MedStar Health

Rehabilitation Research and Training Center
at MedStar National Rehabilitation Hospital

What is Neurogenic Bowel? Why you need a bowel management program. Tips on getting back to life, work, and family.

Neurological injury may also affect other parts of the gastrointestinal tract, such as the stomach and small intestine, but this information sheet will focus on the large intestine, also known as the colon or bowel.

What is Neurogenic Bowel?

Neurogenic bowel is the condition that occurs when nerve damage or injury to the spinal cord disrupts communication between the brain and large intestine leading to challenges with bowel movements. This may occur due to spinal cord injury (SCI), spina bifida, or other neurological conditions.

Neurogenic bowel causes the muscles in the bowel to work less effectively, which can impact motility (movement of stool through the colon), sensation (pressure felt when a bowel movement needs to be excreted or passed), and continence (controlling when stool comes out).

Symptoms may include:
- Constipation
- Diarrhea
- Loss of bowel control (accidents)
- Abdominal distension
- Frequently needing to move bowels (Feeling that your bowels aren't completely empty with the urge to keep straining or "trying to go")

Not only can neurogenic bowel cause bowel-related symptoms, when not well managed, secondary effects may include:
- Skin breakdown, pressure sores, anal fissures, hemorrhoids
- Worsening spasticity and neuropathic pain
- Increased urinary incontinence and urinary tract infections
- Autonomic dysreflexia (for people living with SCI that are at risk)
- Ventriculoperitoneal (VP) shunt malfunctions (for patients with shunts to manage hydrocephalus). A full colon can impair a shunt's ability to drain properly in the abdominal cavity.

The symptoms of neurogenic bowel can also create social challenges and affect quality of life, in ways such as:
- Social isolation to avoid embarrassment due to incontinence
- Missed school/work
- Anxiety that an accident can happen anytime

What is Bowel Management?

A bowel management program is a structured, individualized plan designed to establish planned bowel movements, prevent incontinence, and avoid constipation or impaction.

Plans are individualized for each person's lifestyle, preferences, needs, and goals. Examples of priorities a patient might have include: having a bowel movement at the same time every day, independence with taking medications or inserting a suppository, spending no more than one hour per day on the bowel program, doing the program every other day, etc.
Bowel management techniques include consistent timing, balanced diet (including enough fiber), adequate hydration, oral medications, rectal medications/stimulation and others. Work with your provider to come up with a plan that is safe and effective for you.

Please see "Options for Bowel Management" for more information on specific strategies.

When should a bowel program be initiated?

It is important to be proactive in starting a bowel program to avoid and manage symptoms listed above.

- For acquired neurological conditions such as SCI, start as soon as possible (within days) after the injury occurs.
- For spina bifida and other congenital neurological conditions, conversations about bowel management should start at birth, and a continence plan should start around the same age that neurotypical peers are potty training.

It is essential to work with a healthcare provider who understands and treats neurogenic bowel. You may find knowledgeable providers in gastroenterology, urology, physical medicine and rehabilitation (PM&R), colorectal surgery, or other specialties after a spinal cord injury but always ask the provider if they have experience specifically with neurogenic bowel.

Starting a bowel program can be challenging. Individuals and caregivers must dedicate regular time to their program in addition to many other self-management tasks, sometimes contributing to patient/caregiver burnout. Placement of rectal medications and devices requires some hand dexterity. Some people may need assistance or adaptive devices for these approaches. Those who do not have consistent access to a caregiver or healthcare provider for assistance may be limited in which programs work for them. Troubleshooting issues with a bowel program can include conversations with your doctor or therapists.

How are bowel programs adjusted?

Bowel programs often need to be adjusted when a person starts a program (after injury) or as a person ages. If your bowel program is no longer providing consistent results, taking too long, or in the event of new bowel accidents, it is time to adjust your bowel program. Keeping a bowel diary can help identify patterns and problems. Keep track of stooling–when, how often, how long it took to have a bowel movement, consistency, medications taken, foods eaten, if it was an accident or voluntary, etc. Communicate frequently with the provider during the development and modification of a bowel program until goals are reached.

Depending on the provider's preferences and systems set up by their institutions, these check-ins could be through an online patient portal, phone messages, telehealth, or in-person visits.

When updating a bowel program, it is important to change one part at a time. For example, if a person decides they want to take medicine to soften their stools, they should not change the time of day for the program. This makes it difficult to know when things are helpful or unhelpful.

Resources

Spina Bifida Lifespan Bowel Management Protocol by the Spina Bifida Association
SpinaBifidaAssociation.org/Lifespan-Bowel-Management-Protocol

MSKTC: Managing Bowel Function resources:
MSKTC.org/sci/sci-topics/Managing-Bowel-Function

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