

Commentary

Release and highlights of the *Lifespan Bowel Management Protocol* produced for clinicians who manage neurogenic bowel dysfunction in individuals with spina bifida

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The Spina Bifida Association has spearheaded developing and releasing the first healthcare protocol for managing neurogenic bowel secondary to spina bifida. This protocol, the *Lifespan Bowel Management Protocol (LBMP)*, was developed in collaboration with clinicians, researchers, parents of children with spina bifida, and an adult with spina bifida. It was designed to guide clinicians in managing neurogenic bowel and is based on published literature, the Spina Bifida Guidelines for the Care of People with Spina Bifida [1], and clinical consensus. The LBMP can be downloaded directly from the Spina Bifida Association's website as an interactive PDF (<https://www.spinabifidaassociation.org/lifespan-bowel-management-protocol/>).

Neurogenic bowel is experienced by over 80% of individuals with spina bifida [1–3]. It is rated as one of the three most important concerns of individuals with spina bifida and their care partners (e.g., family members) [4]. Beyond the direct effects of constipation and/or fecal incontinence caused by neurogenic bowel, secondary health effects can occur. These include urinary tract infections, ventriculoperitoneal shunt malfunction, skin breakdown, hemorrhoids, and anal fissures [5–11]. Individuals with bowel incontinence have increased rates of depression and bullying and also have decreased rates of school attendance in childhood, lower overall educational attainment, and lower employment rates [12–15]. Care partners also report a significant burden with managing neurogenic bowel, highlighting its effect on entire family units across an entire lifespan [16–21]. The estimated current rates of bowel continence are 45%, and independence rates for adults are 33% [22].

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Table 1
List of included appendices found in the Lifespan Bowel Management Protocol

I	List of Interventions from Least to Most Invasive
II	Bowel Cleanouts
III	Recommended Dietary Fiber Intake
IV	Recommended Dietary Fluid Intake
V	Oral Medication Dosages
VI	Bowel Diary
VII	Enema Basics
VIII	Helping Parents and Caregivers Prepare to Start a Bowel Program
IX	Timed Sitting
X	Potty Seats and Adaptive Equipment Recommendations
XI	Infant Abdominal Massage for Constipation
XII	Diaper Dermatitis
XIII	Digital Rectal Sweep/Digital Stimulation
XIV	Bowel Program Complications
XV	Independence
XVI	Anal Plugs
XVII	Considerations for a Colostomy
XVIII	Pregnancy Considerations
XIX	Suppositories

The LBMP provides background information on neurogenic bowel prior to providing guidance by age categories (birth-adulthood). In each age group section, readers will find a list of key points specific to that age for clinician and care partner knowledge; goals for bowel management; guidance for history taking and physical examination; and stepwise guidance for interventions. Throughout the protocol, there is a recommendation for close monitoring and follow-up after making alterations to a bowel program. It is also recommended to initiate bowel management in infancy by treating constipation aggressively. The authors believe that preventing constipation will improve continence outcomes in the future. The protocol also proposes early initiation of bowel social continence in the preschool years, which aligns with the neurotypical toilet-training age.

The many appendices (Table 1) in the LBMP consist of user-friendly content, such as dosing guidelines for common bowel management medications, troubleshooting for enema programs, bowel clean-out recommendations, specific durable medical equipment recommendations for families, and pregnancy considerations. The authors hope that with increased usage of the LBMP, there will be earlier and quicker management of constipation, and that continence and independence rates will improve alongside the quality of life of the individuals with spina bifida and their care partners.

Conflict of interest

JK and MSK serve as advisors for Coloplast A/C, Humlebaek, Denmark.

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