

ally have multiple studies going on simultaneously and we are always looking at new therapies and different ways to relieve neuropathic pain.

The Translational Pain Research Program at the Brigham and Women's Hospital in Boston is committed to working with people with TM and the other neuroimmunologic disorders to find an effective approach to treating pain. Our funding sources have included the Paralyzed Veterans of America, The Christopher Reeve Paralysis Foundation, and the National Institute of Neurological Disorders and Stroke (National Institutes of Health). Our program will work with patients and will also consult with and work with your physicians.

We will continue working with you until the goal of relieving your pain is achieved.

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Considerations in Achieving Bowel Continence

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Introduction

Transverse myelitis (TM) is a rare disorder that results in spinal cord inflammation which causes secondary conditions such as immobility, risk of skin breakdown, and bowel and bladder dysfunction. Researchers have found that generally, about two-thirds of those affected by this disorder are left with a moderate to severe degree of permanent impairments. Even in those that recover, there is nearly always a temporary time during which organ systems such as the bowel and bladder are affected.

This article will focus on how an individual with a neurogenic bowel can achieve continence. This author shares the belief of a growing number of health care practitioners that every individual *deserves to* and has *the right to expect* to be continent. If help is not available at your particular location, keep looking, because there are many different types of health care providers who may have expertise in this area.

Terminology

There are many strategies to approaching continence, but unfortunately there is no one way that will absolutely work for every person. That is part of the challenge facing both the provider and the patient. Before it is possible to discuss specific strategies, one must understand some commonly used terms.

Neurogenic bowel is a very broad term that can apply to anyone who has nerve injury (temporary or permanent) to the part of the spinal cord that controls bowel function. The bowel and bladder are controlled both centrally, with messages traveling from the brain to the bladder or bowel, as well as peripherally, by nerves that branch off from the spinal cord. The lowest portion of the spinal cord, located in the sacral area, houses the nerves that impact bowel and bladder continence. Damage or inflammation to either the spinal cord or the pathway through which messages travel from brain to lower spinal cord may result in an inability to sense or feel the need to have a bowel movement. Additionally, there is often lack of voluntary control over the rectal muscles. An individual with intact neural pathways can consciously initiate defecation by relaxing the anal sphincter to allow the passage of stool or conversely, squeeze the anal sphincter to hold back stool which has already passed into the rectal vault. Without the ability to control the anal sphincter, when stool enters the rectum, there is the risk of an unplanned spontaneous bowel movement.

A person is considered continent if they are able to be free from unexpected accidents. For example, an individual without neurological problems, who is toilet trained, anticipates the need to go and can make it to the toilet in time to have a bowel movement. Conversely, an individual with

TM affecting the lower spinal cord would require a bowel regime whereby bowel movements occur on the toilet, but as a result of timed toileting with or without an enema, suppository, or other measures. Both individuals would then be free of accidents (continent) and able to wear regular underwear. There are several other factors that must be contemplated to really understand how to achieve bowel continence.

Developmental Considerations

An individual's developmental age must be considered to know when it is appropriate to start a toileting program. In fact, it is really more important to understand one's developmental age than the actual chronological age. A child is considered developmentally ready for toileting when he or she is able to participate in his or her program. Success can only be achieved if the child (or any individual) is an active participant and believes there are benefits to obtaining continence. This usually occurs around the age of three. If, however, a procedure such as regular enemas must be performed, the child may need to be older. I always encourage my families not to send an otherwise developmentally normal child to school in diapers, if at all possible.

Children like to copy one another, so if a sibling or a parent models a behavior such as going to the bathroom, a child is likely to want to do it too. There are books and videos available that expose the child to going to the bathroom on the toilet. In addition, medical supply companies have coloring books and video's available for children who are learning to catheterize as a part of their continence program.

Behavioral Considerations

Often, incontinent individuals have encountered teasing or ridicule from peers, family members, or other insensitive people who do not understand the situation. The whole subject may be fraught with negative emotion for the incontinent individual. Social punishment is not an effective treatment for incontinence, and is frequently observed to exact a heavy toll on one's self esteem and self efficacy.

Becoming continent takes a lot of work for both the patient and their family or significant others. Comprehensive bathroom habit diaries need to be kept, food and fluid intake must be considered, and ultimately, behavioral changes incorporated with specific regular routines must be followed. This takes sustained motivation, dedication and above all, patience. Children often require tangible rewards and varied approaches to keep them interested. At times, formal behavioral therapy is required to establish lifestyle changes. Often, the difference between continence and incontinence lies in minute details that ultimately, when put together like pieces of a puzzle, yield a solution.

Emotional Impact

Our society expects all individuals to be continent after about the age of three. The inability to control one's bowel and bladder carries an enormous social and emotional stigma. The impact that having accidents or wearing diapers has on a child or an adult cannot be over emphasized. Recent research with children who have spina bifida revealed that chronic incontinence caused greater distress than any other associated problem, including paralysis of the legs and the inability to walk. These results are very likely similar for in-

dividuals with other neurological disabilities.

Becoming continent is a journey that is unique to each individual. There are no "cook book" answers, but at the same time, there are almost an endless number of strategies or combination of strategies to try. Developing trust and confidence in one's medical team is essential to be able to tackle continence both emotionally and physically. After considering the above factors, the basic question is still "but how does one go about this?"

Getting Started

Treatment regimes usually involve a combination of dietary manipulation, behavior modification, medication, and positive reinforcement initiated in a stepwise approach. Laxatives by mouth should be used with caution, because of the difficulty in predicting when they may work.

Taking advantage of the body's natural reflexes and biomechanics should always be used if possible. One example is that of the gastrocolic reflex. This is the body's natural response to a full stomach. After a meal, the stomach becomes stretched and messages are sent telling this to the brain. Involuntary squeezing of the smooth muscles of the gut occurs in waves, known as peristalsis. The food is digested as it moves through the small bowel and then into the large bowel. It becomes more formed as it moves closer to the rectum. As the waves of peristalsis occur, the bowel contents are moved along. What we perceive is sometimes cramping or gas or "the feeling that it is time to go." This reflex occurs even if one can not feel it or perceive it. Some people have a very strong reaction after meals and some do not. Those that say, "I am like clockwork; I go to the bathroom every morning after breakfast no matter what" are usually ones with a

strong gastrocolic reflex. One way to tell if you have a strong gastrocolic reflex and to identify other toileting patterns is to keep a diary of toileting habits for one to two weeks. Variables to track include bowel movement timing and if there is an association with incontinence or not. Every two hour undergarment checks may be necessary for those that have no awareness of when they go. Bathroom habit trackers should also provide information such as size and consistency of the stools.

An example of the use of body biomechanics is one's position on the toilet. Sit comfortably on the toilet. Make sure there is no danger of falling in or off on the floor. A well-fitting seat and something to hold on to for balance goes a long way in assisting with relaxation. Remember, stool is passed when lower pelvic muscles are relaxed. The body is in the best anatomic position for defecation when the pelvic muscles are allowed to relax and descend. Legs should be spread apart and knees should be higher than the pelvis such as when one's feet are up on a stool or telephone books placed on either side of the toilet. When trying to evacuate the stool, push by tightening the stomach muscles. Coughing or laughing help facilitate pushing. When teaching a child to push, I pretend I am holding a birthday cake and tell the child to blow out the candles, or tell the child to imagine he is the wolf in *The Three Little Pigs* and try to "huff and puff and blow the house down."

Finally, one must consider that achieving continence is bit like riding a bike on a tight rope. Stool must pass through the bowel at a rate sufficient to produce soft but formed stool. If the passage is too swift, too much water will remain in the stool and it will be too loose. Conversely, if the passage is too slow, the stool may be-

come hard and "back-up" in the system. How often one has a bowel movement is usually not as important as the consistency and quantity of the stool.

Developing a Plan

Bowel programs start with the practitioner completing a problem history and physical examination. Questions to be answered by the examination include: Is the abdomen soft or firm, which could indicate large amounts of retained stool. Is there stool in the rectal vault? Can the individual voluntarily squeeze the anal sphincter muscle? Is there a perianal wink reflex? Finally, what is the current neurological sensory and motor level of the individual?

In this author's experience, bowel programs are more successful if routine interventions are begun after the colon is cleaned out. Accidents can not occur if there is no stool in the lower colon and rectum. Though an initial cleanout is the first step, the real success lies in making sure the colon stays clean till the next time the person is in a controlled setting (such as in the bathroom) and on the toilet!

Colonic cleanouts can be accomplished in a myriad of ways such as with oral laxatives, enemas, suppositories, or a combination thereof. Colonic cleanouts are not fun, but if orchestrated correctly, take a single day to complete. To most, this is a small price to pay for continence.

The maintenance part of the bowel program should begin immediately after the cleanout to keep stool from backing up in the system again. Beginning with non-invasive measures such as behavioral and dietary changes may be all that is needed, particularly if there is even partial bowel control. If oral laxatives are

used, the doses may need to be **very small**; remember that the ability to predict when a laxative is going to work is very difficult. Laxatives are often better used just to move the stool along at a better pace rather than to actually cause a bowel movement. Interventions such as digital stimulation, suppositories or enemas are generally far more predictable. Add or change one measure at a time so that it is clear what has helped and what has not.

When conservative medical management is inadequate, there are multiple surgical or procedural options including surgical continent stomas, cecostomy buttons, and incontinent ostomies. An option that works for one may not be right for another. Important factors that may influence one's choice include patient age, complication rates of the procedure, knowledge of long-term outcomes, and ability to be independent with the overall bowel program. There is an increased prevalence of pediatric surgeons and interventional radiologists who are committed to working on interdisciplinary teams with the goal of achieving social continence.

Bowel continence in an individual with neurologic injuries such as transverse myelitis is achievable with a multilayered approach, patience and perseverance. It is important to realize that advances are occurring on a regular basis and that there are a variety of professionals that can direct patients and families through the myriad of options available.