

Information Sheet:

Information for Health Care Professionals about autistic people

This information sheet is aimed at all health professionals who come into contact with an autistic adult or child. Doctors, nurses, paramedics, dentists, and opticians may find the information contained in this sheet useful when they are treating autistic individuals.

What is Autism Spectrum Disorder?

Autism Spectrum Disorder (ASD) is a neurodevelopmental condition that affects a person's social interaction and communication. Autistic people may be described as being "on the spectrum". People on the spectrum may have restricted and repetitive patterns of behaviour and interests, as well as sensory processing differences.

The autism spectrum incorporates diagnoses of ASD, Autistic Disorder, Asperger's Syndrome, and Pervasive Developmental Disorder—Not Otherwise Specified (PDD-NOS).

Autistic people can present in many different ways. No two people with the condition are alike. Some may have an intellectual disability, others have average or above average intelligence. Some people may never develop spoken language, others may acquire language at the same rate as their typically-developing peers. Some autistic people may have other conditions, such as ADHD or Tourette's Syndrome.

Autistic people experience the world in a different way. They show differences in:

- **Social Interaction and Communication.** They tend to have difficulty with social relationships (e.g. appearing aloof and indifferent to other people, difficulty understanding others' viewpoints and intentions, and difficulty with verbal and non-verbal communication)
- **Restricted, Repetitive Patterns of Behaviour, Interests or Activities.** Autistic people display repetitive behaviour patterns (e.g. resistance to changes in routine, difficulty with transitions, a preference for sameness, lining up objects or doing things in a certain order).
- **Sensory Processing.** For example, they may be hyper- or hyposensitive to sound, touch, pain, lights, smell, etc.

Recent studies have found that in Australia, up to 1 in 100 school aged children are autistic, so it is likely you will come across autistic people during your career.

Making Appointments

Offering the first or last appointment of the day can be helpful for autistic people. They may find waiting for an appointment stressful. Many autistic people like order and routine, so an update on how long they may need to wait during unexpected busy times could alleviate some anxiety.

Information for Health Care Professionals about autistic people

Waiting in busy hospital corridors may increase the stress levels of an already anxious child or adult. If a separate waiting space can be made available to the patient, this could be ideal. Alternatively, they may prefer to wait outside or in the car and a member of staff or text message/phone call could be used to notify 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 autistic patients

Medical procedures

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

If 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.

Some autistic people take what you say literally. If you say "it will only hurt for a minute" they will expect the pain to be over in exactly one minute.

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

Give direct requests, such as "Please stand up." If you say, "Can you stand up?", this may result in the person answering "yes", but staying seated as they might not be aware that you are asking them to do something.

Check that they have understood what you have said – ask them to repeat it back to you if necessary to check for understanding.

Avoid using body language, gestures or facial expressions without the assistance of verbal instructions as people on the spectrum often have difficulties with non verbal communication.

Ask for the information you need. An autistic person 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. It is important to explain what you are doing and why you need to do it that way.

Information for Health Care Professionals about autistic people

Response by patient

Don't be surprised if the patient doesn't make eye contact, especially if they are 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.

Autistic people may not understand personal space. They may invade your personal space or they may need extra personal space.

Sensory Stimuli

Autistic people can be hypersensitive in a variety of ways and this may create a challenge when they seek medical treatment.

Some autistic people are extremely sensitive to light and can discern the flashing of fluorescent lights. Pen lights can trigger seizures in susceptible individuals. (20-30% of autistic people also experience seizures¹.)

Some autistic people will be hypersensitive to sounds. In a busy Emergency Department or waiting room, for example, some medical equipment makes high-pitched 'whistle' sounds which can be distressing to the autistic person.

Sensory overload

It is easy for an autistic person to be overcome by sensory overload, for example, while waiting in a noisy room crowded with people.

Whereas some might withdraw (e.g. put their fingers in their ears, close their eyes) others may self stimulate or 'stim'. This means to make motions such as flapping hands, rocking, or flicking fingers in order to stimulate sensation or to deal with stress. This kind of behaviour may also be calming to the individual, so do not try and stop it unless absolutely essential. If they are not able to deal with the stress of a situation and become overwhelmed, an autistic person may experience a 'meltdown'.

A meltdown can occur when someone becomes overstimulated (e.g. by sensory input or too much information), which can lead to heightened anxiety and possible behavioural outbursts or withdrawal.

Pain Threshold

Autistic people may have unusual responses to pain. Some may have a very high pain threshold and may not register pain (e.g. may not react to having a broken bone). Others might have a very low pain threshold, or react negatively to even the slightest touch. An autistic person may struggle to communicate what they are feeling. Agitation and behaviour may be the only clues that the individual is in pain.

Information for Health Care Professionals about autistic people

Injections/Blood Tests

As autistic people can be either under or over sensitive to pain or touch, it is difficult to predict how they will react to a needle. It is advisable to assume that the patient will feel the pain and use a local anaesthetic cream or other remedy to numb the site of injection.

Preparation about what to expect will also be important for the autistic person. Again, the use of pictures or a doll is a good idea to demonstrate what is going to happen.

Paramedics

Because autistic people can often experience sensory sensitivities, there are some special considerations for paramedics.

The sound of a siren can be excruciatingly painful to autistic people. It might be helpful to turn the siren off whenever possible. Others may delight in being taken to hospital in an ambulance that has its siren going. It is best to ask the patient (or a parent or carer) how the siren may affect them.

Some autistic people will react negatively to the restraints used to strap people to a stretcher and they may become agitated or distressed by being restrained. Try and explain why you need to strap them or get their parent/ carer to explain.

Emergency Department

Attending the Emergency Departments is a very stressful experience for anybody, but for the autistic person it can be particularly overwhelming. This may result in them becoming distressed or having a meltdown.

If a patient has a meltdown, they may exhibit challenging behaviour. Allow the parent or carer to take control as they will know the best way to calm the patient down.

Sometimes doctors and nursing staff ask relatives/carers to leave the room whilst giving emergency treatment. In treating patients on the autism spectrum, it may be helpful to allow carers to stay. 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 is autistic so that they can be given a higher priority where possible to minimise the time the patient has to wait.

Try to limit the number of staff caring for the patient as predictability helps them understand what is happening to them and to identify the roles of care providers. Allocate a key person to the patient if possible.

Information for Health Care Professionals about autistic people

Special Notes for Opticians and Dentists

Going to the dentist can cause sensory overload for autistic people: the bright light shone in the face, the noise of the drill, and the feel of cold instruments in the mouth or on the skin. The strong taste of mouth-wash or toothpaste can also be problematic. Similarly, the equipment used by the optician, such as heavy eye glasses, can be difficult for the patient to cope with.

If possible, it can be helpful to facilitate an informal visit prior to actual treatment for the autistic person (and their parent/carer if relevant). This can allow the person to meet the health professional, see the room and any equipment, such as a special chair, protective glasses, etc.

Another option may be to allow an autistic child 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 this approach.

It is also a good idea to book a double appointment so that things can be taken at the patient's pace.

Reference

1 Screening electroencephalograms in autism spectrum disorders: evidence-based guideline (2005) Kagan- Kushnir T., Roberts S. W. and Snead O. C. Journal of Child Neurology, 2005, Vol. 20(3), pp. 197-206.

Acknowledgement

Based on the UK National Autistic Society's "Patients with Autism Spectrum Disorder: Information for Health Professionals", with their permission. Updated June 2015

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