

TOILET TRAINING THE CHILD WITH FRAGILE X SYNDROME

**By Franci Crepeau-Hobson, PhD
Rebecca O'Connor MA**

It will probably take longer than usual to toilet train a child with fragile X syndrome. The length of time it takes will depend on the child's motoric or muscular difficulties, the child's awareness of his body and sensations, as well as the level of mental retardation of other cognitive deficits.

Toilet training a child with fragile X syndrome requires that a number of behaviors and abilities first be in place. The child needs to be able to physically perceive that he is wet and communicate this. He needs to have significant periods of dryness, (about two hours) and have a fairly regular time for voiding or bowel movements. He also needs the motor skills and muscle tone to get to the bathroom and to sit on the toilet unassisted. Eventually he needs to be able to coordinate the entire process of feeling the need to go, getting to the bathroom, sitting down (or standing up for some boys) and actually going. All of this requires appropriate timing as well.

If your child is lacking in one or more of these areas, toilet training will be even more challenging. It may require focusing on training the child to go rather than on training him to NOT go. It will therefore be important for your child to be on a frequent toileting schedule, where he will have many opportunities to go in case he needs to.

The following should be considered only as guidelines and suggestions for toilet training your child. It is not intended to be a cookbook recipe that can be expected to be successful with all children. Every child is unique, including every child with fragile X syndrome. There is a wide range of variability when children with fragile X syndrome will be toilet trained, but not starting prematurely and being consistent can help cut down on frustration. In general, a relaxed approach works best.

Toilet training the child with fragile X syndrome often, though not always, takes the same form as it does with other children and involves teaching about the potty and what it's for. You may also need to teach your child about "wet" and "dry". When you check your child's diaper, let him know what you find. For example, if he's dry, say, "Good, your pants are dry". You may also want to place his hand inside the diaper to feel that it is dry. If the child is wet, let him know this as well, and again allow him to feel what wet is. This "pre-training" can begin around age two and may also include allowing your child to watch other family members use the toilet so that he can see first hand how it is suppose to work. This is also a good time to read books about toilet training and diapers to your child or watch potty training videos together. (Learning Through Entertainment puts out a good one entitled "Potty Time". For more information about this video, call 1-800-23POTTY). Once your child has an understanding of the potty, toilet training then shifts to establishing a baseline of your child's toileting behaviors.

It is generally easiest to start with bowel training. Keep a schedule of your child's elimination pattern to determine appropriate toileting times. Once you have a good idea of your child's pattern, begin placing your child on the toilet around the time he usually has a bowel movement. If your child has low muscle tone, a footstool or a small potty chair may help your child feel more secure. Encourage you child to move his bowels and leave him there for about 10 minutes. After this time period, help him off the toilet and praise him for trying and/or succeeding. Continue with this as a consistent pattern until bowel continence is achieved.

Urinary training can be started after bowel training is established. Use another record of elimination to determine when to place your child on the potty. At this point, you may want to put your child in training pants during the day. Using the elimination schedule, place your child periodically on the potty, being sure that enough time has elapsed so that he can feel the sensation of a full bladder. After 5 to 10 minutes, remove the child and praise him, regardless of

whether or not he actually went in the toilet. Sometimes water-prompting can help relax the child's external sphincter muscle which initiates urination. This involves slowly pouring a small amount of lukewarm water over the child's genitalia immediately after sitting the child on the toilet. With success, parents can then begin to tell their children to go to the bathroom rather than actually placing them there. With increasing success, parents can begin to wait for the child to signal that he wants to go to the potty.

Nighttime toilet training should not begin until day training has been established. It is often helpful to reduce the child's fluid intake before bedtime to help him have more control. Begin by waking the child one or two times a night (depending on the child's nighttime elimination pattern) and have him sit for 5 minutes on the toilet each time. Remember to praise and encourage your child each time. Eventually, many children begin awakening by themselves when they need to go and begin to take care of nighttime toileting themselves.

Keep in mind that it is normal for any child, including those with fragile X syndrome, to regress or appear to lose toileting skill at times. Treat accidents lightly and remember that this is a process that cannot be rushed. Pushing a child that is not developmentally ready for toilet training may actually slow or completely disrupt the process. Forcing, scolding, or punishing a child into toilet training may only frighten him and reduce the likelihood of toilet training success. Remember, patience, praise and consistency are the keys to reaching this goal.

**For additional information on toilet training, please contact the National Fragile X
Foundation.
800-588-8765**

www.FragileX.org