# Toileting Guide





# Learning to use the toilet and other associated skills (e.g., self-care routines, staying dry throughout the night) can be a huge milestone for an individual and their family.

Being able to use the toilet independently can have many benefits, including increased independence, providing opportunities to try new things (e.g., using a urinal, going for a sleepover), decreasing associated financial costs (e.g., support person, diapers), and mitigating risk of harm by not having your child be reliant on others to help with toileting activities (e.g., dressing, undressing, wiping). [1] Toileting is often not a simple or straightforward process. For many children with autism, it can take some time to learn how to use the toilet independently. [2]

This can be for a variety of reasons, including (but not limited to):

- Medical issues
- Anxiety
- · Sensory-related differences
- Communication and language differences
- Motivational differences
- Preference for sameness and routines
- Movement differences and difficulties [3]

There are more skills involved in toileting than people often realize. Deciding on which toileting goals to focus on first and which goals are best left for later can help the learning process go smoother and be less overwhelming for you and your child. This resource is intended to support parents and caregivers of individuals with autism who are interested in learning more about:

- Toileting and the various skills it entails
- When it might be time to focus on a particular skill
- · Who can help you with various goals
- · Common strategies that are used to support each toileting skill area

While this resource aims to support individuals of all ages and developmental stages, the term "your child" will be used when referring to the person that requires toileting support throughout this document. We will start by discussing some things to consider; these are things you may need to think about before and throughout your toileting journey. Then we will get into toileting routines, daytime toilet training for urination, daytime toilet training for bowel movements, bedwetting, challenging/upset behaviours associated with toileting, and fecal smearing.

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# **Environmental Considerations**

The bathroom environment can include various noises, smells, and other sensations that can be uncomfortable or overwhelming for your child. [4] Before you start on your toileting journey, you may want to consider some changes to the bathroom environment or some bathroom activities that can support your child in feeling better about the space.

This can help set your child up for success by having an environment they feel comfortable in BEFORE you start working on skills. Here are some examples [4]:

- If your child is interested, show them how the toilet works and offer an opportunity to "flush"
- Make sure your child can sit comfortably on the toilet and has somewhere to rest their feet.
  - Proper positioning, including foot support, is also important during bowel movements (i.e., having a way to brace their feet so they can engage their tummy muscles while having a bowel movement). You may want to consider using a potty chair or adding a stool. Sometimes seats can be added to your toilet (often called a "reducer ring", "potty ring", or "seat cover") to help your child feel more secure when sitting on the toilet.
- Place items within easy reach: toilet paper, wipes, or water for cleaning
- Reduce sensory overload by offering headphones to reduce echoes and address fears of sounds (e.g., flushing)
- Open windows, if possible, to reduce smells
- Help make bathroom visits a positive experience by offering a special book to look at or song to listen to while sitting on the toilet

Outside of the home, bathrooms may include different noises, smells, and other sensations, that your child may not be comfortable with. Planning for unpredictable flushing, hand dryers, and lineups can be hard. Thinking about these new sensations, you can make a plan. You may use sticky notes to block sensors that set things off automatically, a social story, bring noise-canceling headphones, or look for alternative family washrooms. Keep in mind that there are some things you can control and other things that you cannot.



# Who can help?

Occupational Therapist (OT)

# **Communication Considerations**

Being able to tell someone when you need to use the washroom, ask where the washroom is, and communicate if anything is wrong or uncomfortable are important parts of toileting.

Some children may use vocal communication while others may not. If your child doesn't yet have a way to communicate their toileting needs, you may want to work with a professional and explore the use of an Augmentative and Alternative Communication (AAC) system to communicate toileting needs, such as:

- A sign for toilet
- A picture-based system where your child can show you the picture of the washroom
- A speech-generating device, such as a tablet with a communication app



If your child has a good understanding of spoken language or picture stories, then you may want to consider using a social narrative or social story, which is a picture story about the steps in toileting and may also be used to explain some of the social rules around washroom routines.

# Who can help?

- · Speech and Language Pathologist
- Board Certified Behavior Analyst® (BCBA)

# **Social Considerations**

Toilet training and toilet use can be different depending on your culture and environment. Children with autism sometimes have difficulty understanding the social norms or social rules that may change depending on the environment. Often, if they learn a routine in one setting (e.g., home), they may have difficulty generalizing this to another setting (e.g., school). This is especially true if the two settings do not expect the same routines (e.g., fully undressing and sitting on the toilet at home vs. only pulling pants down to the knees at school vs. using a urinal without undressing in a community setting).

There are also many social norms and unspoken rules around washroom use which may need to be directly taught.

While you may not think of social skills when you think of toileting, here are some areas where social skills may be taught in the context of toilet training:

- Spacing oneself from others when using a urinal
- Knocking before entering a stall/washroom with a closed door
- Waiting your turn when there are lineups to use the washroom or sink
- Knowing that you do not need to take your pants down when using a urinal





# Who can help?

- Speech-Language Pathologist
- Board Certified Behavior Analyst® (BCBA)

# **Routines**

This section will include information on

- I) scheduling toileting into your daily routines; and
- 2) self-care routines to help you and your child.

#### Scheduling toileting into your daily routines:

An important aspect of toileting is for children to learn the cues that their body gives them to let them know when to go to the bathroom [4] (sometimes referred to as 'self-initiated'). Until your child can recognize and communicate that they need to go to the bathroom, you may want to set up regular times for toileting as part of your daily routine (sometimes referred to as being 'schedule-trained').



Some suggestions for when to schedule toileting into your child's routine can include:

- · When they wake up in the morning or after a nap
- Before and after an activity (e.g., going to the park, going for a walk)
- Before a meal or snack
- Before leaving the house (community event, school, visiting, etc.)
- Before going to sleep (bedtime or naptime) [4]

#### **Self-Care routines:**

There are other routines that can be part of toileting. We will refer to these as 'self-care routines'. Some examples of self-care routines include:

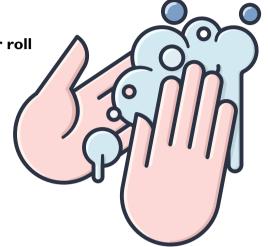
Hand washing Wiping

Getting dressed Using pads or tampons

Getting undressed Changing the toilet paper roll

### Who can help?

- Occupational Therapist (OT)
- Board Certified Behavior Analyst® (BCBA)
- School team



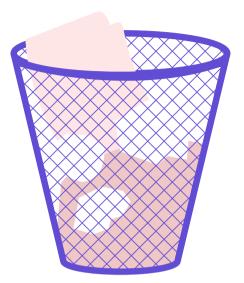
# Common teaching strategies for self-care routines:

Self-care routines can include several steps that can often be overwhelming to teach all at once. Often, professionals will break the routine down into smaller and more manageable steps that can be taught individually. [5,6] This is called a 'task analysis'. Focusing on smaller steps can be less overwhelming than learning a routine all at once. For example, handwashing may be broken down into the following steps:

- Turn on tap
- Wet hands
- Put soap on hands
- Rub hands together
- Rinse hands
- Turn off tap
- · Dry hands with towel



# As another example, individuals that are about to or have gone through puberty may benefit from breaking down the steps of changing a sanitary napkin or pad:



- Pull down underwear past the knee and sit on the toilet
- · Remove the soiled pad from underwear
- · Wrap soiled pad in toilet paper
- Throw soiled pad in garbage
- Wipe vaginal area at least once with toilet paper and throw in toilet
- Open clean pad and dispose of wrapping in garbage
- Fasten sticky side of pad lengthwise in underwear and press into place
- Pull up underwear and pants
- Flush toilet
- Wash hands [6]
- At times, your child may need additional assistance (called 'prompts'). A prompt is a specific form of help given by someone else to support the person with the skill they are learning. [5,6] A variety of prompts can be used to help someone (e.g., verbal prompts, visual prompts, or physical prompts). [5] The type of prompt used depends on an individual's unique needs and preferences. For example, in one research study, individuals with autism improved with their self-care routine when the steps were presented verbally and in a song! [7]
  - Keep in mind that prompts are "help" and once your child understands the expectation, it is important to consider lessening the help over time so that your child can continue to build independence.
- Once your child demonstrates the skill, it is important to use their favourite things (e.g., a special toy, activity, praise, or screen time) as rewards/positive reinforcement to acknowledge their efforts in accomplishing the routine. [5]
- Then, repeat the whole thing (i.e., presenting the routine, assisting when needed, and acknowledging efforts with rewards/positive reinforcement). Practice makes progress!

# **Helpful Tips**

#### **Choices and preferences:**

Consider your child's preference and choice when selecting materials, as this can influence and improve performance on self-care tasks. [8] Take your child to select their menstrual products, pick out a hand soap, or let them select which towel they want to dry their hands with:

#### **Diapers/Training Pants:**

Many professionals recommend switching to underwear early in the toilet training process, as diapers and "pull-up" style training pants do not allow your child to feel the full sensation of being "wet" or "soiled".

#### Clothing:

It is often helpful for children to wear clothes that can be easily removed, such as loosefitting pants with an elastic waistband. [4]

#### Underwear:

Some children don't like the feeling of underwear and prefer to wear nothing under their clothing. This may be something to consider, keeping in mind your child's preference, as well as your family and cultural practices.

#### Wiping:

Your child may need support learning how to physically wipe themselves (e.g., how to reach around back to wipe their bottom after poop, or how to wipe front to back for pee). Your child may need help knowing when to keep wiping and when they can stop wiping (i.e., visually checking when the toilet paper is dirty versus clean). [4] Your child may need help with how much toilet paper to use. [4] You may need to start with placing small, pre-determined amounts of toilet paper out for your child to use and slowly build to having the entire toilet paper roll out. Some families may not use toilet paper or wipes (e.g., some cultures use a jug with water to wash after using the toilet). Be open with the professionals you work with about what your family or cultural practices are so that they can support your child in learning what is important.

### Handwashing:

A stool may help your child to easily reach the sink. Soap and towels should be easy to reach. [4] If your child enjoys sensory play, washing hands with soapy bubbles can be a rewarding activity in itself.

#### Routines related to menstruation:

Consider practicing opening packaging, proper placement on underwear, and appropriate disposal BEFORE menstruation begins. [6] This can help the individual in feeling confident and competent before they need to use skill. Speak with your family doctor or pediatrician to see if they have any suggestions for you.



For more information and support with self-care check out:

- The AIDE Canada Self-Care Toolkit
- Or the ONTABA caregiver webinar Self-care skills during covid-19

# Daytime training for urination

This section talks about getting ready for learning to urinate ("pee") in the toilet. We also talk about who can help, and some common strategies that may be suggested by professionals.

# Your child may be ready to start "peeing" in the toilet if they:

- · Are at least 2-years old
- Show an interest or willingness to use the toilet
- Indicate when they are wet or when they need to go
- Start to have longer periods (2 hours) of being dry at a time [9]



These readiness indicators are from research in pediatrics and are not specific to children with autism. While your child may show indications that they are ready to begin toilet training other children may not and that is not necessarily an indication of whether toilet training will be successful.

# Who can help?

- Family Doctor/ Pediatrician: Speak with your family doctor or paediatrician FIRST to rule out medical reasons for daytime pee accidents
- Occupational Therapist (OT)
- Board Certified Behavior Analyst® (BCBA)

Daytime toilet training for urine, sometimes called 'continence training for urine' can be supported by a BCBA or an OT.

### Typically, the focus of teaching the person with autism will be around:

- Successful urination on the toilet ("peeing" in the toilet),
- Staying dry while off the toilet ("holding it"/bladder control), and
- Self- initiating when the individual feels they need to urinate (asking to "go"/communicating their needs).

# **Toileting Plan:**

There are many different approaches to daytime toilet training for "pee". Often these different approaches have some things in common. Below are some common teaching strategies that may be used.

- Not wearing diapers during the daytime [2,10, 11, 12, 13]
- Increase daytime fluid intake (e.g., water, juice, milk) [10, 11, 13, 14]
- Visiting the bathroom at regular times during the day [2,10,11,12,13,14]
- Using a bathroom task analysis (e.g., go to the washroom, lights on, close door, pants down, sit on toilet, pants up, wash hands, lights off) [2, 11]
- Teaching a way to communicate when they need to go [2,10,13]
- Practicing using the toilet in different washrooms (e.g., at school, in the community) [2,10,12,13]
- Positive reinforcement/rewards for successfully peeing in the toilet [2,10, 11, 12, 13, 14]
- Being prepared for when accidents occur [2,10, 11, 12, 13, 14]
  - Can include having the child help change themselves or redirecting them to the washroom
  - Careful not to send the child to play while you clean up the mess; this can send mixed messages
  - Consider using a moisture-sensing alarm to help with awareness [10]
- Gradually increased the amount of time between bathroom visits [2,10, 11, 12, 13, 14] As the amount of time between visits increases, the goal is for your child to respond to the feeling of a full bladder and communicate/request to use the bathroom rather than waiting to be taken to the bathroom.
- Data collection or a 'pee journal' can help you keep track of your child's successes and challenges with toileting. You may want to record the number of bathroom visits, the number of accidents, the amount of fluid consumed/ingested, the amount of time between pees, and the amount of pee in the toilet (e.g., a lot or a little). Data can help you see progress. In this way, we can keep what is working or modify and change what is not working. [2,10,11,12,13,14] Ask the professionals in the 'Who can help' section if they have a pee journal or datasheet you can help fill out.



# "Pee"/"Poop" Journal

Record information (called "data") on your child's daytime "pee" and "poop" in the chart below. This should be done during your child's waking hours. If you find it challenging to collect all of this information every day, then choose a couple of days per week (i.e., a sample) to record data when you can be more diligent in recording data. Tally each section with a tick or a line (e.g., III). Over time, you can look through these sheets and watch the ticks move more from one box to another. Ideally, with supportive strategies in place, you want to see more ticks in 'successes' or 'self-initiations' and fewer ticks in 'accidents'.

Dates	Tally number of visits to the washroom	Tally the number of times the individual self- initiated or asked for the washroom and went pee or poop	Tally number of successes (peeing on the toilet)	Tally number of successes (pooping on the toilet)	Tally number of accidents (pee or poop)
Monday					
Tuesday					
Wednesday					
Thursday					
Friday					
Saturday					
Sunday					

# Daytime training for bowel movements

This section talks about getting ready for learning to have a bowel movement ("poop") in the toilet.

We also talk about who can help, and some common strategies that may be suggested by professionals. Finally, this section looks at some common challenges related to daytime training for "poop".

Daytime poop accidents, sometimes called 'fecal incontinence' or 'encopresis,' is when an individual has a bowel movement (sometimes called a 'stool') at unwanted times and outside of a toilet or potty. [15]

There can be many explanations for fecal incontinence related to gastrointestinal, neuromuscular, behavioural, and social-emotional processes. [15]

# How do I decide if my child needs additional toileting training for "poop"?

Some urine training programs will include rewards (or positive reinforcement) for appropriate bowel movements (otherwise known as "poop") on the toilet. This can sometimes lead to improvements in bowel movement accidents as children learn to use the toilet for both urine and bowel movements at the same time. [16] Thus, some individuals may not require programs that specifically target bowel movement training, while others may. [16] It is important for your team to collect data (for both "pee" and "poop") and monitor your child's progress during daytime toileting training for "pee" to determine if additional training is needed for "poop".



### Who can help?

- Family Doctor/Pediatrician: Speak with your family doctor or paediatrician FIRST to rule out medical reasons for daytime "poop" accidents
  - Gastroenterologist If your child experiences severe or prolonged challenges with pooping, your doctor may suggest a referral to a specialist such as a Gastroenterologist
- Occupational Therapist (OT)
- Board Certified Behavior Analyst® (BCBA)
- Registered Dietician (problem solve around dietary needs related to bowel movements, such as increasing dietary fibre intake).



# Toileting plan:

There are many approaches to addressing daytime training for "poop". Many of the strategies discussed in daytime toilet training for "pee" are also useful for daytime toilet training for "poop" (e.g., scheduling toilet sits, rewards/positive reinforcement for successful poop on the toilet). [16] However, "pooping" can include more considerations such as diet. functional constipation, and withholding. In such cases, it can be helpful to use a multidisciplinary or interdisciplinary (team of professionals) approach. [17]

### This may include:

- Education on the physiological and behavioural processes of bowel movements [15]
- Dietary and fluid interventions [15]
- Behavioural interventions (e.g., establishing bathroom routines, toileting schedules, positive reinforcement/rewards for successful voiding in the toilet) [15, 17]
- Medical interventions (e.g., laxatives or enemas) [15,17]
  - Maintenance of soft, well-lubricated stools (makes it easier and less painful when pooping)
  - Good perianal skin care (for example, your doctor may prescribe a cream or lotion to help heal and protect your child's bum).

### Things to know about constipation:

A child is considered constipated when they show some — or all — of the following signs for an extended period of time (i.e., happens at least once a week; has been going on for at least a month):

- Poops less than 2 times a week
- Voluntarily holds in poop
- Poop is usually hard and lumpy
- Pooping seems to hurt
- When your child poops, it seems very large or may clog the toilet [18]

The added challenge of constipation is that when a child has a large amount of "poop" inside that isn't coming out, it can lead to accidents. For example, when there is a hard mass of stool (i.e., "poop") in the rectum (the last part of the digestive system), soft stool can slip around and cause "poop" accidents: "rectal overflow". [19]

Constipation can also lead to "toileting refusal", where the child becomes fearful of painful bowel movements ("It hurts when I poop"). [20] Speak to your doctor or pediatrician if you believe your child may be constipated.

Other possible reasons for toileting refusal related to pooping may include sensory issues. For example, if your child dislikes the sensation of pooping or pooping in the toilet or is sensitive to aspects of the bathroom environment. [20]

Work with your family doctor or pediatrician if you feel your child is constipated.



# **Bedwetting**

This section talks about "bedwetting" (sometimes called 'nighttime incontinence' or 'nocturnal enuresis').

Bedwetting is another way of talking about having a "pee" accident at night, or while sleeping; in other words, "wetting" the bed. [21]

While you may feel your child's bedwetting is similar to daytime toileting accidents, they are actually quite different. There are many different reasons why a child may wet their bed at night, including age, family history, and medical reasons (e.g., hormonal imbalances, sleep apnea, chronic constipation, a small bladder, urinary tract infection, other diagnosis like diabetes, inability to recognize a full bladder). [21]

# You may wish to seek support for bedwetting if your child:

- Is over the age of 7 years
- If they previously were dry throughout the night and are now experiencing bedwetting
- If the bedwetting includes other unusual experiences such as painful urination, feeling thirstier than usual, if the urine looks pink or red, if bowel movements result in hard stools, and if there is snoring (that is not typical) [21]



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# Who can help?

- Speak with your family doctor or paediatrician FIRST to rule out medical reasons for bedwetting [21]
- Occupational Therapist (OT)
- Board Certified Behavior Analyst® (BCBA)

# Night time bedwetting journal

Record information (called "data") on your child's bedwetting in the chart below. If you find it challenging to collect all of this information every day, then choose a couple of days per week (a sample) to record data when you can be more diligent in recording data. Complete all sections. Try to stay consistent with a reasonable last time to drink before bed and empty the bladder before bed. A consistent bedtime and wake time can be helpful, too. As mentioned above, there are many reasons for bedwetting, and this journal can be taken to your family doctor or pediatrician to help them understand what is happening.

Dates	Last time to drink before bed	Last time to pee before bed	Time went to bed	Pee accidents (tally number of accidents)	Time woke up
Monday					
Tuesday					
Wednesday					
Thursday					
Friday					
Saturday					
Sunday					

# Challenging or upset behaviour around toileting

Your child may become upset or engage in challenging behaviours around toileting for various reasons. Some children may be trying to communicate they DON'T want something to happen. For example, some children get upset when they need to have a bowel movement if previous bowel movements were painful, [16] or some children may be trying to avoid a specific bathroom where they experienced those loud and unpredictable hand dryers and flushing sounds. Other children may be upset as a way to communicate that they DO want something. For example, some children may be upset because they want to use a specific washroom that they feel more comfortable in but do not have a way to tell you this.

During the toilet training process, it is possible that your child could become upset when they have accidents. This is often the case for children that were used to using a diaper and are now in underwear. This can be because they do not like the feeling of being wet/soiled OR because the accident signals to them that they are not going to be getting rewards/positive reinforcement. [16] Some researchers have found that when children with autism are upset as a result of an accident, this is temporary and may improve as the child learns to "pee" in the toilet. [16]

# What can I do? How can I help them?

There are many different reasons why your child may behave differently than you had expected or even hoped. It can be frustrating not to have the answers to support your loved one right away. If your child shows distress or discomfort (e.g., crying, running away, becoming aggressive) with certain aspects of toileting, you should seek support from a professional. Professionals are likely to investigate underlying reasons for your child's upset behaviour related to toileting so that they can support you with a plan to improve your child's wellbeing.

# Who can help?

- Speak with your family doctor or pediatrician FIRST to rule out medical reasons for challenging or upset behaviour related to toileting
- An Occupational Therapist (OT)
- Board Certified Behavior Analyst® (BCBA)



# Challenging behaviour continued: "fecal smearing"

One example of a challenging behaviour encountered by parents of autistic children is "inappropriate" or "risky" poop behaviour, such as playing with or the spreading around of feces, otherwise known as "fecal smearing".

### Why is my child smearing their feces?

Just like other challenging behaviours, there can be many reasons for fecal smearing. Understanding some of these reasons can be helpful in reducing this behaviour.

#### Some common reasons may include:

- Medical issues: constipation, diarrhea, and other gastrointestinal issues such as abdominal pain can contribute to fecal exploration, including fecal smearing [22]
- Sensory issues: some children may like how poop feels in their hands or might like exploring the smell. On the other hand, some children may be extra sensitive to the feeling of poop in their diaper or underwear and may try to remove it with their hands [22]
- Behavioural factors: as with any behaviour, your child may be using fecal smearing to meet a need, or to communicate a need [22]



# Who can help?

- Speak with your family doctor or pediatrician
  FIRST to rule out medical reasons for challenging or upset behaviour related to toileting
- An Occupational Therapist (OT)
- Board Certified Behavior Analyst® (BCBA)

# **Helpful Tips:**

 Ask your therapy team for recommendations or suggestions for clothing that limits your child's access to their diaper or underwear (for example: onepiece pajamas with fasteners at the back).



### **Toileting Setbacks:**

As with each stage of development, and with each skill your child develops, there may be times when you feel as though you have taken "one step forward and two steps back". In other words, each time you start to feel excited that your child is showing an interest in helping to pull up their pants, use toilet paper, or want to turn off the tap, you may feel equally frustrated when they poop in their underwear (again), or wake up to a wet bed. Setbacks are especially common during toilet training, as there are so many variables that can play a part in how your child is learning and responding each day.

# Some examples of things that might affect your child's progress in toileting:

- Changes in routine (e.g., school, vacation)
- Times of stress (e.g., illness, family dynamics)
- Growth, changes in hormones
- Changes in medication
- Changes in eating or drinking habits



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That said, it is important to keep your medical, therapy, and/or school teams informed about these types of changes and challenges so that you can problem solve together about adjusting strategies if needed. If you are concerned about your child's progress, it's always a good idea to check with a professional to rule out any medical issues.

# What now?

Hopefully, this guide is helpful in your toileting journey by providing you with information on various toileting goals and professionals that can help support your child with their unique strengths and needs. You may be eager to get started or might feel completely overwhelmed. Your feelings are important. Start small and have a discussion as a family about what to prioritize and how some of the common strategies used may or may not fit into your values and culture. If you are comfortable, share your questions, concerns, or apprehensions with your professional teams so that they can support you. On that note, remember to take care of yourself!

### Taking care of you...

Learning new skills around toileting can be exciting and challenging for your child. It can also be exciting, challenging, and exhausting for parents and caregivers. You don't need to feel alone. Taking time for yourself and connecting with other parents and caregivers can be an important way to keep things in perspective. There is an old adage that says, "It takes a village to raise a child". Reach out and ask for support from your "village"; help with soiled laundry, help with preparing a healthy meal, help with taking your child to the park for an hour, or just help by offering a listening ear.

# Who can help?

- Social work/Mental Health support
- Family
- Friends
- Neighbours
- Respite
- School team



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# Resources

#### **RESOURCES:**

- · You can find many professionals who can help on the OAP Provider list
  - OAP Provider List
- If you do not already have a family health care provider (e.g., family doctor) you can find one here:
  - Find an Ontario health care practitioner
- The below toileting-related books, and other books e-books, and audiobooks can be found at the <u>AIDE Canada Library</u>
  - Tom needs to go (A book about how to use public toilets safely)
  - Ellie needs to go (A book about how to use public toilets safely)
  - A feel better book for little poopers
- Did you know there are grants to help with the costs of diapers?
  - Incontinence supplies grant (diaper) program
- For other accessories to support toileting, including moisture sensing alarms, check out the bedwetting store
  - Accessories (e.g., moisture sensing alarm)