not understand you are asking them to do something.

Check that they have understood what you have said – some people with an ASD may speak clearly but can lack full understanding.

Avoid using body language, gestures or facial expressions without verbal instructions. These may not be understood.

Ask for the information you need. A person with an ASD may not volunteer vital information without being asked directly.



## PHYSICAL EXAMINATIONS

These may prove very stressful to the patient and it is essential to warn them before touching them.

Explain what you are doing and why. Enlist the parent/carer's help wherever possible, especially if the patient is nonverbal or uses an alternative communication method or aid.

## RESPONSE BY PATIENT

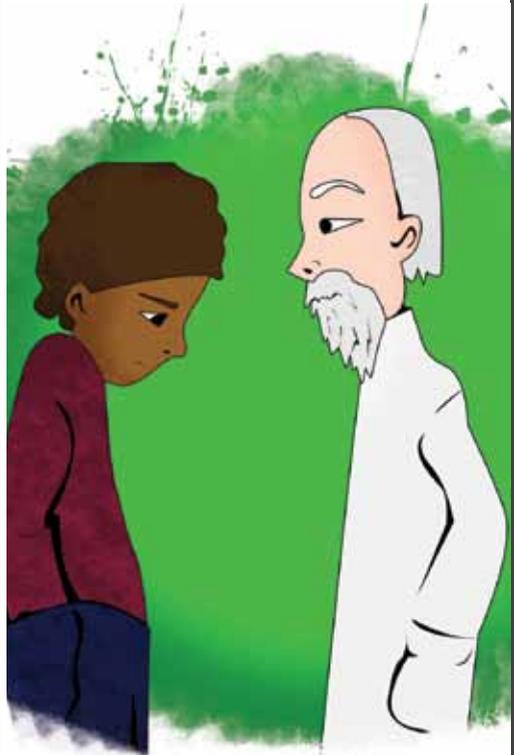
Don't be surprised if the patient doesn't make eye contact, especially if he is distressed. Lack of eye contact does not necessarily mean they are not listening to what you are saying.

Allow the patient extra time to process what you have said.

Don't assume that a non-verbal patient cannot understand what you are saying.

People with an ASD find it difficult to understand another person's perspective. They may not understand what you intend to do, but may expect you to know what they are thinking.

People with an ASD may not understand personal space. They may invade your personal space or need more personal space than the average person.





## SENSORY STIMULI

Some or all of the following may apply to your patient.

### LIGHTS

Some people with an ASD are extremely sensitive to light and can discern the flashing of fluorescent lights.

Pen lights can trigger seizures in susceptible individuals. Seizures occur in approx 40% of people with an ASD.

### SENSORY OVERLOAD

It is easy for someone with an ASD to be overcome by sensory overload, for example in the hustle and bustle of a Casualty department. Emergency lights and machines emit high-pitched 'whistle' sounds which can be agonising to the person with an ASD.

Some might withdraw, eg put their fingers in their ears or close their eyes. Others may 'stim,' eg flap hands, flick fingers or rock. This kind of behaviour is calming to the person with an ASD so do not try and stop it unless absolutely essential.

## PAIN

People with an ASD can have a very high pain threshold. Even if the child does not appear to be in pain, they may, for example, have broken a bone.

They may show an unusual response to pain that could include laughter, humming, singing or removal of clothing.

Agitation and behaviour may be the only clues that the child or adult is in pain.

### PARAMEDICS

Sensory issues – (see section on sensory stimuli above) are particularly relevant to paramedics.

The sound of a siren can be excruciatingly painful to people with an ASD.

Turn the siren off if at all possible.

Others may delight in being taken to hospital in an ambulance that has its siren going. It is best to consult with a parent or carer as to how the siren may affect the patient.

Some people with an ASD can be terrified by the restraints used to strap people to a stretcher. They may become extremely agitated. Try and explain why you are strapping them in or ask their parent/ carer to explain.

### INJECTIONS/BLOOD TESTS

If the patient needs an injection or a blood test, try and divert their attention elsewhere.

As above, the use of pictures or a doll is a good idea to demonstrate what is going to happen.

People with an ASD can be either under- or over-sensitive to pain. This means that some may feel pain acutely and be very distressed whereas others may not appear to react at all.

It is advisable to assume that the patient will feel the pain and use a local anaesthetic cream to numb the site of the injection.





## ACCIDENT AND EMERGENCY

An accident or an emergency are very stressful experiences for anybody, but for the person with an ASD it can be totally overwhelming. Not only is it a strange place and often apparently chaotic but the sensory experience of bright lights, beeping monitors and other equipment can completely overload their system and cause a 'meltdown' or total withdrawal.

A meltdown occurs when someone becomes over-stimulated, for example by noise, too much information or due to anxiety, leading to a state of not being able to cope with any further incoming information and possible behavioural outbursts or withdrawal.

Allow the parent or carer to take control, as they will know the best way to calm the patient down. The patient may exhibit challenging behaviour and parents/carers should be allowed to calm the patient down.

Try to limit the number of staff caring for the patient. Predictability helps them understand what is happening to them and to identify the roles of care providers.

Sometimes doctors and nursing staff ask relatives/carers to leave the room while giving emergency treatment. In treating patients with an ASD, it may be helpful to allow them to stay if possible. This can help reassure the patient and will also allow the relatives/carers to give valuable information about the patient and their behaviour, if appropriate.

Inform the triage nurse that the patient has an ASD so that they can be given a higher priority than would be normal. This is to minimise the time the patient has to wait.



## SPECIAL NOTES FOR OPTICIANS AND DENTISTS

Going to the dentist can cause sensory overload for people with an ASD. They may react to the bright light shone at the face, the noise of the drill and even the feel of cold instruments in the mouth. The strong taste of mouthwash or paste can also be problematic.

Similarly, the equipment used by the optician, such as the heavy eye glasses, can be difficult for the patient to cope with.

All of this can cause the patient to have a 'meltdown' and you need to be aware that the person is overloaded and not just throwing a tantrum.



*Try to limit the number of staff caring for the patient. Predictability helps them understand what is happening to them and to identify the roles of care providers.*

## SUGGESTIONS TO TRY AND MAKE THE TREATMENT EASIER

- \* Plan an informal trip before the actual treatment. The involvement of the health professional at these times is extremely useful so that the person with an ASD can get to know them, their room and any equipment, eg special chair, eye glasses.
- \* Another option may be to allow a child with an ASD to watch while a sibling is being treated so that subsequent appointments will not be such a shock. The advice of the patient's carer will help to inform on this approach.
- \* As with injections, a doll could be given 'treatment,' eg a quick eye test, dental check.
- \* It is also a good idea to book a double appointment so that things can be taken at the patient's pace.

## SUMMARY

A trip to the hospital, optician or dentist can be extremely stressful to the person with an ASD. They may experience sensory overload and challenging behaviour. It is important to involve the parents/carers in all aspects of the patient's care as appropriate. Adults with an ASD should be allowed to make the decision regarding the involvement of parents or carers if they have the capacity.

## FURTHER READING

- \* Autism Steering Committee, North Shore – Long Island Jewish Health System (2004). *Your next patient has autism*. Bethpage, NY: Fay J Linder Center for Autism. <http://www.northshorelij.com/body.cfm?id=2851>
- \* Kaplan, M. (2005). *Seeing through new eyes: changing the lives of children with autism, Asperger syndrome and other developmental disabilities through vision therapy*. London: Jessica Kingsley Publishers
- \* Morton-Cooper, A. (2004). *Health care and the autistic spectrum: a guide for health professionals, patients and carers*. London: Jessica Kingsley Publishers
- \* Shellenbarger, T. (2004). *Overview and helpful hints for caring for the ED patient with Asperger's syndrome*. *Journal of Emergency Medicine*, 30 (3), pp. 278-280
- \* Wilkes, K. (2006). *Going to the dentist: a guide for people with autism and Asperger Syndrome*. London: The National Autistic Society

Autism South Africa has the following brochures available either as downloads from [www.autismsouthafrica.org](http://www.autismsouthafrica.org) or as hard copies that may be requested from the Autism South Africa office.

The material contained in booklets numbered 1 through to 12, was provided by UK National Autistic Society under a Memorandum of Understanding with Autism South Africa.

1. **Early Years and Autism Spectrum Disorders.** By Christine Deudney and Lynda Tucker.
2. **Going to the Shops: a guide for parents of children with autistic spectrum disorders.** By Catriona Hauser
3. **Bullying and how to deal with it: a guide for pupils with an Autism Spectrum Disorder.** By Patricia Thorpe.
4. **Going to the doctor: a guide for children with an Autism Spectrum Disorder.** By Emma Jones.
5. **Patients with an Autism Spectrum Disorder – information for health professionals.** By Christine Deudney.
6. **Classroom and playground support for children with an Autism Spectrum Disorder.** By Prithvi Perepa.
7. **Why does Chris do that?** By Tony Attwood.
8. **Environment and surroundings - How to make them autism-friendly.** By Anh Nguyen.
9. **Asperger's Syndrome from diagnosis to solutions – A guide for parents.** By Tony Attwood.
10. **Working with an Asperger pupil in secondary schools.** By Judith Colley.
11. **The sensory world of the autistic spectrum: a greater understanding.** By Kate Wilkes.
12. **Understanding difficulties at break time and lunchtime guidelines for pupils with an Autism Spectrum Disorder.** By Patricia Thorpe.
13. **Asperger Syndrome.** By Dr Cobie Lombard (Autism South Africa)
14. **Autism – Practical Aspects** (In English, isiXhosa, isiZulu, Setswana, Sesotho, Sepedi and Afrikaans) (Autism South Africa)
15. **Sexuality Brochure – “I’m growing up”.** By Rebecca Johns. (Autism South Africa)
16. **Thoughts of a young sibling.** By Kim Stacey (Autism South Africa)
17. **Dietary Intervention.** By Paul Shattock and Paul Whitely. (Autism South Africa)