



Toileting

How to support a child/young person with an ASD



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How the areas of difficulty for someone with Autism link with toileting (research compiled by Lorraine MacAlister in Nursing Times)

Social Communication

Children and young people might fail to understand the words used to describe toileting. They might be unable to understand what they are being asked to do. They might take language literally, for example “Put the toilet roll in the toilet”. They might be less likely to communicate the need to go to the toilet and they might need instructions or information to be presented visually using PECs or symbols. They might not like being told what to do by another and may experience a meltdown when asked to do something. This can be extremely frustrating for parents and carers and put strain on the parent/child relationship, turning toilet training into a bigger issue for the family.

Social Interaction

Children and young people with an ASD might lack the motivation to make the transition from nappies to pants or use the toilet as their peers do. They might be less likely to copy others to learn new skills. They might lack the motivation to please others by urinating or defecating in the right place. They might be unconcerned about wetting or soiling themselves and they might go to the toilet in inappropriate places.

Social Imagination

Children and young people with an ASD sometimes assume you know they need help and do not always realise they need to communicate this. Sometimes they lack the understanding that soiling themselves may have an impact on others. This specifically links with a child/young person with ASD's difficulty and sometimes inability to emphasise with others. They might have difficulty in changing routines. They might be unable to transfer their toileting knowledge to unfamiliar toilets and they might develop fear and anxiety around using the toilet.

Sensory Differences

Some children and young people might not register that their bowel or bladder is full or do not feel the need to go to the toilet. Some might not be aware of urine and faeces in their nappy/pants while others might enjoy the sensation. Balancing on the toilet may be challenging for some; for others a splash or urine or water on themselves or their clothes may cause distress. Some children and young people may find the bathroom a very overwhelming room or they may love it but be interested in putting things down the toilet or flushing it.



Some children and young people are inquisitive as to how the ‘toilet’ works and therefore will experiment putting different objects down the toilet.

Common Toileting difficulties for children and young people with autism (as evidenced by Lorraine MacAlister in her publication Autism and Toileting)

- Difficulties in learning to use the toilet in the day and at night
- Knowing when they need to use the toilet
- Communicating the need to use the toilet
- Being able to get themselves to the toilet
- Learning to use different toilets
- Sensory and environmental challenges
- Wiping themselves
- Smearing their poo
- A range of continence specific difficulties including bowel or bladder problems

Specific Sensory needs relating to toileting¹ –

Sensitivity to sound or smell

Many children with special needs, especially those on the autistic spectrum, have problems with sensory information and are either overly sensitive to smell, sound, light and feeling or otherwise do not respond to what they feel, hear, see or smell. Because of the number of sounds, smells and sensations involved in using a toilet, for example, a toilet flushing, harsh bathroom lighting or the feel of the toilet seat on the skin, sensitivity to a particular aspect can be a problem.

Inability to recognise sensations

These sensory problems can also often get in the way of a child's ability to feel bodily sensations, including bladder and bowel sensations and may affect the way an individual understands what they are feeling. Many young children, both disabled and typically developing, can find it hard to tell exactly where on their body they are feeling something and this includes the sensations needed for self-toileting.

Sensory overload

In addition to general confusion about sensations in the body, some children may not always understand certain sensations if they feel overwhelmed by visual information or sounds changing around them. For example, a child might be able to recognise the need to use the toilet when focused and relaxed, but fail to notice when absorbed in a television programme or out in public because of very exciting or upsetting sensory stimuli.

These distractions can also interfere with the steps involved in toileting if the child is not able to fully concentrate on completing the sequence in the right order, for example, being able to tell the difference between pants half up or half down.

¹ <http://w3.cerebra.org.uk/help-and-information/guides-for-parents/toilet-training/>

Environmental Sensory Audit – created by Dr Eve Fleming, Community Paediatrician and Lorraine MacAlister

(For each item mentioned, consider whether this is something the child is hyper- or hyposensitive to; is it something they are seeking input from or wanting to actively avoid?)

Sensory System	Potential areas of Difficulty	Potential adaptations
Tactile (touch)	Toilet seat Toilet rolls or wipes Nappy Splashes from the toilet Need to fiddle when sitting on the toilet Temperature Touching poo	
Vestibular (balance)	Toilet seat Flooring Reflections	
Proprioception (body awareness)	Toilet seat Body positioning Nappy or pants Clothing Labels in clothes Awareness of need to wee or poo Navigating around bathroom	
Visual (sight)	Walls Lighting Brightness Bathroom fittings Mirrors Items in line of sight	
Auditory (hearing)	Toilet flush Splashing in toilet Sounds from pipes, fans, hand-dryers Echoes	
Olfactory (smell)	Wee and poo Bathroom products (cleaning and toiletries) Air-fresheners	
Gustatory (taste)	Bathroom products (cleaning and toiletries) Air-fresheners Poo	

Could there be an underlying medical issue affecting the toileting?

A child or young person with toileting difficulties could be in pain from a medical reason but that child or young person may not be aware of it or may not be able to communicate it. Autism spectrum disorder (ASD) and incontinence (nocturnal enuresis (NE), daytime urinary incontinence (DUI), faecal incontinence (FI)) are relevant disorders in childhood. In general, children with special needs such as intellectual disability (ID) or ASD are more often affected by incontinence than typically developing children. Autism spectrum disorder is an incapacitating disorder with significant impairment in social functioning. In most cases, psychological symptoms and disorders co-occur. Additionally, children with ASD are at a greater risk of being affected by different forms of incontinence and LUTS. **Therefore, screening for incontinence and, if indicated, treatment of these disorders is recommended.²**

There might be a concern around **Constipation**. Constipation and soiling is often blamed on their disability and sometimes not picked up or treated appropriately. They are less likely to have investigations to rule out any possible underlying problems. Constipation means that bowel movements are less frequent and are difficult or painful to pass. Generally we should open our bowels no more than three times a day and no less than three a week. Constipation is present in 5 – 30% of all children and the exact cause is not fully understood.

There are NICE Guidelines on Constipation in children and young people: diagnosis and management – <https://www.nice.org.uk/guidance/cg99/chapter/1-Guidance>

This is the following recommended course from the NICE Guidelines for if you suspect your son/daughter has constipation

If you are concerned about constipation you can talk to a healthcare professional (it could be the school nurse, health visitor or GP). They will ask about the symptoms of the child or young person. This will help them to diagnose constipation and check that there is no serious underlying cause. They should also do a physical examination. Your healthcare professional may then do some tests. You should only have tests if they think there may be another condition that is causing the constipation. In this case they should also offer referral to a specialist. If the examination and tests do not find a cause for the constipation, your child has idiopathic constipation. Your GP or the specialist should explain what this means, reassure you that there are treatments and discuss any treatments they recommend.

Children's Continence Team (Norfolk Community Health & Care NHS Trust)

The Children's Continence service aims to support those children and young people in managing bladder and / or bowel problems. They aim to promote continence where possible, support children and young people to achieve a good quality of life and avoid unnecessary admission into hospital. **They can offer advice and information around toileting, day-time wetting, supply of containment products (criteria apply), constipation and / or soiling and night-time wetting.**

Referral Details

All referrals must be made via the Single Point of referral. **Those referrals made requesting support around daytime and / or night time wetting, constipation / soiling must come via the child's / young person's GP.** Referrals requesting support for toilet training issues and / or containment products can be made via a **health / education / social care professional i.e. school nurse or health visitor**

² <https://www.ncbi.nlm.nih.gov/pubmed/26052001>

Treatment for Constipation in children and young people

Some treatments may not be suitable for a child or young person, depending on their exact circumstances. If you have questions about specific treatments and options covered in this information, please talk to a member of your healthcare team.

Your healthcare professional should feel the tummy of the child or young person to see if they have a blockage in the bowel caused by a build-up of poo. This poo must be cleared before the constipation can be treated (this is called disimpaction). To clear it, the child or young person should be offered medicine (called a laxative) that can be mixed with a cold drink. It is important to know that symptoms of soiling and tummy ache can get worse to begin with as the bowel empties.

The child or young person should be seen again within 1 week to check that the medicine has worked. Sometimes the healthcare professional may increase the dose or offer another laxative if the first one hasn't worked.

As soon as the build up of poo has been cleared, you will be offered more of the same medicine for the child or young person to take in a drink. This is to help them get into a regular routine of going to the toilet, and usually takes several weeks or months to work.

During this time a healthcare professional should see the child or young person frequently to make sure poo does not build up again.

Bedwetting (sometimes called nocturnal enuresis) is a common condition that affects many children and young people. Although most children grow out of it, this may take many years and some may need help to become dry at night. It can be very distressing and have a considerable impact on the child or young person. It can also be very stressful for their family.

The causes of bedwetting are not fully understood and a number of factors may be involved, such as difficulties with holding on or waking up when the bladder is full during the night, or needing to pass a larger than normal volume of urine at night. It often runs in families. Less often, there may be a bladder problem. This can mean the child or young person needs to empty their bladder frequently (even when it contains only a small amount of urine) or urgently before it is full. Children and young people with bladder problems may also have problems with wetting themselves during the day. This can be important when deciding on the best treatment. However, the assessment and treatment of children and young people with daytime wetting is not covered here.

For most children and young people, bedwetting can be successfully treated, boosting self-esteem. Even if treatment is not successful at first, it is important to persist. Advice and encouragement should continue and different treatment options should be considered. The information here applies to all children and young people under 19 years, including younger children (under 7 years), unless otherwise stated. The care offered should be suitable for the child or young person's needs and circumstances, regardless of age. Children and young people with bedwetting may be assessed and treated by a variety of different healthcare professionals, which may include nurses and doctors at a paediatric continence clinic, GPs, school nurses and health visitors.

Again there is NICE Guidelines for Nocturnal Enuresis

<https://www.nice.org.uk/guidance/CG111/ifp/chapter/Bedwetting-in-children-and-young-people>

Planning for Toilet Training³

Make sure you take the time to prepare. Preparation could include considering choosing what words everyone is going to use, planning a visual routine, getting a child or young person used to going in the bathroom, observing the behaviour they are doing and thinking what alternatives could be provided to replace this.

- ➡ Talk to everyone involved - because every person in the child/young person's life needs to be clear and consistent

Make sure you have covered the following

- Does the child or young person have the ability to go into the bathroom
- Do they understand what a toilet is for
- Have you considered a reward system
- Have you got strategies to ensure the child/young person is able to cope with changes in their routines
- Have you addressed the child/young person's anxiety and stress levels

Key Questions

- ➡ Does the child or young person have an awareness of wee/poo?
- ➡ Are things associated with toileting/nappy changes in the bathroom?
- ➡ Have you tried changing the child/young person standing up and putting the poo into the toilet afterwards
- ➡ Have you tried explaining to the child/young person how the body works, what poo is and where it goes?

Environmental questions

- ➡ Have you thought about clothing and ease of removal?
- ➡ Do they need an alternative from the potential sensory input they are getting from wearing a nappy?
- ➡ Have you made the bathroom safe and comfortable with equipment such as a toilet seat, foot stool or toilet frame?
- ➡ Have you practiced sitting on the toilet as part of their daily routine

Visual Aids

- ➡ Have you thought about how they might understand the process?
- ➡ Could you use visual aids to help understanding?

N.B make sure you use pictures/symbols or photos that the child/young person will understand to help them learn what they are asked to do

Sensory needs - Have you considered the following factors?

- The toilet flush
- Reflective mirrors
- Cold tile floors
- Noisy fans
- Strong smelling cleaning products
- Splashes in the toilet
- Introducing a fiddle toy
- A weighted lap blanket
- Installing grab rails

³ Lorraine MacAlister – Autism and Toileting for the National Autistic Society 21 November 2014

Keep in touch

Find out more about how we can help you and your family, and how you can get involved with our work. Just fill in this form and post it back to us



Title
First Name
Surname
Address (line 1)
Address (line 2)
Address (line 3)
Town
Postcode
Telephone number
Mobile number
Email address

ASD Helping Hands would like to keep you informed about our services, upcoming news, events and fundraising activities. We will look after your data as set out in our privacy and data protection policy.

- If you prefer not to receive information by post, please tick this box
- If you prefer not to receive information by telephone, please tick this box
- We'd like to keep in touch by email, if you are happy with this, please write your email address in the space provided above

What is the date of birth of the person you are contacting us about?

□ / □ / □

We would like to tailor our communication with you to ensure they are relevant to your interests.

What is your connection with autism?
(Please tick all that apply)

- I am autistic
- I am the parent/carer of someone on the Autistic Spectrum
- Someone in my family is diagnosed with autism
- I know someone who's autistic
- I am a professional working in the field of autism
- I have another connection with autism
Please
Specify _____

- I have no connection with Autism

Please return this form to:

Room 219 Breckland Business Centre
St Withburga Lane
Dereham
Norfolk
NR19 1FD

"ASD Helping Hands will support all service users affected by an Autistic Spectrum Disorder (ASD) regardless of age or what stage of life they are at. We aim to offer guidance, practical advice and support whether you are personally affected or you are an associated family member, carer, friend or professional. We will actively champion the rights of all people affected by ASD's and aim to make a positive difference to their lives while delivering a service that is accessible, reliable and trustworthy."

The organisation is for all affected by the Autistic Spectrum, this covers a wide variety of difficulties. We believe that all families and individuals have the right to good quality information, support and guidance in order to promote empowerment to allow positive choices to be made, enabling access to the same opportunities as everybody.

Currently working across Norfolk and Suffolk

ASD Helping Hands

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ASD Helping Hands is a voluntary organisation and relies on voluntary income to support its work, including the development of resources like this one for parents and carers

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