
Editor's Note: This and the previous article are derived from the latest additions to the National Fragile X Foundation's "Special Topics" Pamphlet Series. Earlier publications are:

- *Females and Fragile X Syndrome*
- *Sexuality and Fragile X Syndrome*
- *Behavior and Fragile X Syndrome*
- *Aggression and Fragile X Syndrome*
- *Occupational Therapy and Fragile X Syndrome*
- *An Overview of Fragile X-associated Tremor Ataxia Syndrome*
- *Speech and Language Therapy and Fragile X Syndrome*

As always in the special topics series, this pamphlet is intended to be an overview and introduction to a complex topic. Therefore, each pamphlet includes a listing of additional resources. It is our hope that parents use these pamphlets as guideposts and references as they learn how to assist those (including themselves) who are impacted by Fragile X. All special topics pamphlets are available from The National Fragile X Foundation free of charge.



Toilet Training Children With Fragile X Syndrome

An Overview and Guide

Toilet training the child with fragile X syndrome (FXS) often, but not always, takes the same form as it does with other children. It starts with the basics: Parents may need to teach their child about “wet” and “dry” (applied to both urination and bowel movements). When checking your child’s diaper, let him know what you find. For example, if he’s dry, say, “Good, your pants are dry.” You may want to place his hands inside the diaper so he can directly feel what is “dry.” If he’s wet, go through the same procedure (skipping the hands-in-diaper in the case of bowel movements).

This “pre-training” can begin as early as age 2, but may need to be delayed many more years for the child with FXS. The pre-training period can include allowing your child to watch other family members use the toilet so that he or she can see what is supposed to occur. This is also a good time to read books about toilet training to your child or watch toilet training videos together. Consistent use of positive behavior reinforcement and the use of a music video are often helpful. Once your child has a basic understanding of the potty, toilet training then shifts to establishing a baseline until bowel continence is established.

SIGNS OF READINESS

- Awareness of wet or soiled condition

- Ability to communicate that they are wet or dry
- Periods of dryness for two hours or more
- Motor skills to get to the bathroom and to sit on the toilet unassisted, or with minimal assistance
- Watches others with interest and tries to imitate
- Sits on toilet/potty chair without complaining
- Anticipates elimination by signing or otherwise indicating toileting need
- Basic dressing skills, such as pulling down pants
- The desire to be independent

CRITICAL PARENT ATTITUDES

- Try to wait until your child is interested
- Be calm and patient
- Use a “matter-of-fact” tone and approach with accidents
- Praise any amount of success, and understand accidents are a normal part of learning
- Do not punish, shame or scold
- Remember that toilet training is a complex process
- Provide clear messages of confidence

- Anticipate gradual, intermittent successes
- Remember that regression may occur with any major change in your child and family
- Be prepared, and consider “what ifs”
- Remember that it is always better coming out than staying in!

RELEVANT FACTORS

- Delays in onset of readiness are typical in the child with FXS
- Structure and predictability are necessary
- Visual cues are helpful in transitions
- Diet (adequate roughage and fluid intake) is important
- Food is usually a good reward
- Fear/anxiety and impulsivity issues may need to be addressed
- Trust-building activities are key
- Natural rather than fluorescent lighting can be less agitating

SENSORY ISSUES

Children with FXS often exhibit a delayed ability to sense if their bladders or intestines are full and ready to void. Because of tactile defensiveness and/or insecurity about sitting without their feet supported on the floor, they may need to be

desensitized to sitting on the toilet. The use of adapted toilet seats or footrests may thus be advisable. The toileting area may need to be cleared of visual distractions and/or have noise level reduced. The use of quiet, calming music may be helpful in facilitating overall relaxation.

If you have instituted many of the procedures discussed above and your child begins to show signs of constipation or withholding of bowel movements, discontinue toilet training and consult your physician.

SUMMARY

The best approach to toilet training is always based on the needs of your child, regardless of age. Urinary training can be started after bowel control is established. Nighttime training should not be initiated until daytime control has been clearly established. It is often helpful to reduce the child’s fluid intake before bedtime. Begin by waking the child one or two times a night (depending on the child’s nighttime elimination pattern) and have him or her sit for five minutes each time. Remember to praise and encourage your child each time, regardless of the results. Eventually, most children with FXS begin awakening by themselves and taking care of nighttime toileting. ☺

This article and the pamphlet from which it was adapted was prepared by Deborah Kwan, OTR/L, of The National Fragile X Foundation, with assistance from Glenn Penkava, MS Ed, and Rebecca O’Connor, MA.

FOR FURTHER INFORMATION AND RESOURCES ADDRESSING TOILETING ISSUES, THE NFXF SUGGESTS THE FOLLOWING:

For parents:

Toilet Training in Less than a Day
Nathan Azrin

Dry All Night: The Picture Book Technique That Stops Bedwetting
Allison Mack

Toilet Training: A Practical Guide to Daytime & Nighttime Training
Vicki Lansky

Toilet Training Without Tears
C. Schaefer, Ph.D. & Theresa Foy Digeronimo

Toilet Training for Individuals with Autism and Related Disorders
Maria Wheeler

For children:

No More Diapers
Jo Graham Brooks

Annie’s Potty
Judith Casely

Once Upon a Potty
Alona Frankel

Going to the Potty
Fred Rogers

The Potty Chronicles
Anne Reiner

It’s Potty Time (Video)
Duke Family Series
(800) 23POTTY