

Going to the doctor: A guide for children with an Autism Spectrum Disorder (ASD)

By Emma Jones

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INTRODUCTION

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

This booklet 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.

Throughout this booklet the terms autism and autistic spectrum disorder (ASD) are used to include Asperger syndrome and high functioning autism (HFA).

POSSIBLE TRIGGERS AT THE DOCTOR

FEAR OF THE UNEXPECTED

Although a visit to the GP can provide the structure that people with autism require in that there is a definite routine involved, it can still cause anxiety.

This may be due to the fact that in most cases it is not known 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 the future associations and fear of the experience of a person with an ASD.



SENSORY DIFFICULTIES

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

LIGHTS

Sensitivity to certain lighting can be a particular problem for people with autism. 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)

Some people with an ASD are not very sensitive – hypo-sensitive – to touch. This means that they may have a high threshold to pain or temperature and not mind heavier pressure when touched. This can 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.

The person with an ASD may be unable to decode the different body sensations to recognise it as a pain.

They can display unusual responses to pain such as laughing, humming or taking their clothes off 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 autism is in pain.

On the other hand, a person with autism may be very sensitive – hyper-sensitive – to touch. They may experience the slightest touch as uncomfortable or even painful and will therefore withdraw from touch. This 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.





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NOISE

Some doctors 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.

With this heightened volume, surrounding sounds could also 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 + BODY AWARENESS

A crowded waiting room may be quite distressing for someone with an ASD who may need their personal space. Similarly, closeness 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. 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 before the appointment to familiarise the person with autism with the environment. Photos, e.g. of staff or the surgery, can help as an object of reference when preparing at home.

Using a toy doctor's set at home can help to familiarise the person with an ASD with the doctor's 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 autism can sit in if the waiting room is too much for them.

You may also want to take along ASD information cards. These give a brief explanation of what Autism Spectrum Disorders 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. Please see recommended reading for further details.

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.

The Nemours Foundation's website provides health information for parents, teens and children, including going to the doctors. Although it is an American website it still has relevant information that may be useful:

http://www.kidshealth.org/kid/feel_better/people/going_to_dr.html

http://www.kidshealth.org/parent/system/doctor/dr_visits.html



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SOCIAL STORIES™

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

See www.thegraycenter.org

Social Stories™ were developed by Carol Gray, President of The Gray Center.

“A Social Story™ describes a situation, skill, or concept in terms of relevant social cues, perspectives, and common responses in a specifically defined style and format. Social stories (often capitalized as Social Stories) interventions attempt to improve the social skills of children with autism spectrum disorders (ASD) by using individualized short stories to help them interpret challenging or confusing social situations. The stories have a specifically defined style and format. They describe a situation in terms of relevant social cues, the perspective of others, and often suggest an appropriate response. A social story is an individualized short story that describes social relevant cues in any given situation.

It breaks down a challenging social situation into understandable steps by omitting irrelevant information and by being highly descriptive to help an individual with an ASD understand the entirety of a situation. It includes answers to questions such as who, what, when, where, and why in social situations through the use of visuals and written text. Social stories are used to teach particular social skills, such as identifying important cues in a given situation; taking another's point of view; understanding rules, routines, situations, upcoming events or abstract concepts; and understanding expectations.”
(Ref: Wikipedia)

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

The GP may need to be informed of sensory issues so that the examination and equipment can be adapted accordingly, eg replacing a paper sheet on the examination table with a cloth one. This information could be given by phone before the appointment.



It may help to give the person with an ASD visual supports explaining the process and what may be involved during the visit.

VISUAL SUPPORTS

It may help to give the person with an ASD visual supports explaining the process and what may be involved during the visit. These 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. Please see the following links:

Paediatric pain profile:

www.ppprofile.org.uk

Body part pictures:

www.do2learn.com/picturecards/print-cards/selfhelp_bodyparts.htm

A scale could be developed with different pictures, facial expressions or colours to show the severity of pain next to each number. Stress scales could also be used.

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 person with autism during their experience at the doctors. 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

Comforters/distracters can help the individual with autism with sensory issues, fear or boredom in the waiting room. These could include personal stereos, earplugs, glasses, books or favourite toys.

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

Using objects such as stress balls, can help during experiences of pain or discomfort.

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

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RECOMMENDED READING

- * Adamson J. (2003) *Topsy and Tim go to the doctor*. Ladybird Books Ltd
- * Civardi A. (2000) *Going to the doctor*. Usborne Publishing Ltd
- * Deudney C (2006) *Patients with autistic spectrum disorders – information for health professionals*. Autism South Africa & The National Autistic Society
- * Gray C. (2002) *My social stories book*. Jessica Kingsley Publishers
- * Hollins S. et al. (1996) *Going to the doctor*. St George's Mental Health Library
- * Hudson J. (2006) *Prescription for success: supporting children with ASD in the medical environment*. Autism Asperger Publishing Company
- * May F (2005) *Understanding behaviour*. The National Autistic Society
- * Morton-Cooper A. (2004) *Health care and the autism spectrum: a guide for health professionals, parents and carers*. Jessica Kingsley Publishers
- * Nguyen A. (2006) *Creating an ASD environment*. Autism South Africa and The National Autistic Society
- * Volkmar F.R and Wiesner L.A. (2004) *Healthcare for children on the autism spectrum: a guide to medical, nutritional and behavioural issues*. Woodbine House
- * Wilkes K (2006) *Going to the dentist*. The National Autistic Society
- * Wilkes K (2004) *The sensory world of the autistic spectrum – a greater understanding*. Autism South Africa and The National Autistic Society
- * Wolde G. (1989) *Thomas goes to the doctor*. Hodder and Stoughton

Reference

Kushnir T., Roberts S.W. and Snead O.C. (2005) 'Screening electroencephalograms in spectrum disorders: evidence-based guideline.' *Journal of Child Neurology*, Vol. 20(3), pp197-206.

Autism South Africa has the following brochures available either as downloads from 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)