




Autism and continence

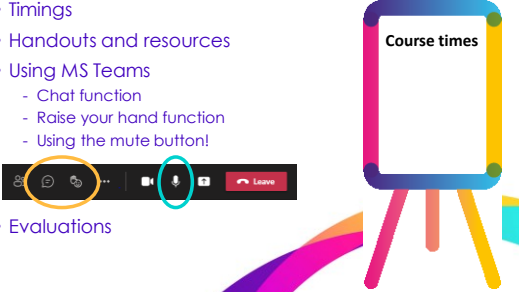

Learning to wee and poo in the right place - common toileting difficulties in autistic children

Lorraine MacAlister



Practicalities

- Timings
- Handouts and resources
- Using MS Teams
 - Chat function
 - Raise your hand function
 - Using the mute button!
- Evaluations

Autism & continence Resource list

Downloadable information or booklets

One Day at a Time
A practical guide to help you through the process of developing a toilet training plan for your child. This book is available for free download at www.nas.org.uk/one-day-at-a-time

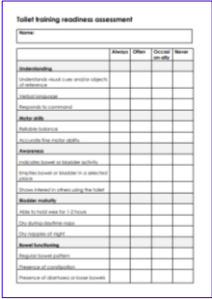
MS Teams: Using the chat
This guide explains how to use the chat function in MS Teams to help you communicate with your colleagues and share resources. It is available for free download at www.nas.org.uk/ms-teams-using-the-chat

Bookable resources MS Teams for free
This resource pack contains a range of downloadable resources, including a continuum of care, a toilet training readiness assessment, and a toilet training plan. It is available for free download at www.nas.org.uk/bookable-resources

Support organisations

Autism
The National Autistic Society (NAS) provides support and advice for autistic people, their families, and professionals. For more information, visit www.nas.org.uk

Autism & Disability
This resource pack contains a range of downloadable resources, including a continuum of care, a toilet training readiness assessment, and a toilet training plan. It is available for free download at www.nas.org.uk/bookable-resources





Learning outcomes

Course aim:
increase understanding of potential toileting difficulties from an autistic and a continence perspective.

Course outcomes:

- develop skills to support toilet training and specific continence issues
- have ideas about management of specific autism-related challenges
- share experiences and support strategies with colleagues in other settings
- develop the ability to support parents in approaches to developing continence.



Course outline

- Autism and common toileting difficulties
- Toilet training
- Poo
- Wee
- Specific autism issues
- Effective joint working
- Getting support




Introductions



Toileting difficulties



What are some of the main challenges that you are having with toileting?




Autism and common toileting difficulties







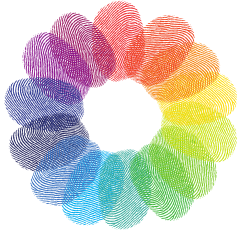
Introduction



- Toileting difficulties may be common in autistic children
- Initial advice may have been misleading
- Variation in timing of autism diagnosis
- Other difficulties may have had priority
- Parental feelings and emotions




The autism spectrum





- Social communication and interaction
- Restricted and repetitive behaviours, activities and interests
- Sensory differences


Common difficulties



- Basic toilet training skills
- Anxiety and fears about using toilet
- Constipation, withholding and soiling
- Smearing
- Going to the toilet in inappropriate places
- Using different toilets
- Having a restricted diet
- Wetting in the day
- Wetting at night




Communication and interaction



Potential differences in:

- language development
- expressive and receptive language
- verbal and non-verbal communication
- spending time with other people
- responses to other people.



Potential difficulties



Some autistic children may:

- not understand words or signs used
- not understand what you are asking them to do
- take language literally "put the toilet roll in the toilet"
- be less likely to communicate the need to go to the toilet
- need instructions or information presented visually.



Potential difficulties



Some autistic children may:

- not be socially motivated to wear pants or use the toilet
- be less likely to copy others to learn new skills
- not be motivated to please you by weeing or pooing in the right place
- not mind if they are wet or have soiled themselves
- go to the toilet in inappropriate places.

Restricted and repetitive behaviours, activities and interests



Potential differences in:

- processing information
- generalising learning from one situation to another
- ability to understand and cope with change
- interests
- organisation and planning.

Potential difficulties



Some autistic children may:

- assume you know they need help – so they do not tell you
- not understand that soiling themselves is a problem
- have difficulty in changing routines
- remove all their clothes when they use the toilet
- not transfer their toileting skills to unfamiliar toilets
- have fears and anxiety about using the toilet.

Our sensory world



- Sight (visual)
- Sound (auditory)
- Touch (tactile)
- Taste (gustatory)
- Smell (olfactory)
- Balance (vestibular)
- Body awareness (proprioception)
- Inside body (interoception)



Sensory sensitivities may lead to different awareness and interpretation of sensory information.

Potential difficulties



Some autistic children may:

- not feel that their bowel or bladder is full
- not respond to their bowel or bladder signals
- have limited awareness of being wet or soiled
- like the sensation of having poo in their nappy
- have difficulties in dealing with wee and poo, e.g. wiping or smearing.

Potential difficulties



Some autistic children may:

- struggle with body positioning when sitting on the toilet
- be sensitive to splashing on their clothes or body
- **dislike** sensory input
- **love** and seek sensory input

Sensory differences




Think about the bathroom from a sensory perspective.


What difficulties might arise for each of the senses?




Responding to sensory differences




- Be the detective
- Sensory profile
- Environmental audit
- Avoid or limit exposure
- Build in positive experiences
- Make toileting fun!




Responding to sensory differences




Toilet seats	Reduce risk of splashes
Non-slip mats	Grab rails or enclose area
Weighted items	



Responding to sensory differences



Lighting and reflections	
Noises	Smells
Things to fiddle with	Temperature



Toilet training




Importance of toilet training



- Human rights, dignity and independence
- Good for the child and the family
- Enables more social access and inclusion
- Time for fun activities
- Opportunities for other learning and education
- Personal safety and security

Preparation for toilet training



- Developing language about wee and poo
- Learning signs and symbols for wee and poo
- Getting used to bathrooms and toilets
- Understanding how the body works
- Clothing and adaptations needed



Readiness for toilet training

What kind of things should we consider when assessing toilet training readiness?

Toilet training readiness assessment

Name: _____

	Always	Sometimes	Rarely	Never
Understanding				
Understands that wees and poo are wet				
Understands that wees and poo are messy				
Understands that wees and poo are smelly				
Motor skills				
Can walk to the toilet				
Can sit on the toilet				
Awareness				
Shows awareness of wees and poo				

Behavioural assessment

Behaviours	Present	Intermittent	Absent
Bladder stability			
Wants to hold wee or poo			
Wants to hold wee for 1-2 hours			
Wants to hold wee for 3-4 hours			
Wants to hold wee for 5-6 hours			
Hand functioning			
Can hold a nappy			
Can hold a nappy for 1-2 hours			
Can hold a nappy for 3-4 hours			
Can hold a nappy for 5-6 hours			
Other skills			
Can follow simple instructions			
Can understand the concept of 'no' or 'stop'			
Can understand the concept of 'wee' or 'poo'			
Can understand the concept of 'flush'			
Can understand the concept of 'wash hands'			

Timing for toilet training



- **Parental readiness** – time of year, family circumstances, support required, emotions.
- **Child readiness** – stress and anxiety, timing of changes.
- **Physiological readiness** – bowel and bladder maturity.



Readiness for toilet training



Physiological factors

- Can stay dry for one to two hours at a time.
- Stays dry during short naps.


Cognitive age & understanding

- Cognitive level of two years or more.
- Demonstrates awareness.

Other skills

- Physical ability to sit and hold body upright.
- Largely cooperates with undressing.
- No medical conditions that may affect toilet training.

Developing general toileting awareness



Include toileting in the daily routine.

- Change nappy in the bathroom.
- Change child standing up (if possible).
- Encourage child to empty poo from nappy into toilet.
- Flush toilet.
- Wash and dry hands.




Daytime dryness – first steps



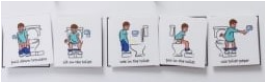
- Use trainer pants or liner in nappy to identify when wet.
- Keep an elimination record.
- Teach how to sit on toilet.
- Try an hour in the morning without wearing nappy.
- Take to toilet at regular times (but not every 30 minutes!).

Elimination record			
Time	Day 1	Day 2	Day 3
7am	D	D	
7.30 am	BM	D	
8am	U	U/BM	
8.30am	D	D	
9am	D	D	
9.30am	D	U	
10am	U	D	
10.30am	D	D	
11am	D	U	
11.30am	U/BM	D	


When to take away the nappy




- Make a clear plan with parents as soon as possible.
- Sooner rather than later.
- Clear messages that wee and poo go in the toilet.
- Consistency between home and other settings.



When you take away the nappy



- Ensure regular intake of clear fluids (seven drinks a day.)
- Take to the toilet at regular times, linked to cues in daily routine.
- Encourage child to sit on the toilet for a short time.
- Teach child to ask or sign for the toilet – this may take time



Supporting toilet training



- Make toilet training fun
- Clear and specific language
- Alarms or vibrating watches
- Visual supports



Supporting toilet training

- Rewards and motivators
- Activities and jigsaws to build rewards
- Learning how the body works
- Social Stories™
- Visit to sewage works or museums
- Portable urinals






Poo







Poo




How often do children poo?

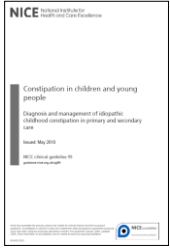
Why do some children find poeing upsetting?


NICE Guideline



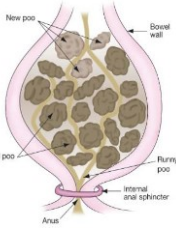
- NICE has produced the clinical guideline *Constipation in children and young people*.
- Contains information on assessment, investigations, management and treatment.




Constipation




- The rectum becomes full of poo.
- A distended bowel does not send signals to the brain about needing to go to the toilet.
- Withholding of poo to avoid pain is common.
- Overflow soiling often misdiagnosed or confused with diarrhoea.
- Often goes undiagnosed.




Potential signs and symptoms



- Fewer than three complete stools per week.
- Overflow soiling.
- 'Rabbit droppings' (type 1).
- Large, infrequent stools that may block toilet.
- Poor appetite that improves with passage of large stool.
- Waxing and waning of abdominal pain with passage of stool.
- Evidence of retentive posturing: typical straight legged, tiptoed, back arching posture.
- Straining.
- Anal pain.




Red flags




Potential underlying disorder or condition:

- reported from birth or first few weeks
- failure to pass meconium
- 'ribbon stools'
- abdominal distention with vomiting.





Contributing factors



- Dietary factors
- Psychological problems and stress
- Poor fluid intake
- Fear of toilets
- Medication


Treatment



- Disimpaction using laxatives 
- Maintenance dose of laxatives
- Different types of laxatives work in different ways (stimulant or softening)
- For autistic children – treatment influenced by what they will accept

Other considerations:

- Balanced diet – if possible
- Sufficient fluids
- Scheduled toileting routines and information.



Treatment






Nursing Times Awards 2017 Winner


www.thepoonurses.uk

Managing constipation

- Sitting position – feet on flat surface, knees ideally higher than hips.
- Foot stool, seating, hand-rails.
- Child may need convincing that poo needs to go in the toilet.
- Abdominal massage to help encourage bowel movements.
- Blowing activities may help use same muscles needed to push out poo.





Supporting the child



Explain how the body works and what happens when they get constipated by:

- visually demonstrating constipation
- Social Stories™
- trips to the sewage farm
- books
- party blowers
- foot stool
- feet marks.




Smearing



Consider possible reasons behind this behaviour.



Smearing



"I didn't know this happened to other people. I've never told anyone about this before, as I thought it was all my fault and they'd think I was a bad parent, and they'd take her away and put her in care."


Parent of an eight-year-old autistic girl

- Think about potential reasons – including autism, emotional and physical needs.

↓ ↓


- Consider how these may interact to cause or maintain the problem.

Smearing



Causes	Response
Constipation	Treat and manage
Inability to wipe effectively	Teach skills
Motor skills and coordination	Assess skills and arrange for further assessment if needed
Sensory stimulation or enjoyment	Offer alternatives
Psychological stress, anxiety and emotional difficulties	Support to provide predictability, stress management and relaxation. Assess and refer to a specialist service if needed
Enjoys the response from others	Modify the responses
Curiosity	Reduce response and encourage help in cleaning. Provide other activities to explore

Pooing in the wrong place



Common problems include:

- only pooing in nappy
- pooing in the bath
- pooing in 'inappropriate' places.

Reasons could include:

- thinking this is where the poo should go
- fear and anxiety about using the toilet or bathrooms
- sensory differences (feel of nappy, splashing of poo in the toilet).

Pooing in the wrong place



- Establish reasons before thinking about interventions.
- Support child to feel familiar and comfortable in the bathroom.

Staged approach:

- keep nappies in bathroom
- only put nappy on in bathroom
- empty nappy into toilet
- child moves nearer to toilet
- child sits on toilet
- nappy loosened, made smaller or replaced with toilet roll.




Wee







Wee




How often do children wee?


What is the average age for coming out of nappies?

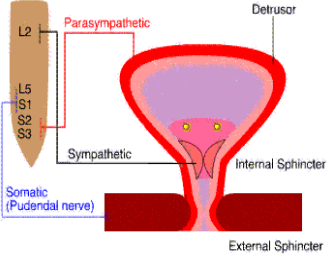
What is the average age for getting dry at night?

Does bedwetting run in families?



Here is a bladder!





Bladder difficulties



Potential reasons:

- anxiety
- more likely to drink too much or too little
- constipation
- less awareness of body signals
- differences in communication and understanding
- other developmental difficulties.

Bowel and bladder abnormalities more common in children with developmental problems (especially genetic conditions)

Children with persistent daytime bladder difficulties should be referred for further investigation.

Bladder difficulties



Types of difficulty:

- bladder immaturity
- frequency and urgency – overactive bladder
- postponing emptying bladder
- underactive bladder
- dysfunctional voiding
- recognition of bladder signals.

Things that affect bladder function:

- anxiety and stress
- constipation
- urine concentration
- caffeine
- colourings and flavourings
- medication.

Interventions



- Reminders - visual timetables, vibrating watches, alarms.
- Regular clear fluid intake – seven drinks a day.
- Rewards – for effort rather than success.
- Medication for bladder instability – Oxybutynin or Tolterodene
- Evaluation and possible medication for constipation.



Night-time dryness



- When dry in the day for six months, useful to consider night time training.
- Remove nappy and protect bed – maintain for three or four weeks.
- Encourage a wee before sleep.
- Regular clear fluid intake (seven drinks a day).
- Avoid caffeine (including chocolate).
- Many autistic children achieve night time dryness at the usual time.



NICE Guidelines



- NICE has produced the clinical guideline *Nocturnal enuresis: The management of bedwetting in children and young people*
- Contains information on assessment, investigations, management and treatment.



Bedwetting



Three main reasons why children wet the bed:


- bladder doesn't stretch enough
- produce too much wee (lack of vasopressin)
- don't wake up when bladder sends 'full' signal.

Autistic children may be:


- affected by stress and anxiety
- more tired or have sleep problems
- constipated.

Other factors may include an overactive bladder, constipation and genetic predisposition.

Bedwetting



- **Advice, information and reassurance:**
 - fluid intake
 - bladder emptying at bedtime
 - bed protection and night-time nappies.
- Usual treatments include medication and bedwetting alarms.
- Families may not want treatment for bedwetting.




Autism-related challenges, suggestions and solutions





Understanding behaviour



"To change your child's behaviour – you need to be able to make sense of that behaviour...
...and making sense of your child's behaviour means making sense of the autism."
Philip Whitaker, 2001

What? → Why? → How?

Understanding behaviour




An eight-year-old autistic girl has suddenly started wetting in the classroom and not telling anyone.


What could be the underlying reasons for this?




Understanding behaviour




What behaviours (linked to toileting) do you find it difficult to understand or manage?



Autism-related challenges



- Using toilets differently
- Transferring skills
- Playing with toilets
- Regression
- Not engaging with toileting



Using toilets differently



Some children may:

- position themselves to feel safe or gain sensory input
- have got used to using toilets in a particular position, e.g. squatting.

Support through:

- information on how to sit – using pictures or Social Stories™.
- adaptations – toilet seat, squatty potty, feet marks.
- choosing a toilet to practice on.

Using other toilets



Try and use a variety of toilets from the start.

Potential challenges :

- difficulties transferring knowledge to new situations
- may be toilet trained at home but not school
- may be toilet trained at school but not at home
- finding other toilets very scary.

Using other toilets



- Consistent toileting routines for ALL toilets.
- Share information between home and school.
- Encourage familiarity with toilets in other places.
- Take familiar objects to other toilets.
- Radar key.



Playing with toilets



- May not understand what the toilet is for
- Posting things down it or flushing may be fun!
- Bathroom may be very distracting, overwhelming or exciting

Practical ideas:

- create low arousal and organised environment
- time for similar activities that achieve the same effect
- specify flushing on visual routine
- visual information about how much toilet paper to use.



Not engaging



Important to try and gain insight into the child's perspective.

Possible causes may include:

- lack of understanding
- expectations too complicated
- fear of change
- not realising they need to go
- need to feel in control
- demand-avoidant profile.



Useful strategies



Give the child options

Empower by offering more choice in other activities

Prioritisation

Use variety of pace and presentation when asking

Use puppets or toy animals as a 'third person'

Avoid direct verbal commands

Include requests as part of normal conversation

Depersonalise demands



Role-play or pretending

Try and vary strategies and introduce new ones



Effective joint working



"I found that having a child with autism demanded contact with many agencies, and at times created conflicting situations with schools.

Sometimes the huge amount of communication, mediating and diplomatic interventions needed seemed entirely overwhelming and totally exhausting.

When this includes toileting issues in addition, it can feel like the last straw."

Parent of an autistic child



Making toileting programmes work

What are the difficulties and barriers to effective joint working?

How can we try and overcome these?




Transition planning

- It's never too late to address toileting.
- Transition may be a good time to consider reassessment.
- Teenagers with chronic conditions may need support and strategies.
- Continence should be documented on all relevant care plans.




Getting support






Schools

- Schools must not discriminate against or disadvantage disabled children or those with special educational needs (Equality Act 2010).
- No legal requirement for two members of staff to be present when a child is being changed.
- Not generally acceptable practice to oblige parents to come into school in order to change their child after they have wet or soiled themselves (*Supporting pupils at school with medical conditions*, Statutory Guidance 2014)

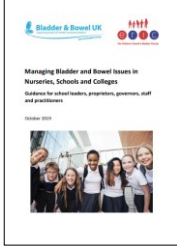


www.eric.org.uk/help-at-school-faqs

Managing continence issues at nursery, school and college



- ERIC and Bladder & Bowel UK have teamed up to produce comprehensive, practical information for school leaders, governors, staff and practitioners across the UK regarding bladder and bowel issues and toileting in schools.



Practical support



- Accessible toilets
- Changing Places website
- 'Just Can't Wait' card
- Disability Living Allowance
- Apps



Sources of support




ERIC
www.eric.org.uk



Bladder and Bowel UK
www.bbuk.org.uk



Toilet Training and the Autism Spectrum
www.jkp.com

Summary



- Autistic children need individual assessment and solutions.
- Inter-agency working and involving families essential to achieving success.
- Continence is important for employment, leisure, relationships and self-esteem.

Thank-you for taking part in today – we hope you have found the day useful.



Please complete your evaluation!




www.autism.org.uk