



Down Syndrome & Toilet Training



Boston Children's Hospital
Down Syndrome Program

Congratulations! If you are reading this, you are probably thinking about toilet training and wondering how to introduce your child to the toilet. Perhaps you have already purchased a little potty or insert for the toilet and started to use it. Maybe you are just wondering if, when, or how to start the process, and whether the process will be any different for your child with Down syndrome. This guide will provide you with information to get you on your way to toilet training your child. So get ready, get set, GO!

CAN MY CHILD WITH DOWN SYNDROME LEARN TO USE THE TOILET?

Like their typically developing peers, children with Down syndrome have a broad range of abilities. Most will achieve their developmental milestones, but on their own trajectory and time frame. Most children with Down syndrome are able to toilet train, and can successfully complete this very important developmental milestone. You will find that the developmental considerations a parent of a child without Down syndrome experiences will also apply to you and your child as you begin this journey toward achieving continence of stool and urine. Likewise, patience, flexibility, consistency, repetition and humor all contribute to a successful process for both of you.

DEVELOPMENTAL CONSIDERATIONS

During the toddler or preschool years, children inherently have a need to please their parents or caregivers and imitate what they see. At the same time, they start to realize they are separate and independent from their parents and begin to exert that autonomy in their environment. Once a child gains self-awareness and understands what your expectations are, toilet training becomes easier. Incorporating play into the process improves cooperation and decreases the natural power struggle that is inherent to this stage of development. By understanding and working within this dichotomy, stress-free toilet teaching can be achieved.

Start by assessing your child's readiness skills. If your child isn't showing the signs below, then the best course of action is to be patient, keep an eye out for the cues and set the stage to provide a solid base from which to start.

ASSESSING READINESS SKILLS.

General considerations

- How long is your child able to remain dry? A good way to determine this is to take a weekend and during their waking hours, keep a log of whether your child is wet or dry. Start by checking every hour. If consistently wet, begin checking more frequently (up to every 15 minutes) to give yourself a baseline.
- Is your child verbal? Does your child have a way to communicate a need either by sign, gesture, facial expression, or other form of communication? It should be noted that verbal skills are not required to begin potty training.
- Is your child walking independently? Again, this in itself doesn't preclude toilet training but if the child isn't able to get to or on the toilet or potty alone, adaptations will be needed.
- Does your child help with the dressing process? Can your child pull pants up and down independently? This can help give you an idea of current motor skills.
- Does your child have awareness of the elimination process? For example, can your child indicate needs/wants? Notify you before or after an accident? Tell you when a change is needed by bringing you a diaper or trying to get out of the soiled/wet diaper? These actions indicate an awareness of the elimination processes.
- Does your child have regular urine or bowel patterns? Dry during naps? Hide or want privacy when having a bowel movement? This information will help you formulate a plan tailored for your child.

Communication Readiness Skills

A way to communicate discomfort about a soiled or wet diaper, either verbally or with nonverbal signs is necessary to begin the process. Some children learn best using a combination of pictures (such as the Picture Exchange System, PECS) and spoken language. Others use the sign for potty with the spoken word. Technology-based augmentative communication can also be used. Occasionally, some children might skip this step of asking to use the bathroom completely and begin initiating the task independently.

Motor Readiness Skills

For an ambulatory child the sequence of events surrounding toileting includes walking to the bathroom, taking pants down, sitting on the toilet, relaxing, pushing (going), wiping, getting off the toilet, pulling pants up, flushing and hand washing. Is your child able to stoop and sit independently or does your child need help to get on and off the toilet? Do their feet touch the ground or dangle? Does your child have to work to avoid slumping into the hole on the toilet seat? For children who do not walk, adaptive toileting equipment (often best assessed by a physical therapist) may be necessary to afford enough comfort to relax and be successful on the toilet. A firm base for the child's feet to rest upon and a comfortable, stable seat on which to sit, help to align the body, promote relaxation and make it easier to push out a bowel movement.

Cognitive Readiness Skills

Your child will need to understand what you are asking them to do and should be able to follow instructions. The first step is to recognize the potty as a chair and become comfortable sitting on it. The second is to understand the potty's use. Learning this connection may take some time. Your child will need to have a long enough attention span to perceive the signal that something is coming, "hold" it long enough to get to the toilet or the potty, relax and then release the bowel movement or urine. Timed (also known as scheduled) sitting times of no more than 5 minutes are integral in setting the stage for success. In the beginning these times are used to accustom a child to the seat and bathroom and not dependent upon the child's ability to request to sit.

Social/Emotional Readiness Skills

Young children often want to be just like their parents, as well as to please them. These two factors can be used to your advantage when you're ready to work on the toilet training process. As with most new things, consistency and repetition are two key requirements. If there is a lot of stress or anxiety or other new changes going on in the home (i.e., the birth of a new sibling, move to a new home, change in routine at school or at home), it may be best to wait to start the process.

Remember how we mentioned earlier that children ready to begin toilet training, are also at that stage of wanting more autonomy/ independence? This is when they realize THEY can say no too! By being aware of how this normal developmental phase is coming into play, you can be ready for it and give them more control in other areas of their life (what do they want to wear, do they want to have carrots or peas, do they want to sleep with their stuffed rabbit or their stuffed cat), so that they won't be as likely to resist the toilet training. In addition, if there are external forces outside of their control (such as having to share a parent with a new sibling, or their teacher is out on maternity leave), that too has the potential to effect a negative response in a completely different area (perhaps toilet training). Each child's program should be built upon their abilities and acquired skills. For some children, the stress of becoming a "Big Boy" or "Big Girl" can backfire and result in refusal/regression. For these children, gradual change works best, such as keeping the pull-ups only in the bathroom and offering quiet praise for any successes.



TEN STEPS TO SUCCESSFUL TOILET TRAINING

STEP 1: Make Diaper Changing Time Less Fun

When your child was a baby, diaper changing was a “special time” to provide comfort, bonding and play. Now that your child is ready for the toilet, make diaper changing time less fun. Provide less talk, make it more goal-directed, and do diaper changes in the bathroom, with the child in a standing position. This will reinforce the concept that bowel movements and urine ONLY belong in the bathroom, as do pull-ups, wipes and changes of clothes.

STEP 2: Get a Potty

Many families buy a potty when their child is around 2 years old. Even if the child is not yet ready to begin toilet training, this will “set the stage.” Older children can decide whether they want an insert or a small potty. If you use an insert, be sure to have a step stool where your child’s feet can rest securely (integrated step stool/insert systems are also available). Place the potty in the bathroom and let them sit on it to play or when you are sitting on the toilet. Try not to place them on the toilet or potty unless they are physically unable to accomplish this, as it can cause resistance. If they refuse, give them the option of now or in two minutes or use transitioning techniques (i.e., a visual timer, this/then or visual schedule). Try playing with toys, reading books, singing songs, or listening to music. Give stickers, high fives or some other low-cost or time-based incentive for cooperating.

IDEAS TO ACHIEVE A SITTING TIME	TIME BASED/LOW COST INCENTIVES
Read	Play your child’s favorite game
Sing songs	Have a tea party
Use blow toys (pinwheels, party favors, whistles)	Watch a funny YouTube video
Listen to music	Paint their nails
Look at photos on your phone	Stay up 15 minutes later that evening
Play a game on your phone	Do a round of high 5’s
Play with a special toy	Call a relative or friend

STEP 3: Encourage Dressing and Undressing

Have your child help with dressing and undressing. Dressing in clothes that are easy to put on or take off, such as pants with elastic waists, skirts or dresses, makes the process a bit easier. Let your child practice putting pull-ups on and taking them off.

STEP 4: Avoid Constipation

Remember that although children are motivated to please parents and accomplish toilet training, they are more motivated to avoid pain, so constantly assess for constipation by checking bowel patterns, frequency and amounts. Soft bowel movements alone don’t necessarily mean that the child is not constipated. If you start to see harder bowel movements, smaller amounts, very large bowel movements or a change in the frequency of the bowel movements, let your child’s health care provider know. If your child begins to resist or avoid using the toilet or crosses their legs while having a bowel movement, this may be a signal to be extra vigilant for constipation.

STEP 5: Encourage Imitation

Make it fun!!! Try having your child practice sitting on the potty while you are sitting on the toilet. Use stuffed animals or dolls and pretend that they are learning to use the toilet also. Some baby dolls can “drink” bottles filled with water and then urinate in a toy potty. Social stories or video models about using the toilet, which you can find free online or can create yourself, can also be helpful.

STEP 6: Regular Practice

Consistency and repetition are keys to success! Start with one 5 minute sitting time per day and let your child set the timer, so they are in control. Bath time is often a good time for this, as your child will already be undressed. Next, start implementing sitting 5-10 minutes after meal time to take advantage of the gastric-colic reflex (food in, bowel movement out) or before or after nap or bed time. Choose a time that works best for you, and when you do not have to rush, so that your child can be most successful. Finally, add in verbal or nonverbal reminders, limited to a frequency of every 2 hours.

STEP 7: Wiping and Hand Washing

Your child may already have learned hand washing. Learning to wipe is usually a skill that comes more gradually. Some children find it easier to use wet wipes rather than toilet paper, while others don't like that wetness. Start by having them do the last wipe (after you've done the entire clean up), then the next to the last wipe, and so on, until they are gradually assuming the entire process. You should check at the end to provide feedback for thoroughness. Fine motor control may impede the process, and some will find it helpful to have a long mirror placed strategically in the bathroom, in order to see what they are doing.

STEP 8: Wear Underwear

Establish an "Underwear Time"! We recommend starting this once a day after a child is able to be dry for 2 hour stretches. A good time to implement this is after a diaper change or a success on the toilet. If you run into resistance, try to implement wearing underwear during a favorite movie. Gradually extend this time to longer periods at home before trying them outside of home. Once your child can be dry 50% of the time, they should be ready for wearing underwear all day long.



STEP 9: Encourage independence

Your child will go independently when they're ready. Before then, continue to remind them. Gentle reminders before leaving the house, going outside to play, watching TV or playing a computer game can be helpful. For a child that resists parental reminders, consider trialing an alarm watch or FitBit (check that your FitBit can be programmed multiple times during the day). Remember to give just enough praise (but not too much) when your child independently uses the toilet.

STEP 10: Putting It All Together

Toilet training completion is:

- Becoming aware of the signal to use the toilet.
- Being able to "hold", tell or get to the bathroom.
- Undressing, getting on the toilet, going, wiping, dressing, flushing, and hand washing.

Until these steps are automatic, it is important to support and reinforce the process.

A Picture Exchange System or social story may be helpful for your child. A visual schedule posted on the bathroom wall or singing a song about the required steps can be helpful as well.

Play and songs are also good tools for teaching.

Flexibility, adaptation, repetition and consistency are key elements in any successful toilet training program!

PARENT ROLE

- Provide direction, motivation and acceptance as your child learns.
- Model the process by allowing your child to accompany you to the bathroom.
- Eliminate any expression of disappointment as accidents WILL happen!
- Break the process down into small attainable steps.
- Remember that the initial goal should not be complete daytime training but gradual acquisition of each skill (recognition of the urge, getting there, undressing, releasing, etc.) until all the skills can be put together and that these skills don't have to be learned in order. If you seem to be stuck on one particular step, try another step and once that one is achieved, go back to the one that was more problematic. Try to keep the momentum of success going!
- Notice your child's cues, and if you sense resistance or regression, take a step back.
- Provide continuity of the toilet training plan and routine at both home and school.
- Make sure your child is not constipated.

STRUCTURING YOUR APPROACH

Children do best with a positive approach to learning. You can take advantage of your child's desire to please and response to praise. Use positive reinforcement for each toileting step and resist the urge to talk about disappointments.

Avoid using "high stake" incentives such as a trip to Disney World, as these don't work. The best reinforcements are low-cost or time-based incentives (see table above). Often we find special time alone with a parent to do an activity of choice (e.g., an extra book to read together) is most valuable to a child.

Remember that too much praise can feel like pressure, so gauge your praise accordingly.

Don't be surprised if regression or resistance is encountered along the way. Both are quite common and can "spill over" to other aspects of your child's life. If this occurs, try to assess the cause (too much pressure, a new baby, a vacation, surgical procedure, illness, marital conflict) and make appropriate adjustments.

POTENTIAL ROADBLOCKS

The start of school, a new school year, or a new school, teacher or classroom can be a major undertaking for some children. Some children have difficulty adjusting to these transitions, and balancing learning and instruction in other areas with learning the concept and control of using the toilet. For some, increased stress in these settings may result in more frequent voiding patterns and withholding behaviors, which can lead to constipation and encopresis.

You know your child best! Don't be afraid to be flexible. Some children may become anxious about using the toilet or giving up their diapers, so be willing to alter your plan. Others may do well with a more structured approach at school and the maintenance of that consistency at home. In this case, consider including toileting in your child's Individualized Educational Program (IEP). In some cases, incorporating a behaviorist to augment the program and help develop



a plan will be needed. Sometimes, it may be beneficial to wait until vacation to work with your child on toileting and then transition that new skill into the school setting. Other suggestions include timed sittings of no more than 5 minutes, data collection (as to success, time of day, etc.), watches with alarms to remind a child to sit, and bowel retraining to avoid stooling at school. Bowel retraining can reduce stress for some children and improves the ability to predict when a stool is more likely to occur by taking advantage of the gastric-colic reflex. Using the action time of laxative medications in conjunction with scheduled sitting times can provide this retraining but should be done with the help of your provider.

HOW TO AVOID ROADBLOCKS

Know your child's voiding (urination) and bowel movement timing history. Most children are ready to begin toilet training when they are able to remain dry / clean for 2 hours at a time.

Does your child have recurrent bouts of constipation or diarrhea? If so, then consult with your pediatrician before starting a toileting program. Constipation can be one of the biggest barriers to toileting success. If the child is constipated, consider checking for hypothyroidism, which commonly occurs in children with Down syndrome and can result in constipation. When constipation develops, hard large bowel movement can occur which are painful to pass and thus result in withholding because of the associated pain, leading to more withholding, distension of the bowel and finally encopresis (incontinence of stool), which can look like constant diarrhea, leaking of stool or smearing of stool.

Hypotonia is another factor to consider. Hypotonia (low muscle tone) may make it more difficult to use the right muscles to evacuate and fully expel stool, resulting in stool retention, constipation and distension of the bowel.

ADDITIONAL INFORMATION

AVERAGE ACQUISITION OF POTTY TRAINING IN DOWN SYNDROME

- Dry during the day: average, 36 months (range 18-50 months).
- Bowel control: average, 36 months (range 20- 60 months; some sources report 2-7 years).
- Dry at night: 60% between 7-14 years.
- Uses toilet/potty independently: 4-5 years.
- Fully continent day and night: 98% by 11-12 years.

The above information was taken from the Down syndrome Education Online, Social development for individuals with Down syndrome and the National Down Syndrome Society.

CONSTIPATION

Definition:

Hard, dry or difficult to pass stools in small to large amounts.

Causes:

- Not enough fluid intake
- Not enough exercise
- Not enough fiber
- Withholding (fear, habit)
- Inattentive, hyperactive behaviors
- Disease, illness, allergies, sensitivities, stress
- Hypotonia (low truncal muscle tone), resulting in incomplete evacuation



ENCOPRESIS

Definition:

Diagnosed over the age of 4 years (or a developmental age of 4 years); Repeated passage of stool into places other than the toilet; Includes soiling and staining, small pellets, or full formed bowel movements.

Causes:

- Developmental
- Behavioral
- Long term constipation

Statistics:

accounts for more than 25% of all visits to pediatric gastroenterologists¹; very common in the general population²:

- 2.8% of 4 year olds
- 1.9% of 6 year olds
- 1.6% of 10-11 year olds

More than 90% of encopresis due to functional (non-medical cause) constipation

Treatment:

- Bowel cleanouts with high dose polyethylene glycol (Miralax) and senna (Ex-Lax) or other similar medications, followed by maintenance of these medications.
- Scheduled sitting times.
- Blow toys / games during sitting times to encourage a bowel movement: whistles, pinwheels, party favors, bubbles, blowing a square of toilet paper and letting a parent catch it.
- Diet high in fiber (fruits and vegetables, whole grains) and plenty of water.
- Active daily exercise.
- If behavioral/psychological/medical concerns: address appropriately with medical or psychological support.

DAYTIME URINARY INCONTINENCE

Definition:

Persistent involuntary release of a normal volume of urine during the waking hours after the age of 4 years (or a developmental age of 4 years); among the most common problems in childhood.

Causes:

- Urinary Tract Infection
- Medical illnesses that increase the volume of urine produced (e.g. Diabetes insipidus or mellitus)
- Medical conditions that affect the nerves to the bladder and the muscles that control the release of urine (e.g. tethered spinal cord)
- Increased stool burden / constipation
- Inattention
- Other: Developmental, Behavioral, etc.

Treatment:

- Treat underlying cause (constipation, infection, other)
- Cue to void during waking hours
- Consider use of alarm watch
- Stay hydrated throughout the day
- Seek appropriate behavioral/medical/psychological supports



NOCTURNAL ENURESIS

Definition:

Bedtime wetting after the age of 7 years (or a developmental age of 7 years); NOT considered to be willful; common in the general population with about 1% of adolescents wetting the bed into their teens.³

Causes:

- Increased stool burden (constipation)
- Smaller bladder
- Family history of bed wetting until a later age
- Diabetes insipidus or mellitus
- Urinary tract infection
- Sound sleeping/overly tired

Treatment:

- Address stool burden, if needed
- Distribute fluid intake throughout the day
- Sometimes fluid restriction after dinner and voiding before bed helps.
- Consider use of nocturnal alarm system ("bed-wetting alarm"). Work with your provider to learn about the use of these systems to promote success.
- Remember that just like snoring at night, your child cannot control their bedwetting.



NEXT STEPS AND RESOURCES THAT MAY HELP YOU

Your local Pediatrician.

Boston Children's Hospital's Down Syndrome Clinic Webinar on toilet training

Boston Children's Hospital's Pains and Incontinence Program (PIP) for individual consult (617-355-7025).

Boston Children's Hospital's Toilet School (617-355-7025), to learn more about the 6 week parent and child program using a group dynamic for parents and children).

References

1. Colombo JM, Wassom MC, Rosen JM. Constipation and encopresis in childhood. *Pediatr in Rev*; 36: 2015; 392-401.
2. Schonwald A, Rappaport L. Encopresis: assessment and management. *Pediatr in Rev*; 25: 2004;278-283.
3. Swithinbank LV, Brookes ST, Shepard AM, Abrams P. The natural history of urinary symptoms during adolescence. *Br J Urol*:81, 1998 (suppl 3): 90-93.



RESOURCES



Books

Toilet Tales written and illustrated by Andrea Wayne vonKonigslow, Annick Press Ltd., Tornot, Canada M@M1H9

A Potty for Me by Karen Katz

Once Upon a Potty by Alona Frankel (Boy and Girl Version)

Mr. Rogers Potty Training

Everyone Poops by Taro Gomi

Books that encourage trying

The Little Engine that Could by Watty Piper

Franklin Rides a Bike by Paulett Bourgeois and Brenda Clark, Scholastic Inc

Franklin in the Dark by Paulett Bourgeois and Brenda Clark, Scholastic Inc

Potty dolls

Elmo

Melissa and Doug doll

Potty duck bath toy

Anatomically correct boy doll (also a girl doll but the boy doll urinates if you squeeze his belly)

“Potty Scotty” or Potty Patty

Potty Monkey, comes with toy toilet

Cabbage Patch Kids Doll Potty (makes flushing and urinating sounds).

Toilet inserts/Aids

Baby Bjorn Toilet Trainer (has a dial to securely fasten to your toilet seat and is nicely contoured): www.amazon.com

The Bemis 1483Slow Next Step potty seat: replaces your normal toilet seat; easy to install and solid; slow close mechanism so there’s no pinched fingers: www.homedepot.com

The First Years Soft Grip Potty Seat, has handles for child security and splash guard for boys: www.t.store.schoolspecialty.com

Squatty Potty sold on-line or in Bed Bath and Beyond.

Visual Timers

www.funandfunction.com

Visual Schedules: See Pinterest: Toilet Training for ideas.

Picture Exchanges

www.do2learn.com

iPhone Apps

Potty Training: Learning with the Animals, \$1.99.

Potty Training Story, \$3.99.

See Me Go Potty, English, \$1.99.

One Step at a Time Toilet Tips, \$1.99 (Also, very detailed PECS out of Australia)

Video about how your body works and how constipation can be subtle and result in encopresis

The Poo in You from the Childrens Hospital of Colorado:
www.childrenscolorado.org

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