

Constipation in Children with PWS

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Difficulty passing bowel movements (BM) is a common problem in PWS, even during infancy. Very soft daily bowel movements are the goal – no bunny pellets, no liquid stools, no pain or discomfort. Some children will release just a small BM, unaware that there is a bigger load behind – so don't be afraid to ask to see what has been produced. Complete evacuation is the goal.

PWS Challenges

Poor motility in the entire GI tract - from sucking, chewing, and swallowing to stomach emptying, to finally pooping - things just don't move along in a typical pattern. There may be slow spots along this pathway, not just at the exit.

Low muscle tone (hypotonia) - movements such as crawling and walking help the passage of food, but are generally delayed skills for children with PWS.

Time - Parents and children are so busy with the many therapies and appointments that life is often too rushed to think about the last bowel movement or to take time for the potty.

Sensation - not feeling pain may also mean they miss the “full” signal that it is time to poop.

Gut microbes, probiotics, and fiber – gut microbes may not be typical in people with PWS, so a probiotic is worth trying. PWSA no longer recommend a high fiber/raw foods diet for persons with PWS because of the risks of fermentation if the digestive tract is not moving well. Fruits and vegetables, softened and in small pieces, are an essential focus of a healthy diet.

Top down, Bottom Up

If your child has had constipation, prevention should start at the “top” – over the counter medications that will make the food hang onto water, making the BM less likely to dry out. Miralax and milk of magnesia are examples of stool softeners. Stool softeners do not make the bowels contract or stimulate a bowel movement. Other oral medications, such as senna, activate the colon to propel a bowel movement along. Some families use these medications daily, and others add these only if things are not moving along. Taking these medications by mouth or feeding tube can take 1-3 days to produce results.

The “bottom up” approach is helpful when there is already a backup of stool. Children quickly learn to “hang on” to a BM if it hurts to pass. Stimulating the anus can help release

the BM and may bring fast relief. A glycerin suppository, which has no medication, only a lubricant, will stimulate the rectum slightly and can be enough to prompt a BM. Dulcolax suppositories have medication which causes the rectum to squeeze and is a faster therapy. Neither one works unless it is touching the inside wall of the rectum – not stuck right into the BM. Grease up the anus with some Vaseline for your child's comfort in passing the large BM; this will also stimulate defecation. Have them lie on their side to insert the suppository, with their knees up to their chest. If they can wait 10 minutes to push, it is more likely to produce the best results. Drinking a glass of water before sitting on the toilet is also helpful – you may have to use your usual tricks to get them to drink.

Once a child has had lots of constipation bouts, they may lose the sensation that it is time to “go”. They will have to retrain their bowels. Swallowing stimulates a reflex in the colon, so the best time to sit on the toilet is right after a meal. Make it a habit after breakfast. A chart with stickers can be a motivator!

Some parents find abdominal massage is helpful for any age child; there are YouTube videos explaining this technique. Blowing up a balloon or blowing bubbles can help a child relax their bottom muscles while sitting on the toilet. This is no time for speed or impatience. Bring a book to read together, or play music.

Toilet Tricks

Use statements rather than questions (e.g., "It is time to sit on the toilet", not "Do you need to use the bathroom?"). They may be unaware of the fullness in the colon.

You may need to reward the sitting, even without any results – think sticker charts.

Correct positioning on a toilet is very important for children – and adults. American toilets are poorly designed for good bowel elimination; we are designed to squat when pooping. For a child, or a short adult, the toilet height will never be ideal for good bowel health. The knees should be at least as high as the hips – a true squat is best to open up the muscles that release the BM. A small footstool at the toilet is a good investment – there are toilet footstools, such as the Squatty Potty, which may be very helpful -www.squattypotty.com

Keep their hands occupied so they cannot hold onto the toilet seat. This position can increase muscle tension of the pelvic floor and make it harder to pass the stool comfortably and completely.

Before adding any over the counter medication, call your health care provider to discuss the unique issues for your own child. These are just guidelines for a very common problem for children with PWS.

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