

Learning to use the toilet can be challenging for some children with autism. Nurses have an important role in supporting children and their families

# Toileting problems in children with autism

## In this article...

- › How autism affects children
- › Why learning to use the toilet can be challenging
- › Strategies to support children and their families

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Children with autism may experience continence problems for various reasons. Some are related to their autism but may also be the result of other physical difficulties. This article explores some of the underlying reasons for toileting difficulties in this group of children and offers strategies to improve the quality of life of both children and their families.

Autism is a lifelong developmental disability that affects how a person communicates with, and relates to, other people. It also affects how they make sense of the world around them. It is a spectrum condition, which means that, while all people with autism share certain difficulties, their condition will affect them in different ways. Some people can live relatively independent lives but others may also have learning disabilities and need specialist support. People with autism may also experience over- or undersensitivity to sounds, touch, tastes, smells, light or colours.

The three main areas of difficulty that all people with autism share are sometimes known as the “triad of impairments” and comprise difficulty with:

- › Social communication;
  - › Social interaction; and
  - › Social imagination.
- Other characteristics include:
- › A love of routines;
  - › Sensory sensitivity;

- › Special interests; and
- › Learning disabilities.

Autism is a broad term, under which several distinct conditions fall. Asperger syndrome is a form of autism and people with the condition are often of average or above-average intelligence. They have fewer problems with speech than people with other forms of autism but may still have difficulties understanding and processing language.

### Autism and toileting

Common toileting difficulties for children with autism are listed in Box 1. It is important to recognise there may be various reasons why they find toileting skills difficult to acquire; some may be related to their autism, some to specific physical difficulties and some a combination of the two. Various characteristics of autism, as outlined above, can lead to children having difficulty learning to use the toilet (Coucovanis, 2008; Wheeler, 2007) and learning how to do so in a socially appropriate way.

### Social communication

Difficulties with social communication include not knowing how to use words, facial expressions and gestures to communicate, or having problems reading faces, and understanding and using verbal and non-verbal communication. These difficulties mean that a child may:

- › Fail to understand the words used to describe toileting;
- › Be unable to understand what they are being asked to do;
- › Take language literally, for example “Put the toilet roll in the toilet”;
- › Be less likely to communicate the need to go to the toilet; and

## 5 key points

**1** Autism affects how a person communicates with other people, as well as how they relate to those around them

**2** Children with autism may experience problems with toilet training

**3** Some of the difficulties experienced by children with autism can impact on toileting

**4** Toileting behaviour can change in different settings

**5** Multiagency working may be required if toileting problems are to be solved successfully



Some children can have difficulty learning to use the toilet correctly and appropriately



## “Be open to development opportunities as they arise”

Debbie Casey ▶ p25

### BOX 1. COMMON TOILETING DIFFICULTIES IN CHILDREN WITH AUTISM

- Difficulties learning to use the toilet during the day and at night
- Knowing when they need to use the toilet
- Communicating the need to use the toilet
- Being able to get to the toilet independently or in time
- Learning to use different toilets with which they are unfamiliar
- Sensory differences
- Wiping themselves
- Smearing faeces
- A range of continence-specific difficulties, including bowel or bladder difficulties such as bedwetting and constipation

- » Need instructions or information presented visually.

#### Social interaction

Difficulties with social interaction include not knowing how to behave around other people, not understanding the “unwritten rules” of behaviour and finding it hard to create relationships. These difficulties can make it hard for someone with autism to establish and keep friendships, which, in turn, could mean that a child may:

- » Lack motivation to make the transition from nappies to pants or use the toilet as their peers do;
- » Be less likely to copy others to learn new skills;
- » Lack motivation to please others by urinating or defecating in the right place;
- » Be unconcerned about wetting or soiling themselves; and
- » Go the toilet in inappropriate places.

#### Social imagination

Difficulties with social imagination include inflexibility in thought and/or behaviour, a need for routines and finding it hard to imagine what may happen next. Children may also have fascinations or special interests based around certain objects or subjects; these can change over time or be lifelong and can vary from art to trains. Such difficulties can mean a child:

- » Assumes you know they need help, and does not realise they need to communicate this;
- » Lacks understanding that soiling themselves may have an impact on others;
- » Has difficulty in changing routines;
- » Is unable to transfer their toileting knowledge to unfamiliar toilets; and
- » Develops fears and anxiety around using the toilet.

#### Sensory differences

People with autism may experience some form of sensory sensitivity (Klintwall,

2010; Smith-Myles, 2005). This can occur in one or more of the seven senses – sight, sound, smell, touch, taste, balance and body awareness – and means senses are either intensified (hypersensitive) or decreased (hyposensitive). What we see, hear, feel, smell and taste gives us information about our environment and ourselves. It helps us make sense of the world and enables us to act appropriately within it.

Examples of sensory differences could include a person who is hypersensitive who may find certain background sounds – for example, other people talking, the sound of pipes in the house, or the fan in the overhead projector – that other people ignore or block out, unbearably loud or distracting. This can cause anxiety or even physical pain. People who are hyposensitive, on the other hand, may not feel pain or extremes of temperature. Some may rock, spin or flap their hands to stimulate sensation, help with balance and posture, or to deal with stress.

People with sensory sensitivity may also find it hard to use their body awareness system. This system tells us where our bodies are, and lack of awareness makes it harder to navigate rooms, avoid obstructions, stand at an appropriate distance from other people and carry out fine motor tasks such as tying shoelaces.

When we think about toileting, these sensory differences could mean that some children do not register that their bowel or bladder is full or do not feel the need to go to the toilet (Yack et al, 2002). Some might not be aware of urine and faeces in their nappy while others might enjoy the sensation. Balancing on the toilet may be challenging for some; for others a splash of urine or water on themselves or their clothes may cause distress. Some children may find the bathroom a very overwhelming room or they may love it but be more interested in putting things down the toilet or flushing it.

It can be helpful to consider the different sensory systems and the bathroom

environment from the child’s perspective to try and establish why a child may find it a distracting or challenging environment and to then put in place measures to help alleviate the problems. The following are small things that could be done that might make a difference to how a child with autism perceives and acts in the bathroom:

- » Reducing the amount of visual distractions in the bathroom;
- » Avoiding using strong-smelling products that might be distracting;
- » Placing a mat on the floor to avoid having to walk on cold or shiny tiles;
- » Reducing glare from lighting;
- » Installing rails that a child can hold to help balance themselves when sitting on the toilet;
- » Introducing a weighted lap pad to help the child feel more grounded when sitting on the toilet;
- » Introducing fiddle toys to help children stay focused when on the toilet.

It is important to look at all of the senses and how these may impact on an individual child when trying to make the environment easier for a child to cope with.

One of the more distressing behaviours linked to toileting that some children display can be smearing of faeces. There are many potential reasons for this, including constipation, an inability to wipe properly or the need for tactile or olfactory input. An occupational therapist may be able to help with some of these difficulties by carrying out a sensory profile to assess potential difficulties and recommend strategies.

#### Other considerations

Although it is important to consider the impact of autism on toileting difficulties, it is vital to also look at additional health problems that could contribute to them (Fleming, 2010). For example, a child may be experiencing pain but may not be aware of it or may not communicate it. One of the biggest areas of concern we identified during training for parents and professionals is undiagnosed constipation. Many parents or non-medical staff do not fully understand the symptoms of constipation. Often, when a child has autism or any form of learning disability, physical problems such as this can get missed.

#### The nurse’s role

During a continence assessment it is important to talk to parents as well as other professionals who know the child, to identify whether the child has the same difficulties in every setting, for example home and school. It is very common for children with autism to display different behaviours in

### USEFUL RESOURCES

- **The National Autistic Society** has developed courses on autism and common toileting difficulties for parents and professionals  
[www.autism.org.uk/training](http://www.autism.org.uk/training)
- **The Toilet Time Training Resource Pack** is a 10-page, laminated, wipe-clean, flip-book from Sense Toys that contains velcro-backed pictures that provide a visual sequence for the stages of toileting. A set of larger, laminated picture cards is also available  
[www.sensetoys.com](http://www.sensetoys.com)
- **The Potty Journey** (Coucovanis, 2008) helps families to understand the process of toilet training
- **Constipation, Withholding and Your Child: A Family Guide to Soiling and Wetting** (Cohn, 2007) provides useful information on managing constipation
- Leaflets from the **National Institute for Health and Care Excellence** (2010a; 2010b) provide guidance on constipation and bedwetting
- **Including Me: Managing Complex Health Needs in Schools and Early Years Settings** (Council for Disabled Children, 2011) contains clear guidance on managing continence issues in school
- **PromoCon** promotes continence and product awareness  
[www.promocon.co.uk](http://www.promocon.co.uk)
- **Education and Resources for Improving Childhood Continence** provides a range of resources for children, parents and professionals  
[www.eric.org.uk](http://www.eric.org.uk)

different settings or with different people and it is vital that all adults involved in their life have a clear, consistent approach when implementing new routines.

Along with a standard continence assessment it is key to look at areas such as:

- » Ability to go into the bathroom;
- » Understanding what a toilet is for;
- » Use of rewards; and
- » Ability to cope with changes in routines.

Extra preparation is often needed to support children with autism to learn to use the toilet or to manage other continence-related issues (Rogers, 2007).

#### Raising awareness

It is important to start by raising the child's awareness of urine and faeces, and ensure the bathroom is used for all activities or use of all equipment associated with toileting (including nappy changes). Some children enjoy understanding how the body works, what faeces are and where they go.

Social Stories were created by Carol Gray in 1991 to help teach social skills to people with autism. These are short descriptions of a particular situation, event or activity, which include specific information about what to expect in that situation and why. They can be used to help a child learn some of the skills for toileting. For more information, please visit [www.autism.org.uk/socialstories](http://www.autism.org.uk/socialstories).

#### Establishing healthy habits

Children need to establish healthy habits around eating, drinking and regular exercise but this is not easy for those with autism as they may have very rigid eating and drinking patterns, and find it difficult to suddenly change them. The National Autistic Society has information sheets on both restricted eating and overeating ([tinyurl.com/NAS-diet-child](http://tinyurl.com/NAS-diet-child)).

Many children will also need to be taught dressing skills to help them to become independent as possible and may require clothes that are easy to remove to allow them to access the toilet.

Some children may need to be taught to sit on the toilet. A plan of gradually increasing the amount of time spent sitting on the toilet can help.

Some children may use the toilet for passing urine but defecate in their nappy or pants. Visual supports and rewards can be used to teach them new behaviours. The first step could be to encourage the child to go into the bathroom when they are opening their bowels. The next steps might include standing next to the toilet, then sitting on the toilet (still with their nappy on), then gradually loosening their nappy or pants. Giving appropriate rewards for using the toilet provides feedback and can motivate children if those rewards are given immediately and accompanied with praise, if appropriate.

#### Supportive care

People with autism have difficulties with both verbal and non-verbal language. Many have a very literal understanding of it and think people always mean exactly what they say, while others may not speak or may have fairly limited speech. These children will usually understand what other people say to them, but prefer to communicate their own thoughts through alternative means, such as sign language or visual symbols.

When talking with children who have autism, it is important to speak in a clear, consistent way and give them time to process what has been said. It is important to:

- » Talk positively about urine and faeces;
- » Decide what words for body parts and

functions – for example “wee” and “poo” – are going to be used and make sure you use those words consistently;

- » Make sure any instructions are clear: “Wee in the toilet” is clearer than “sit on the toilet” or “do you want to go?”; and
- » Remember that visual supports can help, such as a planned visual toileting schedule explaining the steps involved.

If there is more than one agency involved with a child it is absolutely vital that there is clear communication between all agencies and all staff.

#### Conclusion

Working towards achieving success with toileting can be daunting for children, families and professionals, but the long-term benefits of more independence for the child are huge. When working with children with autism it is important to try and understand how their autism impacts on them and how they communicate. They need an individual assessment and solutions, and, as discussed, preparation is often key. **NT**

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- » [Bit.ly/NTautismenvironment](http://Bit.ly/NTautismenvironment)

