

Doctor: preparing for a visit

Going to the doctor (GP in the UK) can be a very stressful experience for people with an autism spectrum disorder (ASD) and their carers.

This document provides reasons why this experience may be difficult for a person with an ASD and suggests strategies that can be used to help improve the situation.

Possible triggers

Fear of the unexpected

Although a visit to the GP can provide the structure that people with autism need, in that there is a definite routine involved, it can still cause anxiety. This can be due to the fact that in most cases it is unknown exactly what a doctor will do. The unstructured time in the waiting room and the other patients present can be difficult for a person with an ASD. The unfamiliarity of the consultation room and equipment used can seem quite daunting. Alternatively, negative experiences from the past and associations with pain can influence an individual's future associations and fear of the experience.

Sensory difficulties

Sensory issues can be a large factor in a person with autism's negative experience at the doctors.

Lights

Sensitivity to certain lighting can be a particular problem for people with an ASD. For instance strip fluorescent lighting can be experienced as painful and distracting.

It has also been found that the use of pen lights can trigger seizures in those susceptible (20-30% of people with an ASD). (Kagan-Kushnir, Roberts and Snead, 2005)

Touch (tactile system)

If an individual is hypo-sensitive to touch they may have a high threshold to pain or temperature and not mind heavier pressure when touched. This could cause difficulty when being examined by the doctor as the person with autism may not appear to be in pain but could, for example, have broken a bone. They may be unable to decode the different body sensations to recognise it as pain.

They can display unusual responses to pain such as laughing, humming or stripping which may make it difficult for the doctor to recognise and identify the problem. It may be that change in behaviour is the only indicator that a person with an ASD is in pain.

On the other hand, a person with an ASD may be hyper-sensitive to touch. They may experience the slightest touch as uncomfortable or even painful. They will therefore withdraw from touch which can cause difficulties when a doctor is trying to conduct a physical examination. Materials used could also be a problem, for instance the paper sheet on the examination table, cotton wool or plasters may cause particular discomfort.

Noise

Some doctor's surgeries use buzzers to indicate when it is a patient's turn to see the doctor. They may also have music playing in a waiting room. Crying babies or children in the waiting room may also be quite noisy. For those with hyper-sensitive hearing, these types of noises can be magnified and become quite disturbing. Also with this heightened volume, surrounding sounds could become distorted. For the person with an ASD, this could cause difficulty in recognising sounds, such as a name being called for instance.

Personal space and body awareness

A crowded waiting room may be quite distressing for someone with an ASD who may need their personal space. Similarly close proximity to the doctor could be quite uncomfortable for the patient.

Problems can also occur when trying to explain where pain is experienced. Those who have difficulty with body awareness may not be able to experience where different body parts are.

Communication

It can be a problem for patients with an ASD to indicate where pain is, due to communication difficulties. It may also be difficult for them to understand what a doctor is asking or to understand when the doctor is explaining what they are going to do to them.

Strategies

Preparation

It can help to prepare the individual as much as possible for their visit to the doctor's. Marking the visit on a calendar using visual supports can help. Using flow charts to explain why they have to see the doctor may also be useful.

It may help to visit the doctor's before the appointment to familiarise the person with an ASD with the environment. Taking photos (eg of staff, building) can help to use as an object of reference when preparing at home. Using toy doctor's sets at home can help to familiarise the individual with the equipment and its uses.

It may help to get the first or last appointment of the day to avoid waiting for too long and to book a double appointment as extra time may be needed. Afternoons tend to be a less busy time in doctor's surgeries. It may also be worth checking there are no baby clinics on at the time of visiting as this tends to be a noisy time in the surgery.

It may be worth checking if there is a quiet area that the person with an ASD can sit in if the waiting room is too much for them.

You may also want to take along autism or Asperger syndrome information cards. These give a brief explanation of what autism and Asperger syndrome are and can be handed out to the public. These may be useful in the waiting room if other patients have difficulty understanding certain behaviours.

Patient information

There are a number of story books written for children about going to the doctors.

Going to the doctor (Hollins) is part of the 'Books beyond words' series for people with learning disabilities. Pictures are used to explain the experience of visiting the doctor and feelings involved.

Social stories

Social stories™ could be used to explain the experience of going to the doctor.

Professional support

It may help to provide GPs or nurses at the surgery with information on patients with an ASD so that they are prepared for the visit. We have a separate information pack specifically for this purpose!

It may also be worth letting the doctor know of possible triggers specific to the individual. This can include particular dislikes/likes they have, behaviour and communication strategies that work or interests they have. These may help the GP in forming a relationship with them.

The GP may need to be informed of sensory issues so that the examination and equipment can be adapted accordingly (for example replacing a paper sheet on the examination table with a cloth one). This information could be provided through a letter or phone call before the appointment.

Visual supports

It may help to provide visual supports explaining the process and what may be involved during the visit. This could include sequence cards, checklists or photos.

It may also help to use pain scales or body charts to help the person with autism communicate their pain.

Time indicators

Time indicators may also be useful whilst waiting for the appointment and during examination. Sand timers and clocks can be used as a distracter during things such as injections so that the person with autism can see a definite end. The time timer shows how much time is left in an interval of sixty minutes using a red dial.

Rewards

A reward system may help the individual with autism during their experience at the doctor's. It can provide them with something to look forward to and enable them to see an end to the experience. Using visual supports to reinforce this will also help.

Comforters/distracters and relaxation techniques

Comforters/distracters can help the individual with an ASD with sensory issues, fear or boredom in the waiting room. These could include personal devices for listening to music, earplugs, glasses, books or favourite toys.

Demonstrating on others or toys to show what will happen during a physical examination can help to reassure an individual with an ASD.

Using objects such as stress balls, Chewy TubesTM and Thera tubing can help during experiences of pain or discomfort. Chewy tubes are cylindrical pieces of rubber tubing (which are safe and non-toxic) that can be sucked or chewed on. They can help to release stress. Thera tubing is a similar material that can be made in to a bracelet or necklace to bite down on.

Relaxation techniques such as deep breathing, counting, singing favourite songs, talking about a favourite interest or looking at favourite books/toys could also help during physical examination or treatments.

I freely admit this is 'nicked' from the National Autism Society's website and can be found at:

www.autism.org.uk/19827

So all credit goes to them for this useful article!