



**SPINA BIFIDA
ASSOCIATION**

Lifespan Bowel Management Protocol

A guide to bowel management for clinicians who care for individuals with Spina Bifida and neurogenic bowel.

April 2023

FOR MORE INFORMATION OR A COPY OF THE PROTOCOL, VISIT:
www.spinabifidaassociation.org

Lifespan Bowel Management Protocol

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Lifespan Bowel Management Protocol
Chapter 1: How to Use the Lifespan Bowel Management Protocol

Lifespan Bowel Management Protocol

Chapter 1: How to Use the Lifespan Bowel Management Protocol

This protocol was developed to guide bowel management for clinicians who care for individuals with Spina Bifida and neurogenic bowel. The recommendations are based on published evidence, Spina Bifida Guidelines, and clinical consensus. Recommendations are based on the current information available as of fall 2021, and we hope additional research on neurogenic bowel will allow for changes to this protocol in future editions.

We recommend that all clinicians read the following sections: [Background](#), [Transitioning to Specific Programs and Continence Achievement](#) and [Transitioning to Independence](#) before moving to the age group section for the individual patient.

In each age group, you will see Key Points. This section highlights critical age-related aspects of bowel management and general guidance for a clinician working with a family or individual. The Goals are the outcomes to be achieved using the protocol for that age group. Building Good Bowel Habits should be used as a list of recommendations that most patients should be doing along with any listed interventions.

Once the recommendations for a particular age group have been reviewed, the interventions should be used one at a time unless specified. If there are multiple oral options, use your clinical judgment to determine which is best for your patient based on their current symptoms, history, and physical exam.

The per rectum interventions should generally be used consecutively unless previously used and failed, or other concerns would make using one of the options difficult. Problems can include the amount of assistance available and required to carry out the intervention, cost or insurance coverage, or patient tolerance to the intervention. Unless noted, only one intervention should be used at a time. If improvement is not reported within two weeks (unless stated otherwise), management should move to the next level of intervention. If severe constipation occurs within the two weeks of a new intervention, the most recent intervention should be stopped, and the patient moved to the next more intensive step. The rationale is that if a patient fails one oral medication, continuing through other oral medications will prolong constipation. The interventions should move stepwise to the next level of intervention, per rectal management.

Balloon/cone enemas, transanal irrigation, and surgical options may take longer than two weeks to determine if they are beneficial. Additional adjustments are often needed to these options, and the body can take longer to acclimate to them. It usually takes two to three months before someone is in a good routine with one of these interventions, which is to be expected.

Throughout the age groups, you will see boxes of information that are additional considerations or tips that can be provided to families to improve the likelihood of independence in a child with executive function deficits.





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**Lifespan Bowel Management Protocol
Chapter 2: Background**

Lifespan Bowel Management Protocol

Chapter 2: Background

Individuals with Spina Bifida (SB) commonly have damage to the spinal nerves that communicate with the bowel. The term neurogenic bowel encompasses the manifestations of bowel dysfunction resulting from sensory and/or motor disturbances.⁽¹⁾

Neurogenic bowel can cause:

- Decreased rectal sensation
- Altered blood flow in the bowels
- Dysmotility
- Altered internal and external anal sphincter tone function
- Lack of voluntary control of bowel movements
- Constipation

These changes cause constipation and/or bowel incontinence and are referred to as Neurogenic Bowel Dysfunction (NBD).

When the spinal cord is disrupted such as in Spina Bifida or spinal cord injury, there are generally two types of NBD, reflexic and areflexic. A reflexic bowel often occurs when the spinal cord lesion is T12 and above. An areflexic bowel occurs when the level of lesion is L1 and below. The typical type of NBD that occurs in Spina Bifida is the areflexic bowel. When a bowel is areflexic, the nerve fibers in the colon are poorly innervated which results in slowed peristalsis, poor colonic muscular contractions, and a weak anal sphincter.

Constipation and incontinence are the complications of an areflexic NBD. Typically, the areflexic bowel is better managed through manual stool removal techniques such as manual evacuation or enemas rather than suppositories or digital stimulation. However, as you will see throughout this protocol, we do support the least to most invasive approach to constipation and incontinence management in individuals with Spina Bifida. The type of NBD can be assessed by history and physical exam. A table to assist with this is included at the end of this section. This information can be helpful in guiding recommendations for bowel programs. Although overall we recommend a least to more invasive order to interventions, for those with areflexic bowel (more typical in Spina Bifida) manual evacuation programs will likely work better than digital rectal stimulation, suppositories and per rectum enemas. Digital rectal stimulation, suppositories, and per rectum enemas tend to be more effective in individuals with reflexic bowel because they induce a reflex that is already present.

Bowel dysfunction occurs in children with Spina Bifida because the recto-anal inhibitory reflex (RAIR) is maintained, but the defecation urge is not present. When the internal sphincter relaxes, bowel accidents or soiling occurs. Constipation results from slow colonic transit time and a lack of sphincter contraction with rectal distention. Additional factors leading to bowel dysfunction are a general decrease in activity, level of lesion that impacts abdominal muscle dysfunction, resulting in a decreased ability to push out the stool.

Eighty percent of people with Spina Bifida use a bowel program to manage their neurogenic bowel⁽¹⁾ but likely more than this would benefit from a bowel program to improve their neurogenic bowel dysfunction. This includes those who have had fetal (prenatal) or newborn (postnatal) surgical interventions of Spina Bifida.⁽¹⁾ Bowel programs are intended to optimize the consistency of the stool and the contractility of the bowel. Finding the balance between consistency and contractility for individuals with SB is vital to managing their neurogenic bowel.

The main goals of treating NBD are to prevent constipation and improve bowel continence. A secondary goal is to increase independence in carrying out a bowel program. Constipation and bowel incontinence put individuals at risk for increased urinary leakage, increased urinary tract infections, increased skin breakdown, and potentially reversible shunt failure.⁽²⁻⁹⁾ Studies have shown that children with poorly managed neurogenic

bowel have increased rates of school absences, increased depression, and increased rates of bullying.⁽¹⁰⁾

Adults with poorly controlled neurogenic bowel have been shown to have decreased educational attainment and are more likely to be underemployed or unemployed.⁽¹¹⁾

Management of NBD is important for medical and social reasons. The Spina Bifida Association and your Spina Bifida medical partners want to help you and your patients optimize their bowel function.

Each person with Spina Bifida is unique, as are their manifestations of neurogenic bowel. What works for one person may not work for another. What works for someone right now may not work for them as they get older. An individual's health goals regarding their bowel and continence may change. Establishing a successful bowel program takes time, and bowel program interventions are adjusted with changing developmental expectations. Options for treatment are often tried in the order of least invasive to most invasive ([APPENDIX I - List of Interventions from Least to Most Invasive](#)).

These recommendations for managing neurogenic bowel across the lifespan are based on available evidence, when available, and consensus among an expert panel of healthcare providers for neurogenic bowel care in Spina Bifida patients, caregivers, and individuals with Spina Bifida.

Comparison of Reflexic and Areflexic Bowel Function

Reflexic bowel function	Areflexic (flaccid) bowel function
Anal reflex (anal wink) is present. Technique described in the physical exam section of each age group.	No anal reflex
Bulbo-Anal reflex is present: Contraction of anus in response to pressure on clitoris or glans penis	Absent Bulbo-anal reflex
History of damage or injury to spinal cord and or brain at or above 12th thoracic vertebra	History of injury or damage to conus medullaris or cauda equina at or below first lumbar vertebra
Spastic paralysis	Flaccid paralysis



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**Lifespan Bowel Management Protocol
Chapter 3: Typical Bowel Function**

Lifespan Bowel Management Protocol

Chapter 3: Typical Bowel Function

The typical defecation pathway involves colon contractions to help mix the contents, absorb water, and propel the contents along the intestine. This results in the feces moving from the colon to the rectum.⁽¹²⁾ The presence of stool in the rectum causes a reflexive relaxation of the internal anal sphincter (RAIR- recto anal inhibitory reflex), so the contents of the rectum can move into the anal canal. This causes the conscious feeling of the need to defecate. At a suitable time, the brain can send signals causing the external anal sphincter and puborectalis muscles to relax as these are under voluntary control, and this allows defecation to take place.^(12,13)

There are different types of neurons involved in innervating the lower gastrointestinal tract; these include the enteric nervous system; located within the wall of the gut and the extrinsic nervous system, comprising sympathetic and parasympathetic innervation.⁽¹⁴⁾ The enteric nervous system directly controls the gut motility, whereas the extrinsic nerve pathways influence gut contractility indirectly through modifying this enteric innervation.⁽¹⁴⁾ In most cases of neurogenic bowel dysfunction, it is the extrinsic nervous supply affected, and the enteric nervous supply remains intact.

Parasympathetic input to ascending and near transverse colon comes from the vagus nerve. Parasympathetic input to the remainder of the colon and rectum comes via sacral roots S2-4 through the pelvic nerves. Parasympathetic input causes increased gut motility and relaxes sphincters. Sympathetic input comes from T6-L2 nerve roots and decreases motility and tone in the colon and contracts sphincters.

Defecation involves conscious and subconscious processes. When the extrinsic nervous system is damaged, either of these can be affected. The somatic nervous system controls conscious processes: these are voluntary movements. For example, the brain instructs the contraction of the striated muscle of the external anal sphincter, which sends signals along the nerves innervating this muscle.^(15,16) Subconscious processes are controlled by the autonomic nervous system; these are involuntary movements such as contraction of the smooth muscle of the internal anal sphincter or the colon. The autonomic nervous system also provides sensory information; this could be about the level of distension within the colon or rectum.^(15,16)

Bowel structure and function

Large bowel has 3 parts:

1. Colon: A 1.5 m long muscular tube
2. Rectum: The last 20 cm of the large bowel
3. Anus: The last 2-5 cm of the rectum
 - Internal sphincter: Located within the anus. It is made of smooth muscle and is under reflex control. It has inherent tone. In the absence of normal external innervation, it will still have some tone.
 - External sphincter: Located within the anus. It is made of striated muscle. It does not have inherent tone. It is under both reflex and voluntary control via somatic and lower motor neurons in the pudendal nerve from the sacral cord. In absence of normal external innervation, external sphincter will be areflexic.



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Lifespan Bowel Management Protocol
Chapter 4: Bowel Management (Birth through 12 months of age)

Lifespan Bowel Management Protocol

Chapter 4: Bowel Management (Birth through 12 months of age)

Key Points

- Bowel management should be initiated in infancy.
- It is important to reinforce the life-long need for a bowel program with caregivers during infancy.
- Establishing the need for a bowel management program in infancy may reduce future resistance and improve family and child self-management.
- Early initiation will help with the development of a routine.
- Initiating a bowel program early in life will improve quality of life and bowel continence long-term.^(17,18)
- It is important to maintain frequent follow-up (every two weeks) when initiating the bowel program. Frequent follow-up is also recommended when moving to other management options if success (evidenced by constipation relief) is not adequate on the current management program. Bowel management treatment for infants with neurogenic bowel will be more aggressive than for infants with neuro-typical bowel innervation who experience constipation.

Goals

- Prevent constipation.
- Stabilize stooling frequency.
- Maintain skin integrity.
- Establish regular communication between the healthcare provider and caregivers regarding bowel management.
- Establish the importance of a bowel management program in an individual's life.

Management

The management options in infants are fewer than in older children. It is recommended to educate families on the content in “Building Health Habits” below. Oral medications are first-line treatments. If these fail, then the per rectum medications can be tried.

Step 1: Assessment

- **History**
 - Determine current stool frequency, consistency, and amounts. Caregivers should monitor stool characteristics by using a bowel diary ([Appendix VI - Bowel Diary](#)) for a minimum of 3-5 consecutive days. The use of the bowel diary is critical before a visit for bowel management consultation.
 - Record medications administered to the infant, especially those with known side effects of constipation, such as anticholinergics. Anticholinergics (e.g., oxybutynin) are commonly used in individuals with Spina Bifida.
 - Assessment of potential maltreatment and abuse should be completed. Education of families of the facts of possible abuse is essential to ensure individuals who will be participating in intimate medical management, including bowel management, are trusted by the child and family. Children with Spina Bifida are at an increased risk of maltreatment, including physical and sexual abuse.
 - Evaluation for the presence of positive and negative signs in the medical history to determine if constipation is present in this age group. Recommending a time frame in which to expect a bowel movement in a young infant can be difficult, so assessing positive and negative signs of normal bowel function may be more helpful.

- Signs that the bowel is working well (positive signs): eating well, gaining weight, seedy stool, mushy/creamy stool consistency, no acute changes to a child’s voiding pattern.
- Signs that the bowel may not be working well (negative signs): abdominal distension, irritability, poor intake/change in intake of food or milk/formula, change in stooling pattern, change in stool consistency, stools that are Type 1 or 2 on the Bristol Stool Chart,⁽¹⁹⁾ straining to have a bowel movement, bubbly liquid stool, sandy/grainy stool, vomiting, blood in the stool, increased UTIs.

- **Physical Examination**

- Assessment of the abdomen. Using percussion and auscultation of bowel sounds to evaluate for constipation, obstruction, or pseudo-obstruction when a tympanic and hypoactive abdomen is identified. Palpation is used to assess sensation, tenderness, discomfort, and masses.
- Perineal inspection for anal fissures, external hemorrhoids, and dermatitis.
- Assessment of the anal sphincter for sensation, patulous anus, and prolapse. Evaluation of anal sphincter tone with the use of a gloved finger.
- Digital rectal examination for the presence of a large rectal vault or a fecal mass in the rectum.
- Evaluation of the anocutaneous reflex (anal wink).⁽²⁰⁾ Touch the perianal skin with an object such as a cotton swab (Q-TIP®). Observe for the anal sphincter to contract or “wink.” Perform on both sides (right and left) of the buttocks/perianal skin. A positive contraction or “wink” may indicate intact motor and/or sensory innervation, reflexic bowel function, and is associated with urinary continence in children with Spina Bifida. ([See Background](#))

Knowledge gained from the history and physical will guide the appropriate selection of management interventions. The results of the history and physical will also assist in determining the need for more invasive measures if constipation is a high-risk concern. For example, a child with poor rectal tone and reduced sphincter control along with dermatitis may require additional interventions to maintain skin integrity ([APPENDIX XII - Diaper Dermatitis](#)). Interventions include zinc- or petroleum-based barrier pastes such as Calmoseptine®, Boudreaux Butt Paste®, iLEX®, and Critic-Aid® ([APPENDIX XII - Diaper Dermatitis](#)). Additional wound care expertise may be needed and should be initiated when appropriate.

Step 2: Interventions

- **Preparation**

- Discuss the importance of a bowel program and monitoring with the family. ([See Background](#))
- Educate families that it is normal for infants to have four or more bowel movements a day during the first few weeks of life.

- **Building Good Bowel Habits**

- Encourage breastfeeding as much as possible in the first six months.¹ Parents report that most breastfed babies with Spina Bifida and loose rectal tone defecate almost continuously for the first two to four weeks or longer. After that, defecation frequency in breastfed babies with Spina Bifida may decrease to every few days or once a week. Constipation is less of a problem in exclusively breast-fed babies.
- Formula may worsen constipation, especially soy-based formula, and those with high iron levels. Other formulas should be initiated if appropriate. Parents should be advised against adding rice or cereal to bottles unless needed for swallow therapy and recommended by a specialist for the first six months of life to reduce the incidence of constipation.

*For various reasons, some babies may not be able to be breastfed. Formula-fed babies with Spina Bifida have a greater risk of constipation. Parents and clinicians should be aware of the association between formula type and constipation and assess stooling status (frequency, consistency, and amount) daily.

- Infants will typically pass 5-10 ml of stool. Breastfed infants' stool volume may be slightly more than non-breastfed infants.⁽²¹⁾
- When solid foods are initiated, beginning with fruits and vegetables should be encouraged. If cereal is given, barley and oatmeal cereals are recommended rather than rice or infant cereals. Oatmeal and barley cereals are less constipating. This will also begin the basis for a healthy diet.⁽²²⁾
- Increase fiber and fluids in children eating solid foods. It can be helpful to tell caregivers to increase fruit and vegetables that start with the letter “P” (peaches, pears, peas, prunes) in the diet. These can be commonly made at home to a consistency appropriate for a child or bought in premade baby food jars and pouches. Pureed or mashed food is preferred over juice versions. Fiber supplements are often recommended for managing constipation for people with typical bowels, but they can cause constipation and discomfort for those with neurogenic bowel and are not routinely recommended. More information can be found in [APPENDIX III – Recommended Dietary Fiber Intake](#).
- Several positions can help an infant to have a bowel movement: placing the knees higher than hips, or knees and hips bent, may help push stool out; bicycling movement with the legs; pushing on the outside of the anus to help evacuate stool in the rectum.
- Perform an abdominal massage. Starting in the lower right side of the abdomen, use a gentle, compressive, kneading motion to move in an upside-down “U” around the top of the umbilicus to the lower left side of the abdomen to help move gas and stool towards the rectum. See [APPENDIX XI – Infant Abdominal Massage for Constipation](#) to [view a video with guidance for nurses](#).
- Consider using a probiotic (Culturelle®, Gerber® Soothe®) for general improved gut health and microbiome biodiversity.⁽²³⁾ There was improved bowel frequency when the probiotic, *Lactobacillus reuteri* (L. reuteri), was administered to infants older than six months, although bowel consistency was not changed from those infants who did not receive L. reuteri. For the most up-to-date information on specific probiotics and constipation consider this website: usprobioticguide.com.
- Consider “latex fruit syndrome” as food is introduced. Not all individuals with latex allergy develop latex fruit syndrome. Individuals with latex allergies may be at risk for reactions to foods associated with latex allergy. Foods should not be avoided unless there is a history of a reaction. Empiric food avoidance is not recommended. It is helpful to understand that not all individuals with a true latex allergy have clinical reactions to fruit (~50%) and that few (~10%) of individuals with known allergy to a latex-cross-reacting fruit develop latex allergy symptoms ([Latex and Allergy Guideline](#) and [Guidelines for the Care of People with Spina Bifida](#)⁽²⁴⁾)

• Starting a Bowel Management Program

In general, interventions should be considered stepwise to achieve the least invasive intervention that balances constipation and contractility ([APPENDIX I – List of Interventions from Least to Most Invasive](#)). Programs should be consistently implemented in a stepwise manner for approximately two weeks before alterations are made.

- Oral medication supplementation (Not recommended in infants less than one month of age; oral supplements can be added to bottles for infants older than one month.)
 - Osmotic laxatives - used to improve hard stool consistency by increasing the water content of stool.
 - Lactulose (Kristalose®, Constulose®, Enulose®, and Generlac®): An osmotic laxative can improve hard stool consistency. This medication is not a stimulant. The onset of action is 24-48 hours (Type 1 or Type 2 on the Bristol Stool Chart⁽¹⁹⁾).
- Polyethylene glycol 3350 powder (Miralax®): An osmotic laxative, not a stimulant, can improve hard stool consistency. The onset of action is 24-96 hours. This medication is not a stimulant. (Type 1 or Type 2 on the Bristol Stool Chart⁽¹⁹⁾). Not recommended for children who weigh less than 10kg. ([APPENDIX V – Oral Medication Dosages](#))
- Stimulant laxative - used to increase the frequency of a bowel movement
 - Sennosides-Docusate Sodium Oral or sennosides tablets (Ex-Lax®, Senokot®): A stimulant laxative that can improve bowel movement frequency through intestinal contraction. The onset of action is 6-10 hours. ([APPENDIX V – Oral Medication Dosages](#))

- Per rectum interventions. These interventions can be used for routine management or to alleviate acute constipation concerns. A rectal medication will often be the most rapid intervention.
- **For routine management**
 - Liquid glycerin suppositories (Pedia-Lax®): 2.8 g (4 mL) daily as needed. If a child has weak external sphincter tone, caregivers may have to manually hold the buttock cheeks together to retain the enema solution better. ([APPENDIX XIX – Suppositories](#))
 - Enemeez®: <3 years of age: 10-40 mg/day in 1-4 divided doses
 - Bulb enema: Use only warm tap water ([APPENDIX VII – Enema Basics](#))
 - Digital Rectal Sweep. Caregivers can sweep inside the rectal vault to evacuate any stool present and promote stimulation of any working nerve fibers with a gloved, lubricated little finger gently sweeping in a circular motion in children with poor sphincter tone. The rectal sweep can be done both before rectal medication insertion and after defecation to ensure emptying of the rectal vault ([APPENDIX XIII – Digital Rectal Sweep](#)).
- **For acute constipation relief**
 - Liquid glycerin suppositories (Pedia-Lax®): 2.8 g (4 mL) per suppository. It may be repeated up to three times per day for two days to relieve acute constipation. If a child has weak external sphincter tone, caregivers may have to manually hold the buttock cheeks together to retain the enema solution better. ([APPENDIX XIX – Suppositories](#))

Step 3: Suggested Monitoring and Follow-Up

The frequency of assessment for the effectiveness of any intervention should be carried out as recommended below:

- When a new management intervention is initiated or adjusted, written instructions for dosing, schedule, and titration of medications (if appropriate) should be provided and explained to the caregivers.
- Caregivers should be instructed to complete a bowel diary ([Appendix VI – Bowel Diary](#)) for three consecutive days after initiating a new intervention and again for three consecutive days before the next scheduled follow-up conversation. This diary should be shared with the provider to aid decision-making.
- Frequent contact between providers and caregivers is imperative to the success of the bowel program. Communication should occur ideally every other week during the first month after a new or adjusted management plan. Communication can occur in person, via phone call, telehealth, or email.
- After a change to a management plan, the individual should carry out the intervention for two weeks without additional modifications. This allows time for the body to adjust to the changes. If goals are not achieved after two weeks, but significant improvement is being made, a program should remain unchanged for two to three more weeks to see if further improvement occurs.
 - If goals are not achieved after two weeks, and there is little-to-no improvement, the bowel program should be changed. Careful consideration of both stooling frequency and stool consistency should be used to guide adjustments (i.e., the infant has a good frequency of bowel movements twice a day, but bowel consistency is Type 1 or 2 on the Bristol Stool Chart⁽¹⁹⁾ or pellet-like, indicating a need to improve consistency of the stool).



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Lifespan Bowel Management Protocol
Chapter 5: Bowel Management (12 through 35 months of age)

Lifespan Bowel Management Protocol

Chapter 5: Bowel Management (12 through 35 months of age)

Key Points

- Parents of children with Spina Bifida say it can take years to establish a bowel routine. Parents also relate that it is better to start a bowel program sooner rather than later.⁽²⁵⁾ Ideally, a bowel management program was started in infancy. If a bowel management program was not initiated in infancy, the program should begin as early in childhood as possible. The initiation of a bowel program early in life will lead to improved quality of life and bowel continence long-term.^(17, 18)
- It is important to reinforce the need for a consistent bowel program with families when the child is a toddler. A daily routine will reduce future resistance and improve family and child self-management. An important part of the bowel program is making the toilet environment a positive experience. A tablet, favorite videos or shows, or special toy can help make the time on the toilet positive and playful. Establishing the predictability of the bowel routine is critical for long-term success.
- It is important to maintain frequent follow-up (every two weeks) when initiating the bowel program. Frequent follow-up is also recommended when moving to other management options if success or constipation relief is not adequate on the current management program.
- Children with Spina Bifida are at an increased risk of maltreatment, including physical and sexual abuse. Clinicians should assess potential maltreatment and abuse and educate families. The education will help ensure that individuals participating in intimate medical management, including bowel management, are trusted by the child and family.
- A toddler should eliminate approximately three inches of stool every day—the size of a small sausage.

Considerations to Increase Future Self-Management Beginning at Two Years of Age

- Discuss the bowel program using simple directions and specific steps.
- The parent should be educated to assist the child in learning the steps of the bowel program. The parent should state the steps of the program aloud and ask the child to repeat the steps even if the child is not performing the skill.
- Use drawings of the steps to talk through each step.
- Place bowel program supplies within reach of the child to increase familiarity with supplies and promote child control of the program.

Goals

- Prevent constipation
- Stabilize stooling frequency
- Maintain skin integrity
- Aim to create and maintain a successful bowel program and social continence by kindergarten.

Management

Step 1: Assessment

- **History**
 - Determine current stool frequency, consistency, and amounts. Caregivers should monitor stool characteristics by using a bowel diary ([Appendix VI - Bowel Diary](#)) for a minimum of three to five



consecutive days to achieve a reliable assessment. If a bowel program is in use, the time between program initiation (i.e., suppository, enema) and when defecation occurs should be noted.

- Record medications administered to the toddler, especially those with known side effects of constipation, such as anticholinergics. Anticholinergics (e.g., oxybutynin) are commonly used in individuals with Spina Bifida.
- Evaluation for the presence of positive and negative signs in the medical history to determine if constipation is present in this age group. Recommending a time frame in which to expect a bowel movement in a young infant can be difficult, so assessing positive and negative signs of normal bowel function may be more helpful.
- Signs that the bowel is working well (positive signs): eating well, gaining weight, seedy stool, mushy/creamy stool consistency, no acute changes to a child's voiding pattern.
- Signs that the bowel may not be working well (negative signs): abdominal distension, irritability, poor intake/change in intake of food or milk/formula, change in stooling pattern, change in stool consistency, stools that are Type 1 or 2 on the Bristol Stool Chart,⁽¹⁹⁾ straining to have a bowel movement, bubbly liquid stool, sandy/grainy stool, vomiting, blood in the stool, increased UTIs.

• **Physical Examination**

- Assessment of the abdomen. Using percussion and auscultation of bowel sounds to evaluate for constipation, obstruction, or pseudo-obstruction when a tympanic and hypoactive abdomen is identified. Palpation is used to assess sensation, tenderness, discomfort, and masses.
- Perineal inspection for anal fissures, external hemorrhoids, and dermatitis.
- Assessment of the anal sphincter for sensation, patulous anus, prolapse. Evaluation of anal sphincter tone with the use of a gloved finger. If anal sphincter tone is flaccid during exam this patient may benefit from a cone enema rather than a balloon catheter enema.
- Digital rectal examination for the presence of a large rectal vault or a fecal mass in the rectum.
- Evaluation of the anocutaneous reflex (anal wink). Touch the perianal skin with an object such as a cotton swab (Q-TIP®). Observe for the anal sphincter to contract or “wink.” Perform on both sides (right and left) of the buttocks/perianal skin. A positive contraction or “wink” may indicate intact motor and/or sensory innervation, reflexic bowel function, and is associated with urinary continence in children with Spina Bifida ([See Background](#)).

Knowledge gained from the history and physical will guide the appropriate selection of management interventions. The results of the history and physical will also assist in determining the need for more invasive measures if constipation is a high-risk concern. For example, a child with poor rectal tone and reduced sphincter control along with dermatitis may require additional interventions to maintain skin integrity. Interventions include zinc- or petroleum-based barrier pastes such as Calmoseptine®, Boudreaux Butt Paste®, iLEX®, and Critic-Aid® ([APPENDIX XII – Diaper Dermatitis](#)). Additional wound care expertise may be needed and should be initiated when appropriate.

Step 2: Interventions

• **Preparation**

- Discuss the importance of a bowel program and monitoring with the family (see [Background](#) for more information).
- The frequency of an assessment of the effectiveness of any intervention should be carried out as recommended below.
- Educate families/caregivers that when changes are made to a bowel program, it can take multiple adjustments and several weeks to months for positive changes to occur and stabilize.

• **Building Good Bowel Habits**



Preparation for future interventions should include establishing the foundation of good bowel habits below. However, these bowel habit foundations are unlikely to achieve optimal bowel regularity and continence without other measures (i.e., medications, enemas).

- Dietary - Encourage a healthy, balanced diet including fruits, vegetables, plenty of water, and limited constipating foods such as cheese and white rice. Fiber-rich foods may be beneficial to bulk up the stool and draw water from the colon to the stool, but inadequate fluid intake with increased fiber may make constipation worse. Fiber supplements may be especially more likely to increase constipation and should be used cautiously for those with neurogenic bowel. Recommendations for fiber and water a child should have can be referenced in [APPENDIX III – Recommended Dietary Fiber Intake](#) and [APPENDIX IV – Recommended Dietary Fluid Intake](#)
- Positioning - Several positions can help a child of this age defecate: placing the knees higher than hips; knees and hips bent in a typical squatting position; bicycling movement with the legs; pushing on the outside of the anus to help evacuate stool in the rectum. The child’s feet should always be supported when sitting on a toilet by using a footstool or stack of books.
- Timed toilet sitting - Some children may be able to sit on a toddler potty chair to help with defecation. Parents should be encouraged to initiate using a potty chair when their child can sit if the child has trunk stability. The goal of timed toileting is habit formation rather than actual defecation. Children should be praised when sitting, even if they don’t defecate ([APPENDIX IX – Timed Sitting](#)). Parents can practice with children by sitting with them for 10-15 minutes after one meal a day (usually after breakfast or after dinner is best) and gradually increase the sitting time if needed to a maximum of 30 minutes. The potty time should be a positive experience for children by using special toys, shows, or books available.
- Abdominal massage - Using a gentle compressing kneading motion, starting in the lower right side of the abdomen, and moving in an upside-down “U” around the top of the umbilicus to the lower left side of the abdomen can help to move gas and stool towards the rectum. See [APPENDIX XI – Infant Abdominal Massage for Constipation](#) to [view a video with guidance for nurses](#).
- Consider using a probiotic (Culturelle®, Gerber® Soothe®) for general improved gut health and microbiome biodiversity. For the most up-to-date information on specific probiotics and constipation consider checking this website: usprobioticguide.com.

• Starting a Bowel Management Program

In general, interventions should be considered in a stepwise manner to achieve the least invasive intervention that balances stool consistency and frequency, thus optimizing continence ([APPENDIX I – List of Interventions from Least to Most Invasive](#)). Programs should be implemented stepwise for approximately two weeks before alterations in the program are made. The two-week time frame should be discussed with the family and past practices considered for potential barriers and facilitators to implementation.

- Before starting a bowel program, a bowel cleanout is recommended ([APPENDIX II – Bowel Cleanouts](#)).
- Oral supplementation
 - Osmotic laxatives - used to improve consistency of hard stool
 - Lactulose (Kristalose®, Constulose®, Enulose®, and Generlac®): An osmotic laxative can improve hard stool consistency. This medication is not a stimulant. The onset of action is 24-48 hours. (Type 1 or Type 2 on the Bristol Stool Chart(19)) ([APPENDIX V – Oral Medication Dosages](#)).
 - Polyethylene glycol 3350 powder (Miralax®): An osmotic laxative can improve hard stool consistency. This medication is not a stimulant. The onset of action is 24-96 hours. (Type 1 or Type 2 on the Bristol Stool Chart (19)). Not recommended for children who weigh less than 10kg. ([APPENDIX V – Oral Medication Dosages](#)).
 - Stimulant laxative - used to increase the frequency of a bowel movement

- Sennosides-Docusate Sodium Oral or sennosides tablets (Ex-Lax®, Senokot®): A stimulant laxative that can improve bowel movement frequency through intestinal contraction. The onset of action is six to 10 hours. ([APPENDIX V – Oral Medication Dosages](#)).
 - Per rectum interventions. These interventions can be used for routine management or to alleviate acute concerns on constipation. A rectal medication will often be the most rapid intervention to produce defecation.
- **For routine management**
 - Liquid glycerin suppositories (Pedilax®): 2.8 g (4 mL) daily as needed. If a child has weak external sphincter tone, caregivers may have to manually hold the buttocks cheeks together for better retention of the enema’s solution. ([APPENDIX XIX – Suppositories](#))
 - Enemeez®: <three years of age: 10-40 mg/day in one to four divided doses.
 - Bulb enema: Use only warm tap water ([APPENDIX VII – Enema Basics](#)).
 - Digital Rectal Sweep: Caregivers can sweep inside the rectal vault to evacuate any stool present and promote stimulation of any working nerve fibers with a gloved, lubricated little finger gently sweeping in a circular motion in children with poor sphincter tone. ([APPENDIX XIII – Digital Rectal Sweep](#))
 - Balloon enema: It is recommended to stop any of the above oral medications when starting a balloon enema program (the addition of oral medications has been associated with decreased continence rates for enemas).⁽²⁶⁾ Warm tap water may be used to instill an enema through a balloon (Foley) catheter placed in the rectum. The recommended amount of water is 10-20 mL/kg. It is not recommended in children under 24 months of age ([APPENDIX VII – Enema Basics](#)).
 - Cone enemas: It is recommended to stop any of the above oral medications when starting a cone enema program (the addition of oral medications has been associated with decreased continence rates for enemas).⁽²⁶⁾ Warm tap water may be used to instill an enema through a cone device placed in the rectum. The recommended amount of water is 10-20 mL/kg. It is not recommended in children under 24 months of age ([APPENDIX VII – Enema Basics](#)).

For acute constipation relief, see [APPENDIX II – Bowel Cleanouts](#).

Step 3: Suggested Monitoring and Follow-Up

The frequency of assessment for the effectiveness of any intervention should be carried out as recommended below:

- When a new management intervention is initiated or adjusted, written instructions for dosing, schedule, and titration of medications and/or interventions (if appropriate) should be given and explained to the caregivers.
- Caregivers should be instructed to complete a bowel diary ([APPENDIX VI – Bowel Diary](#)) for three consecutive days after starting a new intervention and again for three consecutive days before the next scheduled follow-up conversation. This diary should be shared with the provider to aid decision-making.
- Frequent contact between providers and caregivers is imperative to success and should occur ideally every other week during the first month after a new or adjusted management plan. Communication can occur in person, via phone call, telehealth, or email.
- After a change to a management plan, the individual should carry out the intervention for two weeks without additional modifications. This allows time for the body to adjust to the changes. If goals are not achieved after two weeks, but significant improvement is being made, a program should remain unchanged for two to three more weeks to see if further improvement occurs.
- If goals are not achieved after two weeks, and there is little to no improvement, the bowel program should be changed. For balloon enemas, it can take two to three months until a regimen is stable and successful. Small changes in enema volume or frequency of enema administration are generally needed rather than moving to the subsequent more invasive treatment at the first or second two-week interval. Clinical

judgment should be used in these cases. [APPENDIX VII – Enema Basics](#), the section on Balloon Enemas, offers suggestions on small changes that can be made. Careful consideration of both stooling frequency and stool consistency should guide adjustments (i.e., the child has a good frequency of bowel movements twice a day, but bowel consistency is Type 1 or 2 on the Bristol Stool Chart⁽¹⁹⁾ or pellet-like, indicating a need to improve consistency of the stool).





SPINA BIFIDA
ASSOCIATION

Lifespan Bowel Management Protocol
Chapter 6: Transitioning to Specific Programs and Continence
Achievement

Lifespan Bowel Management Protocol

Chapter 6: Transitioning to Specific Programs and Continence Achievement

Bowel programs transition from reducing constipation and preserving skin integrity to attaining bowel continence around the time of typical toilet training for the culture a child lives within. For many, this will be between the ages of 3-5 years.

Neurogenic bowel management was recently cited as a top concern among individuals with Spina Bifida.⁽²⁵⁾ The following guidance will help the clinician to recommend timely interventions to optimize bowel continence for patients. The ultimate goal is a bowel program that results in bowel continence and the most independence possible. Each patient may take a slightly different path unique to their physical, developmental, and social situation to achieve these goals. Recent studies have revealed that 23% of individuals with Spina Bifida were able to achieve full independence with their bowel management, and 45% were able to achieve continence (defined as less than one incontinent episode a month).⁽²⁶⁾ We believe both numbers can be improved with the intentional and timely implementation of the recommended interventions. Ongoing discussions with patients and caregivers reiterate the importance of implementing a bowel management program that should occur at every provider visit. It is reasonable to expect toddlers to be engaged with a clinician and perform a bowel program with their caregivers to be bowel continent at the same age as other neuro-typical children.

This protocol is written with the goals of continence and independence for individuals with Spina Bifida. However, individual patients may have slightly different goals specific to their abilities and lifestyle. The personal goals should be discussed and revisited and prioritized for a bowel program for that individual.

The general information, which is shared here, applies to all subsequent age categories. As an individual ages, the characteristics of their neurogenic bowel may change. This may result in the need to alter a bowel program periodically throughout an individual's lifetime. The patient and caregivers must understand the concept of intermittent changes in bowel function.

- Abdominal radiographs may be used to assess stool burden in cases of unexpected fecal incontinence, but routine abdominal radiographs are not recommended. Radiographs should be interpreted carefully as their clinical use for evaluation of constipation has not been supported by published evidence.^(27–29)
- In individuals who are not fully independent with their bowel program, the goal is to identify and train more than one person to assist/perform the program. When only one individual can assist with the bowel program, the caregiver role strain significantly increases, and the continuation of a long-term successful bowel program significantly decreases.^(30, 31) Consideration of a bowel program and the likelihood of self-management should include knowledge of who is needed to perform the program and the time commitment and availability of a caregiver(s). For those who cannot achieve independence, some health care insurances may cover a health professional to assist with a bowel program. This should be investigated as needed.
- The stepwise approach to bowel management outlined in this document will help individuals find a program that meets their goals using the least invasive method possible. Surgery may be the best option for some individuals, although, in a recent analysis, 60% of those who achieved fecal continence could do so without surgical intervention.⁽²⁶⁾
- The individual should be encouraged to perform as much of their bowel program independently as they are safely able to do starting in preschool years.
- Individuals with Spina Bifida are at increased risk for maltreatment, including physical and sexual abuse. Clinicians should screen for potential abuse and ensure trusted caregivers are selected to assist with intimate activities, such as a bowel management program. Individuals should be given tools and empowered to speak up if they feel uncomfortable with anyone assisting in their care. Individuals need to understand that they control their bodies, even if someone is helping them with their care.



SPINA BIFIDA
ASSOCIATION

Lifespan Bowel Management Protocol
Chapter 7: Bowel Management (3 to 5 years 11 months)

Lifespan Bowel Management Protocol

Chapter 7: Bowel Management (3 to 5 years 11 months)

Key Points

- More than 80% of individuals with Spina Bifida require a bowel program to manage their bowels.(2) Early adoption of a bowel management program and frequent reassessment of the program will likely allow most individuals with Spina Bifida to achieve bowel continence if desired.
- Sharing expectations of a bowel routine between children, caregivers and clinicians is essential. Clinicians should understand the family's goals and share bowel program expectations, including time commitments, frequency of communication, and the importance of routine. These are necessary to establish a successful bowel management routine.
- Even with a bowel program, there may still be occasional accidents.
- Bowel management programs should be discussed at routine follow-up visits to ensure they are still meeting the needs of the individual. Bowel routines may need to change to best manage symptoms and maintain social continence.
- Appropriate bowel management can help to reduce other medical complications (See [Background](#) for more information).
- The ages of 3-5 years are ideal for establishing a bowel routine to optimize bowel continence before school. Children in this age group are gaining independence. The selection of a bowel program should take advantage of this milestone in a child's development. Maximizing how a child can be involved in their routine is a priority. (See section, [Transitioning to Specific Programs and Continence Achievement](#) below, and [APPENDIX VIII – Helping Parents and Caregivers Prepare to Start a Bowel Program](#))
- Body autonomy is important to instill in children with Spina Bifida at a young age. This will allow them to take ownership of their bodies and their functions. This may also increase the likelihood they will advocate for themselves if they feel they are in an uncomfortable situation that could lead to abuse. Empowering caregivers and children about their ability to say no if the child or the caregiver feels uncomfortable is very important. Individuals with Spina Bifida may have altered sensation in the genitals. Awareness of the increased risk for sexual abuse and inappropriate touching should be clearly discussed. Children with Spina Bifida are at an increased risk of maltreatment, including physical and sexual abuse. Clinicians should assess for potential maltreatment and abuse and educate families. The education will help ensure that individuals participating in intimate medical management, including bowel management, are trusted by the child and family.
- It is important to be aggressive about follow-up and moving to other management options if relief is not adequate on a management program.
- Consider an occupational or physical therapy referral in conjunction with a bowel program if accommodations for independence are needed. The occupational therapist referral can assist children with fine motor deficits in manipulating objects such as catheters, container tops, or rollerball clamps on the enema bag. The physical therapy referral can assist with children who may have trunk instability to sit on the toilet or recommend adaptive equipment.
- A preschool child should eliminate four to six inches of stool every day. This will ensure that the descending colon is empty, accidents will not occur, and constipation will not become a problem.

Considerations to Increase Future Self-Management

- Discuss the bowel program using simple directions and specific steps.
- The parent should be educated to assist the child in learning the steps of the bowel program. The parent should state the steps of the program aloud and ask the child to repeat the steps even if the child is not performing the skill.
- Use drawings of the steps to talk through each step.
- Place bowel program supplies within reach of the child to increase familiarity and move toward a program that they control.

Goals

- Establish or maintain a bowel management routine. A bowel routine should become second nature to a child, just like daily tooth brushing. Set a goal to achieve bowel continence close to the socially acceptable age of four to five years of age or kindergarten/first grade.
- Prevent constipation.
- Maintain skin integrity.

Management

Step 1: Assessment

• History

- Determine current stool frequency, consistency, and amounts. Caregivers should use a bowel diary to record the time of day when a bowel movement (BM) occurs and the presence of BM urge or awareness. The bowel diary ([APPENDIX VI – Bowel Diary](#)) should be used for a minimum of 3-5 consecutive days to achieve a reliable assessment. If a bowel program is in use, the time between program initiation (i.e., suppository, enema) and when defecation occurs should be noted.
- Obtain an accurate history of prior bowel programs that have been attempted and facilitators and barriers to success. Determine the reasons for previously discontinued bowel programs. For example, if a program was stopped because it was too burdensome, then a simpler plan should be designed. If an enema program failed, determine the details regarding the types of enemas, the volume of fluid, additives, and frequency of use. This information will help providers to recommend a program most likely to succeed.
- Record medications the child is taking, especially those with known side effects of constipation, such as anticholinergics. Anticholinergics (e.g., oxybutynin) are commonly used in individuals with Spina Bifida.
- It is essential to evaluate different positive and negative signs in the medical history to determine if constipation is present in this age group. Using a time frame in which to expect a bowel movement can be difficult, so assessing for positive and negative signs may be more meaningful.
 - Signs that the bowel is working well (positive signs): eating well, gaining weight, seedy stool, mushy/creamy stool consistency, no acute changes to a child's voiding pattern.
 - Signs that the bowel may not be working well (negative signs): abdominal distension, irritability, poor intake/change in intake of food or milk, change in stooling pattern, change in stool consistency, stools that are Type 1 or 2 on the Bristol Stool Chart,(19) straining to have a bowel movement, bubbly liquid stool, sandy/grainy stool, vomiting, blood in the stool, increased UTIs.

• Physical Examination

- Assessment of the abdomen. Using percussion and auscultation of bowel sounds to evaluate for constipation, obstruction, or pseudo-obstruction when a tympanic and hypoactive abdomen is identified. Palpation is used to assess sensation, tenderness, discomfort, and masses.
- Perineal inspection for anal fissures, external hemorrhoids, and dermatitis.
- Assessment of the anal sphincter for sensation, patulous anus, prolapse. Evaluation of anal sphincter tone with the use of a gloved finger. If anal sphincter tone is flaccid during exam this patient may benefit from a cone enema rather than a balloon catheter enema.
- Digital rectal examination for the presence of a large rectal vault or presence of a fecal mass in the rectum.
 - Evaluation of the anocutaneous reflex (anal wink). Touch the perianal skin with an object like a cotton swab (Q-TIP®). Observe for the anal sphincter to contract or “wink.” Perform on both sides (right and left) of the buttocks/perianal skin. A positive contraction or “wink” may indicate intact motor and/or sensory innervation, reflexic bowel function, and is associated with urinary continence in children with Spina Bifida ([See Background](#)).

Knowledge gained from the history and physical will guide the selection of appropriate management interventions. The results of the history and physical will also assist in determining the need for more invasive measures if constipation is a high-risk concern. For example, a child with poor rectal tone and reduced sphincter control along with dermatitis, may require additional interventions to maintain skin integrity. Interventions include zinc- or petroleum-based barrier pastes such as Calmoseptine®, Boudreaux Butt Paste®, iLEX®, and Critic-Aid® ([APPENDIX XII – Diaper Dermatitis](#)). Additional wound care expertise may be needed and should be initiated when appropriate.

Step 2: Interventions

• Preparation

- Assessment of the family is important before changing or starting a bowel program. The caregivers' readiness to assist the child with the bowel program and the child themselves needs to be assessed. Most regimens will require daily activities that vary regarding the complexity and amount of time to perform the bowel program: the family and individual need to consider what they can realistically fit into their daily routine. If an ideal program is not practical, a reassessment of the ability to perform this program should be carried out every three to six months. Families may feel intimidated to initiate a program or be hesitant to change their home routines to accommodate a typical bowel program.
- Children at this age will need assistance performing their bowel program in nearly all cases. Identifying who is willing and able to help them is important. Ideally, this will be more than one individual in a family to reduce caregiver role strain and act as a backup for any unexpected life events. These individuals all need to be trained in the bowel program.
- Children should be encouraged to participate as fully as possible in their bowel program. Work with the family and child to determine what tasks of a bowel program the child can complete. Remember, these may be simple tasks such as gathering supplies, opening items, or holding items. Start with tasks that the child can do easily and allow them to be actively involved in the process and not just the receiver of the program. The goal is for the child to see their bowel program as being done with and for them, rather than to them.
- Discuss with the family the importance of a bowel program and monitoring (see [Background](#) for more information).
- The frequency of an assessment of the effectiveness of any intervention should be carried out as recommended below.
- Educate caregivers that when changes are made to a bowel program, it can take multiple adjustments and several weeks to months for positive changes to occur and stabilize.

• Building Good Bowel Habits

Preparation for future interventions should include the good foundational habits below. These preparations are unlikely to achieve optimal bowel management on their own.

- Dietary - Encourage a healthy, balanced diet including fruits, vegetables, plenty of water, and limit constipating foods such as cheese and white rice. Fiber-rich foods may be beneficial to bulk up the stool and draw water from the colon to the stool, but inadequate fluid intake with increased fiber may make constipation worse. Fiber supplements may be especially more likely to increase constipation and should be used cautiously for those with neurogenic bowel. See [APPENDIX IV – Recommended Dietary Fluid Intake](#) and [APPENDIX III – Recommended Dietary Fiber Intake](#) for recommendations on the amount of fiber and water a child should have.
- Positioning - Several positions can help a child of this age defecate: placing the knees higher than hips; knees and hips bent in a typical squatting position. Feet should always be supported when sitting on a toilet; a footstool or stack of books can be used for this. Teach the child to push by coughing, blowing bubbles, laughing, or bearing down.

- Timed toilet sitting - Some children may be able to sit on a toddler potty chair to help with stooling. Encourage parents to initiate using a potty chair when their child can sit if the child has the stability to do so. The goal of timed toileting is habit formation rather than the production of a bowel movement. When children sit, praise should be provided even if they don't produce a bowel movement ([APPENDIX IX – Timed Sitting](#)). The parent can practice with the child by sitting with them for 10-15 minutes after one meal a day (usually after breakfast or after dinner is best to take advantage of the gastrocolic reflex), and gradually increase the time if needed until a maximum of 30 minutes. Make this a positive time for the child by using special toys, shows, or books available.
- Abdominal massage - Use a gentle compressing kneading motion, starting in the lower right side of the abdomen, and moving in an upside-down “U” around the top of the umbilicus to the lower left side of the abdomen can help to move gas and stool towards the rectum. See [APPENDIX XI – Infant Abdominal Massage for Constipation](#) to [view a video with guidance for nurses](#).
- Consider using a probiotic (Culturelle®, Gerber® Soothe®) for general improved gut health and microbiome biodiversity. For the most up-to-date information on specific probiotics and constipation consider checking this website: usprobioticguide.com.

• Starting a Bowel Management Program

In general, interventions should be considered in a stepwise manner, with the goal of finding the least invasive intervention that balances stool consistency and frequency, thus optimizing continence ([APPENDIX I – List of Interventions from Least to Most Invasive](#)). Programs should be implemented for a minimum of 2 weeks consistently before altering the program. This time frame should be discussed with the family and past practices considered for barriers and facilitators. Many families may prefer to initiate enemas sooner rather than later.

- If an individual is new to a bowel program or has had unclear adherence to a prior program, a bowel cleanout should be carried out. Bowel cleanouts before any program change should also be carried out. Cleanouts prepare the bowel for bowel management by reducing current stool burden/constipation ([APPENDIX II – Bowel Cleanouts](#)).
 - Oral supplementation
 - Osmotic laxatives - used to improve consistency of hard stool
 - Polyethylene glycol 3350 powder (Miralax®): An osmotic laxative, not a stimulant, and can improve the consistency of hard stool. The onset of action is 24-96 hours. (Type 1 or Type 2 on the Bristol Stool Chart.⁽¹⁹⁾) Not recommended for children who weigh less than 10kg ([APPENDIX V – Oral Medication Dosages](#)).
 - Lactulose (Kristalose®, Constulose®, Enulose®, and Generlac®): An osmotic laxative can improve the consistency of hard stool. This medication is not a stimulant. The onset of action is 24-48 hours (Type 1 or Type 2 on the Bristol Stool Chart⁽¹⁹⁾) ([APPENDIX V – Oral Medication Dosages](#)).
 - Linaclotide (Linzess®): An osmotic laxative capsule. Black Box warning for children under 2 years of age.
 - Stimulant laxative - used to increase the frequency of a bowel movement
 - Sennosides-Docusate Sodium Oral or sennosides tablets (Ex-Lax®, Senokot®): A stimulant laxative that can improve bowel movement frequency through intestinal contraction. The onset of action is 6-10 hours ([APPENDIX V – Oral Medication Dosages](#)).
 - Timed sitting and use of a stimulant laxative are not likely to work (timed sitting for a bowel movement is used by only 3% of those with SB, and less than half of those individuals have bowel continence doing this).⁽²⁶⁾ If this approach is tried, it is appropriate to use it for less than two weeks if success is not achieved. A bowel cleanout likely would be needed before moving to the next program.

Per rectum interventions. These interventions can be used for routine management or to alleviate acute concerns. The most rapid intervention will be rectal medications.

- **For routine management**

- Liquid glycerin suppositories (Pedilax®): 2.8 g (4 mL) daily as needed. If a child has weak external sphincter tone, caregivers may have to manually hold the buttocks cheeks together for better retention of the enema solution. ([APPENDIX XIX – Suppositories](#)).
- Enemeez®: Children 2 to 12 years of age
- DocuSol® Kids: Docusate 100 mg (contents of one mini-enema) daily as needed
 - Children >12 years of age: Enemeez®: Docusate 283 mg (contents of one mini-enema) daily as needed
- Balloon or cone enemas: It is recommended to stop any of the above oral medications when starting a balloon/cone enema program (the addition of oral medications has been associated with decreased continence rates for enemas).⁽²⁶⁾
- Transanal irrigation: It is recommended to stop any of the above oral medications when starting a balloon/cone enema program (the addition of oral medications has been associated with decreased continence rates for enemas).⁽²⁶⁾

For acute constipation relief, [see APPENDIX II – Bowel Cleanouts](#).

Step 3: Suggested Monitoring and Follow-Up

The frequency of assessment for the effectiveness of any intervention should be carried out as recommended below:

- When a new management intervention is initiated or adjusted, written instructions for dosing, schedule, and titration (if appropriate) should be given and explained to the caregivers.
- Caregivers should complete a bowel diary ([Appendix VI – Bowel Diary](#)) for three consecutive days after starting a new intervention and again for three consecutive days before the next scheduled follow-up conversation. This diary should be shared with the provider to aid decision-making.
- Frequent contact with caregivers is imperative to success and should occur ideally every other week during the first month after a new or adjusted management plan; this can be done in person, phone call, telehealth, or email.
- After a change is made to a management plan, the individual should carry it out for two weeks without additional modifications. This allows time for the body to adjust. If goals are not achieved after two weeks, but significant improvement is being made, a program should remain unchanged for two to three more weeks to see if further improvement occurs. If goals are not achieved after two weeks, and there is little to no improvement, the bowel program should be changed.
- For balloon enema, cone enema, and transanal irrigation, it can take two to three months until a regimen is stable and working. Careful, small changes in enema solution volume or frequency of enema administration are generally needed rather than skipping to the next most invasive treatment at the first or second two-week interval. Clinical judgment should be used in these cases. Suggestions on small changes that can be made are included in [APPENDIX VII – Enema Basics](#).
- Careful consideration of both the frequency and the consistency of the stool should be used to guide adjustments (i.e., the child has a good frequency of bowel movements twice a day, but bowel consistency is Type 1 or 2 on the Bristol Stool Chart⁽¹⁹⁾ or pellet-like, indicating a need to improve consistency of the stool.



SPINA BIFIDA
ASSOCIATION

Lifespan Bowel Management Protocol
Chapter 8: Bowel Management (6 to 12 years 11 months)

Lifespan Bowel Management Protocol

Chapter 8: Bowel Management (6 to 12 years 11 months)

Key Points

- More than 80% of individuals with Spina Bifida require a bowel program to manage their bowels.⁽²⁾ Early adoption of a bowel management program and frequent reassessment of the program will likely allow most individuals with Spina Bifida to achieve bowel continence if desired.
- Sharing expectations of a bowel routine between children, caregivers and clinicians is important. Identification of the child's goals is important. Their bowel health goals should be the driver of interventions. This increases their perception of things occurring for them rather than to them, which likely will improve compliance and communication. Clinicians should share the expectations with the child and their caregivers, including time commitments, frequency of communication, and the importance of routine. These are necessary to establish a successful bowel management routine.
- Even with a bowel program, there may still be occasional accidents.
- Bowel routines may need to alter slightly during menstruation for females as often their bowel habits change during different phases of their menstruation cycle. Charting by the individual and family will aid in this determination.
- Conversations should shift toward the child as the primary focus rather than the caregiver as the child's development allows. Bowel management programs should be discussed at routine follow-up visits to ensure they are still meeting the needs of the individual. Bowel routines may need to change to best manage symptoms and maintain social continence.
- Appropriate bowel management can help to reduce other medical complications (See [Background](#) for more information).
- It is important to be aggressive about follow-up and moving to other management options if relief is not adequate on a management program.
- Optimizing continence at this age will likely improve school attendance and self-esteem at a critical age for identity formation.
- The ability for independence should be discussed with the child. If independence is possible, consider which bowel management program is likely to result in independence. A balance of independence and continence is desirable. If there is difficulty achieving independence and continence, the child should help determine whether to prioritize independence or continence. Not all bowel programs can be managed entirely independently by everyone. Some may decide that a level of bowel dysfunction is preferable if the routine can be completed independently. Consider an occupational or physical therapy referral in conjunction with a bowel program if accommodations for independence are needed.
- More frequent follow-ups (phone, telehealth, email, in-person) may be needed as children enter pre-teen and teen years. This age group has a higher risk of nonadherence, and an established relationship with a trusted health care provider is essential.
- Body autonomy is important to instill in children with Spina Bifida at a young age. This will allow them to take ownership of their bodies and their functions. This may also increase the likelihood they will advocate for themselves if they feel they are in an uncomfortable situation that could lead to abuse. It is crucial to empower caregivers and children about their ability to say no if they think a child is in an uncomfortable position. Individuals with Spina Bifida may have altered sensation in the genitals. Awareness of the increased risk for sexual abuse and inappropriate touching should be clearly discussed. Children with Spina Bifida are at an increased risk of maltreatment, including physical and sexual abuse. Clinicians should assess potential maltreatment and abuse and educate families. The education will help ensure that individuals participating in intimate medical management, including bowel management, are trusted by the child and family.

Considerations to Increase Future Self-Management

- Discuss the bowel program using simple directions and into specific steps.



- The parent should be educated to assist the child in learning the steps of the bowel program. The parent should state the steps of the program aloud and ask the child to repeat the steps even if the child is not performing the skill.
- Use drawings of the steps to talk through each step. When a child can read and write, have them write out the steps on notes that can be placed in order or hung on the wall as a reference. When appropriate, place the steps on a phone/tablet, which can be accessed during the bowel program.
- Place bowel program supplies within reach of the child to increase familiarity and promote control for the program.
- Develop a step-by-step reminder.
- Talk about/review the steps for the program.
- Teach bowel accident management in a stepwise manner.
- Reward for the performance of tasks that should be done.

Goals

- Establish or maintain a bowel management routine. A bowel routine should become second nature to a child, just like daily tooth brushing. Bowel continence should be established by the school-age years.
- Prevent constipation.
- Maintain skin integrity.
- Optimize continence.
- Optimize independence.

Management

Step 1: Assessment

- **History**
 - Determine current stool frequency, consistency, and amounts. Caregivers should use a bowel diary to record the time of day when a bowel movement (BM) occurs and the presence of BM urge or awareness. The bowel diary ([Appendix VI – Bowel Diary](#)) should be used for a minimum of three to five consecutive days to achieve a reliable assessment. If a bowel program is in use, the time between program initiation (i.e., suppository, enema) and when defecation occurs should be noted.
 - Obtain an accurate history of prior bowel programs that have been attempted and facilitators and barriers to success. Determine the reasons for previously discontinued bowel programs. For example, a simpler plan should be designed if a program was stopped because it was too burdensome. If an enema program failed, gather details regarding the types of enemas, fluid volume, additives, and frequency of use. This information will help providers to recommend a program most likely to succeed.
 - Record medications the child is taking, especially those with known side effects of constipation, such as anticholinergics, commonly used in individuals with Spina Bifida.
 - Children with Spina Bifida are at an increased risk of maltreatment, including physical and sexual abuse. Clinicians should assess potential maltreatment and abuse and educate families. The education will help ensure that individuals participating in intimate medical management, including bowel management, are trusted by the child and family.
 - It is important to evaluate different positive and negative signs in the medical history to determine if constipation is present in this age group. Using a time frame in which to expect a bowel movement can be difficult, so assessing for positive and negative signs may be more meaningful.
 - Signs that the bowel is working well (positive signs): eating well, gaining weight as expected, mushy/creamy stool consistency or formed (Bristol Stool Chart Type 4),(19) no acute changes voiding pattern.
 - Signs that the bowel may not be working well (negative signs): abdominal distension, irritability, poor intake/change in intake, change in stooling pattern, change in stool consistency, stools that are Type 1 or 2 on the Bristol Stool Chart,(19) straining to have a bowel movement, bubbly liquid stool,



sandy/grainy stool, vomiting, blood in the stool, increased UTIs.

- **Physical examination**

- Assessment of the abdomen. Using percussion and auscultation of bowel sounds to evaluate for constipation, obstruction, or pseudo-obstruction when a tympanic and hypoactive abdomen is identified. Palpation is used to assess sensation, tenderness, discomfort, and masses.
- Perineal inspection for anal fissures, external hemorrhoids, and dermatitis.
- Assessment of the anal sphincter for sensation, patulous anus, prolapse. Evaluation of anal sphincter tone with the use of a gloved finger. If anal sphincter tone is flaccid during exam this patient may benefit from a cone enema rather than a balloon catheter enema.
- Digital rectal examination for the presence of a large rectal vault or presence of a fecal mass in the rectum.
 - Evaluation of the anocutaneous reflex (anal wink). Touch the perianal skin with an object like a cotton swab (Q-Tip®). Observe for the anal sphincter to contract or “wink.” Perform on both sides (right and left) of the buttocks/perianal skin. A positive contraction or “wink” may indicate intact motor and/or sensory innervation, reflexic bowel function, and is associated with urinary continence in children with Spina Bifida ([See Background](#)).

Knowledge from the history and physical will aid in determining which management should be initiated and the urgency that more invasive measures should be considered. For example, a child with poor rectal tone and reduced sphincter control along with dermatitis may require additional interventions to maintain skin integrity. Interventions include zinc- or petroleum-based barrier pastes such as Calmoseptine®, Boudreaux Butt Paste®, iLEX®, and Critic-Aid® ([APPENDIX XII – Diaper Dermatitis](#)). Additional wound care expertise may be needed and should be initiated when appropriate.

Step 2: Interventions

- **Preparation**

- Assessment of the family is important before changing or starting a bowel program. The caregivers’ readiness to assist the child with the bowel program and the child themselves needs to be assessed. Most regimens will require daily activities that vary regarding the complexity and amount of time to perform the bowel program: the family and individual need to consider what they can realistically fit into their daily routine. If an ideal program is not practical, a reassessment of the ability to perform this program should be carried out every three to six months. Families may feel intimidated to initiate a program or be hesitant to change their home routines to accommodate a typical bowel program.
- Children at this age need assistance performing their bowel program in most cases. Identifying who is willing and able to help them is important. Ideally, this will be more than one individual in a family to reduce caregiver role strain and act as a backup for any unexpected life events. These individuals all need to be trained in the bowel program.
- Children should be encouraged to participate as fully as possible in their bowel program. Work with the family and child to determine what tasks of a bowel program the child can complete. Remember, these may be simple tasks such as gathering supplies, opening items, or holding items. Start with tasks that the child can do easily and allow them to be actively involved in the process and not just the receiver of the program. The goal is for the child to see their bowel program as being done with and for them, rather than to them.
- Discuss with the family the importance of a bowel program and monitoring (see [Background](#) for more information).
- The frequency of assessment for the effectiveness of any intervention should be carried out as recommended below.
- Educate caregivers that when changes are made to a bowel program, it can take multiple adjustments and several weeks to months for positive changes to occur and stabilize.



• Building Good Bowel Habits

Preparation for future interventions should include the good foundational habits below. These preparations are unlikely to achieve optimal bowel management on their own.

- Dietary - Encourage a healthy, balanced diet including fruits, vegetables, plenty of water, and limit constipating foods such as cheese and white rice. Fiber-rich foods may be beneficial to bulk up the stool and draw water from the colon to the stool, but inadequate fluid intake with increased fiber may make constipation worse. Fiber supplements may be especially more likely to increase constipation and should be used cautiously for those with neurogenic bowel. Recommendations for fiber and water a child should have can be referenced in [APPENDIX III – Recommended Dietary Fiber Intake](#) and [APPENDIX IV – Recommended Dietary Fluid Intake](#).
- Positioning - Several positions can help a child of this age physically pass a bowel movement: placing the knees higher than hips; knees and hips bent in a typical squatting position. Feet should always be supported when sitting on a toilet; a stool or stack of books can be used for this. Teach the child to push by coughing, blowing bubbles, laughing, or bearing down.
- Consider using a probiotic (Culturelle®, Gerber® Soothe®) for general improved gut health and microbiome biodiversity.(32) For the most up-to-date information on specific probiotics and constipation consider checking this website: usprobioticguide.com

• Starting a Bowel Management Program

In general, interventions should be considered in a stepwise manner, with the goal of finding the least invasive intervention that balances stool consistency and frequency, thus optimizing continence ([APPENDIX I – List of Interventions from Least to Most Invasive](#)). Programs should be implemented for a minimum of two weeks consistently before altering the program. This time frame should be discussed with the family and past practices considered for barriers and facilitators. Many families may prefer to initiate enemas sooner rather than later.

If an individual is new to a bowel program or has had unclear adherence to a prior program, a bowel cleanout should be carried out. Bowel cleanouts before any program change should also be carried out. Cleanouts prepare the bowel for bowel management by reducing current stool burden/constipation ([APPENDIX II – Bowel Cleanouts](#)).

- Oral supplementation
 - Osmotic laxatives - used to improve consistency of hard stool
 - Polyethylene glycol 3350 powder (Miralax®): An osmotic laxative, not a stimulant, can improve hard stool consistency. The onset of action is 24-96 hours. This medication is not a stimulant (Type 1 or Type 2 on the Bristol Stool Chart⁽¹⁹⁾). It is not recommended for children who weigh less than 10kg ([APPENDIX V – Oral Medication Dosages](#)).
 - Lactulose (Kristalose®, Constulose®, Enulose®, and Generlac®): An osmotic laxative can be used to improve the consistency of hard stool (Type 1 or Type 2 on the Bristol Stool Chart⁽¹⁹⁾) ([APPENDIX V – Oral Medication Dosages](#)).
 - Linaclotide (Linzess®): An osmotic laxative capsule. Black Box warning for children under 2 years of age.
 - Stimulant laxative - used to increase the frequency of a bowel movement
 - Sennosides-Docusate Sodium Oral or sennosides tablets (Ex-Lax®, Senokot®): A stimulant laxative that can improve bowel movement frequency through intestinal contraction. The onset of action is 6-10 hours ([APPENDIX V – Oral Medication Dosages](#)).
 - Timed sitting and use of a stimulant laxative are not likely to work (timed sitting for a bowel movement is used by only 3% of those with SB, and less than half of those individuals have bowel continence doing this). If this approach is tried, it is appropriate to use it for less than two weeks if success is not achieved. A bowel cleanout likely would be needed before moving to the next program.



Per rectum interventions. These interventions can be used for routine management or to alleviate acute concerns. The most rapid intervention will be rectal medications.

- **For routine management**

- Liquid glycerin suppositories (Pedilax®): 2.8 g (4 mL) daily as needed. If a child has weak external sphincter tone, caregivers may have to manually hold the buttocks cheeks together to retain the enema's solution better. ([APPENDIX XIX – Suppositories](#))
- Enemeez®: Follow packing directions for dosing.
- Balloon or cone enemas: It is recommended to stop oral laxative medications when starting a balloon/cone enema program (the addition of oral medications has been associated with decreased continence rates for enemas).⁽²⁶⁾
- Transanal irrigation: It is recommended to stop any of the oral laxative medications when starting a balloon/cone enema program (the addition of oral medications has been associated with decreased continence rates for enemas).⁽²⁶⁾
- MACE/Cecostomy: Surgical intervention may be needed ([APPENDIX VII – Enema Basics](#), MACE (Malone Antegrade Continence Enemas) / ACE (Antegrade Continence Enemas), Chait, and Cecostomy).

For acute constipation relief, [see APPENDIX II – Bowel Cleanouts](#).

Step 3: Suggested Monitoring and Follow Up

The frequency of assessment for the effectiveness of any intervention should be carried out as recommended below:

- When a new management intervention is initiated or adjusted, written instructions for dosing, schedule, and titration (if appropriate) should be given and explained to the caregivers.
- Recommend having the individual/caregiver complete the Kelly Pediatric Neurogenic Bowel Dysfunction Score⁽³³⁾ at each visit to have an objective measure from the patient/caregiver perspective of their neurogenic bowel symptoms to track progress and changes in symptoms. A score of nine or higher is considered positive for neurogenic bowel dysfunction. This score is validated to be used from ages 6 to 18 years.
- Caregivers should complete a bowel diary ([Appendix VI – Bowel Diary](#)) for three consecutive days after starting a new intervention and again for three consecutive days before the next scheduled follow-up conversation. This diary should be shared with the provider to aid decision-making.
- Frequent contact with caregivers is imperative to success and should occur ideally every other week during the first month after a new or adjusted management plan; this can be done in person, phone call, telehealth, or email.
- After a change is made to a management plan, the individual should carry it out for two weeks without additional modifications. This allows time for the body to adjust. If goals are not achieved after two weeks, but significant improvement is being made, a program should remain unchanged for two to three more weeks to see if further improvement occurs. If goals are not achieved after two weeks, and there is little to no improvement, the bowel program should be changed.
- For balloon enema, cone enema, transanal irrigation, and surgical management, it can take two to three months until a regimen is stable and working. Careful small changes in enema volume or frequency of enema administration are generally needed rather than skipping to the next most invasive treatment at the first or second two-week interval. Clinical judgment should be used in these cases. Suggestions on small changes that can be made are included in [APPENDIX VII – Enema Basics](#). Careful consideration of both the frequency and the consistency of the stool should be used to guide adjustments (i.e., the child has a good frequency of bowel movements twice-a-day, but bowel consistency is Type 1 or 2 on the Bristol Stool Chart⁽¹⁹⁾ or pellet-like, indicating a need to improve consistency of the stool).



SPINA BIFIDA
ASSOCIATION

**Lifespan Bowel Management Protocol
Chapter 9: Transitioning to Independence**

Lifespan Bowel Management Protocol

Chapter 9: Transitioning to Independence

The teen years are a critical time to work towards a reliable continence program if it has not already been in place. It is also necessary to work towards independence with the bowel program and other self-management tasks to prepare for a more autonomous adult life. Independent self-management includes the physical ability to do the bowel management program oneself, adherence to the program, ability to order/obtain supplies for the program, knowledge of what clinician to contact if there are concerns, and an understanding of what constitutes an emergency and what to do if that occurs ([APPENDIX XIV – Bowel Program Complications](#)).

Physical ability to manage one's bowel program varies based on the effects of Spina Bifida, including balance and gross and fine motor skills. Some bowel management programs are more difficult to do independently than others. The current rates of independence noted with each management technique can be found in [APPENDIX XV – Independence](#). We hope all of these will increase with the implementation of this protocol. Suppose the bowel program effectively provides continence, but it cannot be done independently. In that case, the clinician, patient, and caregivers should discuss the next steps to increase independence, if desired. This may require an occupational therapy or physical therapy consult to assess for adaptations or transitioning to a different bowel program that can be done with more patient autonomy.

Even as the emerging teenager becomes increasingly able to perform bowel management tasks, adherence to the program remains a significant challenge in this age group and population. In the Spina Bifida population, executive dysfunction causes difficulties with planning, organizing, initiating, problem solving, and other cognitive skills needed for medical self-management. When a patient with Spina Bifida appears to caregivers and clinicians to be lazy, unmotivated, or disinterested in self-management, altered executive functioning skills may be to blame. When possible, a neuropsychological assessment may assist the patient, caregivers, and providers in understanding the individual's challenges and how to mitigate them and improve skills. Increasing the patient's self-management knowledge and self-efficacy can improve self-management behaviors.⁽³⁴⁾ Caregivers walk a delicate line of promoting autonomy and monitoring adherence.⁽³⁵⁾ Caregivers must promote self-management skills and expect to provide support and monitoring for longer than might be expected for a similar age neurotypical child.

Ability and motivation for independence will vary widely among patients and even over time with the same patient. Teens with Spina Bifida tend to gain independence skills and responsibility as they age, but many may not achieve this until late adolescence or early adulthood.⁽³⁵⁾ Providers can support patients and caregivers by giving appropriate options for independence and encouraging self-management behaviors. If a patient has not implemented an effective bowel program by the time they age out of pediatric care, they will be less likely to find providers who are knowledgeable about bowel management once they become adults. This is because there is a scarcity of providers who are familiar with the needs of adult patients who have Spina Bifida. (A current list of adult clinics/providers can be found at <https://www.spinabifidaassociation.org/clinics/>) The teen's continence level, ability to perform a bowel program independently, and self-management skills impact opportunities in adulthood for work, independent living, relationships, and quality of life.⁽¹¹⁾



SPINA BIFIDA
ASSOCIATION

Lifespan Bowel Management Protocol
Chapter 10: Bowel Management (13 to 17 years 11 months)

Lifespan Bowel Management Protocol

Chapter 10: Bowel Management (13 to 17 years 11 months)

Key Points

- More than 80% of individuals with Spina Bifida require a bowel program to manage their bowels.⁽²⁾ Adoption of a bowel management program and frequent reassessment of the program will likely allow most individuals with Spina Bifida to achieve bowel continence, if desired.
- Sharing expectations of a bowel routine between children, caregivers and clinicians is important. Identification of the teen's goals is important. The teen's bowel health goals should be the driver of interventions. This increases their perception of things occurring *for* them rather than *to* them, which likely will improve compliance and communication. Clinicians should share the expectations with the teen and their caregivers, including time commitments, frequency of communication, and the importance of routine. These are necessary to establish a successful bowel management routine.
- Even with a successful bowel program, there may still be occasional accidents. Bowel programs may need to be changed or altered over time, even in adulthood.
- It is important to be aggressive about follow-up and moving to other management options if relief is not adequate on a management program.
- Bowel routines may need to alter slightly during menstruation for females as often their bowel habits change during different phases of their menstruation cycle. Charting by the individual and family will aid in this determination.
- Conversations should focus on the adolescent rather than the caregiver as development allows. Bowel management programs should be discussed at routine follow-up visits to ensure they are still meeting the needs of the individual.
- Appropriate bowel management can help to reduce other medical complications (See [Background](#) for more information).
- Optimizing continence at this age will likely improve school attendance and self-esteem at a critical period for identity formation. It will also allow the individual, as they become an adult, the freedom to attend college, live independently, travel, or enter the workforce with the reduced worry of fecal incontinence.
- The ability for independence should be discussed and stressed with the teen. If independence is possible, consider which bowel management program is likely to result in independence. A balance of independence and continence is desirable. If there is difficulty achieving independence and continence, the teen should determine whether to prioritize independence or continence. Not all bowel programs can be managed entirely independently by everyone. Some teens may decide that a level of bowel dysfunction is preferable if the routine can be completed independently. Consider an occupational or physical therapy referral if accommodations for bowel independence are needed.
- More frequent follow-ups (phone, telehealth, email, in-person) may be needed as children enter pre-teen and teen years. This age group has a higher risk of nonadherence, and an established relationship with a trusted healthcare provider is essential.
- Body autonomy is important in teens with Spina Bifida. Body autonomy will allow the teen to take ownership of their body and functions. This may also increase the likelihood they will advocate for themselves if they feel they are in an uncomfortable situation that could lead to abuse. It is essential to empower caregivers and teens about their ability to say no if they feel a teen is in an uncomfortable position. Individuals with Spina Bifida may have altered sensation in the genitals. Awareness of the increased risk for sexual abuse and inappropriate touching should be clearly discussed. People with Spina Bifida are at an increased risk of maltreatment, including physical and sexual abuse. Clinicians should assess potential maltreatment and abuse and educate families. The education will help ensure individuals participating in intimate medical management, including bowel management, are trusted by the teen and family.

- **Considerations to Increase Future Self-Management**

- Discuss the bowel program using simple directions broken down into specific steps.
- Ask the individual to repeat the steps even if not performing. When the patient can articulate the steps of the bowel program, if assistance from an unfamiliar caregiver is needed, there will be less risk of errors during the bowel program.
- Have the individual write out the steps on notes placed in order or hung on the wall as a reference. When appropriate, place the steps on a phone/computer.
- Place bowel program supplies within reach of the individual to increase familiarity and move toward a program that they control.
- Develop a step-by-step reminder.
- Talk about/review the steps for the program.
- Teach bowel accident management in a stepwise manner.
- Reward for the performance of tasks that should be done.
- Teach how and where to order supplies.
- Communicate using technology, if possible.
- Explore the barriers they have that may reduce their ability to comply with the program and troubleshoot these with the individual.
- Discuss the advantages of doing the program clearly with the individual: prevent unnecessary bowel cleanouts; avoid hospitalizations for cleanouts or shunt malfunction; reduce UTIs; avoid the embarrassment of an incontinent episode.

Goals

- Establish or maintain a bowel management routine. A bowel routine should become second nature, just like daily tooth brushing.
- Prevent constipation.
- Maintain skin integrity.
- Optimize continence.
- Optimize independence.

Management

Step 1: Assessment

- **History**

- Have caregivers monitor stool frequency, consistency, and amounts. Caregivers should record the time of day of a bowel movement and any urge or awareness of the need to have a bowel movement. Recommend using a bowel diary ([Appendix VI – Bowel Diary](#)) for a minimum of three to five consecutive days to achieve a reliable assessment. Suppose a bowel program is being carried out, the timing between when a program is initiated and when the passage of stool occurs should be noted.
- Obtain an accurate history of prior bowel programs that have been attempted and facilitators and barriers to success. Determine the reasons for previously discontinued bowel programs. For example, a simpler plan should be designed if a program was stopped because it was too burdensome. If an enema program failed, determine the details regarding the types of enemas, the volume of fluid, additives, and frequency of use. This information will help providers to recommend a program most likely to succeed.
- Record medications the teen is taking, especially those with known side effects of constipation, such as anticholinergics. Anticholinergics (e.g., oxybutynin) are commonly used in individuals with Spina Bifida.
- It is important to evaluate different positive and negative signs in the medical history to determine if constipation is present in this age group. Using a time frame in which to expect a bowel movement can be difficult, so assessing for positive and negative signs may be more meaningful.

- Signs that the bowel is working well (positive signs): eating well, gaining weight as expected for puberty stage, mushy/creamy stool consistency or formed (Bristol Stool Chart Type 4⁽¹⁹⁾), no acute changes in voiding pattern.
 - Signs that the bowel may not be working well (negative signs): abdominal distension, irritability, poor intake/change in intake, change in stooling pattern, change in stool consistency, stools that are Type 1 or 2 on the Bristol Stool Chart,⁽¹⁹⁾ straining to have a bowel movement, bubbly liquid stool, sandy/grainy stool, vomiting, blood in the stool, increased UTIs.
- **Physical examination**
 - Assessment of the abdomen. Using percussion and auscultation of bowel sounds to evaluate for constipation, obstruction, or pseudo-obstruction when a tympanic and hypoactive abdomen is identified. Palpation is used to assess sensation, tenderness, discomfort, and masses.
 - Perineal inspection for anal fissures, external hemorrhoids, and dermatitis.
 - Assessment of the anal sphincter for sensation, patulous anus, prolapse. Evaluation of anal sphincter tone with the use of a gloved finger. If anal sphincter tone is flaccid during exam this patient may benefit from a cone enema rather than a balloon catheter enema.
 - Digital rectal examination for the presence of a large rectal vault or presence of a fecal mass in the rectum.
 - Evaluation of the anocutaneous reflex (anal wink). Touch the perianal skin with an object such as a cotton swab (Q-TIP®). Observe for the anal sphincter to contract or “wink.” Perform on both sides (right and left) of the buttocks/perianal skin. A positive contraction or “wink” may indicate intact motor and/or sensory innervation, reflexic bowel function, and is associated with urinary continence in children with Spina Bifida ([See Background](#)).

Knowledge from the history and physical will aid in determining which management should be initiated and the urgency that more invasive measures should be considered. For example, a child with poor rectal tone and reduced sphincter control along with dermatitis may require additional interventions to maintain skin integrity. Interventions include zinc- or petroleum-based barrier paste such as Calmoseptine®, Boudreaux Butt Paste®, iLEX®, and Critic-Aid® ([APPENDIX XII – Diaper Dermatitis](#)). Additional wound care expertise may be needed and should be initiated when appropriate.

Step 2: Interventions

- **Preparation**
 - Assessment of the family is important before changing or starting a bowel program. Readiness of the caregivers who will initially be assisting the teen with the bowel program and the teen themselves needs to be assessed. Most regimens will require daily activities that vary regarding the complexity and amount of time to perform the bowel program: the family and individual need to consider what they can realistically fit into their daily routine. If an ideal program is not practical, a reassessment of the ability to perform this program should be carried out every three to six months. Families may feel intimidated to initiate a program or be hesitant to change their home routines to accommodate a typical bowel program.
 - Some will need assistance with their bowel management program, especially in the earlier ages of this age group. Identifying who is willing and able to help is important. Ideally, this will be more than one individual in a family to reduce caregiver role strain and act as a backup for any unexpected life events. These individuals all need to be trained in the bowel program.
 - Adolescents should be encouraged to participate as fully as possible in their bowel program. Work with the family and teen to determine the bowel program tasks that the teen can complete. Remember, these may be simple tasks such as gathering supplies, opening items, or holding items, but the teen can likely do much more. Start with tasks that the teen can do easily and allow them to be actively involved in the process and not a passive participant in the program. The goal is for the teen to see their bowel program as something that is being done with and for them, rather than to them.

- Discuss with the family the importance of a bowel program and monitoring (see [Background](#) for more information).
- The frequency of an assessment of the effectiveness of any intervention should be carried out as recommended below.
- Educate caregivers that when changes are made to a bowel program, it can take multiple adjustments and several weeks to months for positive changes to occur and stabilize.

Preparation for future interventions should include the good foundational habits below. These preparations are unlikely to achieve optimal bowel management on their own.

- **Building Good Bowel Habits**

- Dietary – Encourage a healthy, balanced diet including fruits, vegetables, plenty of water, and limited constipating foods such as cheese and white rice. Fiber-rich foods may be beneficial to bulk up the stool and draw water from the colon to the stool, but inadequate fluid intake with increased fiber may make constipation worse. Fiber supplements may be especially more likely to increase constipation and should be used cautiously for those with neurogenic bowel. Recommendations for the amount of fiber and water a child should have can be referenced in [APPENDIX III – Recommended Dietary Fiber Intake](#) and [APPENDIX IV – Recommended Dietary Fluid Intake](#).
- Positioning – Several positions can help with defecation: placing the knees higher than hips; knees and hips bent in a typical squatting position. Feet should always be supported when sitting on the toilet, either by the floor or a footstool.
- Consider using a probiotic (Culturrelle®, Gerber® Soothe®) for general improved gut health and microbiome biodiversity. For the most up-to-date information on specific probiotics and constipation consider checking this website: usprobioticguide.com

- **Starting a Bowel Management Program**

In general, interventions should be considered in a stepwise manner, with the goal of finding the least invasive intervention that balances stool consistency and frequency, thus optimizing continence ([APPENDIX I – List of Interventions from Least to Most Invasive](#)). Programs should be implemented for a minimum of two weeks consistently before altering the program. This time frame should be discussed with the family and past practices considered for barriers and facilitators. Many families may prefer to initiate enemas sooner rather than later.

If an individual is new to a bowel program or has had unclear adherence to a prior program, a bowel cleanout should be carried out. Bowel cleanouts before any program change should also be carried out. Cleanouts prepare the bowel for bowel management by reducing current stool burden/constipation ([APPENDIX II – Bowel Cleanouts](#)).

- **Oral supplementation**

- Osmotic laxatives - used to improve consistency of hard stool
 - Polyethylene glycol 3350 powder (Miralax®): An osmotic laxative, not a stimulant, and can improve the consistency of hard stool (Type 1 or Type 2 on the Bristol Stool Chart⁽¹⁹⁾). Not recommended for children who weigh less than 10kg. ([APPENDIX V – Oral Medication Dosages](#)).
 - Lactulose (Kristalose®, Constulose®, Enulose®, and Generlac®): An osmotic laxative can improve the consistency of hard stool. This medication is not a stimulant. The onset of action is 24-48 hours (Type 1 or Type 2 on the Bristol Stool Chart⁽¹⁹⁾) ([APPENDIX V – Oral Medication Dosages](#)).
 - Linaclotide (Linzess®): An osmotic laxative capsule. Black Box warning for children under 2 years of age.
- Stimulant laxative - used to increase the frequency of a bowel movement

- Sennosides-Docusate Sodium Oral or sennosides tablets (Ex-Lax®, Senokot®): A stimulant laxative that can improve bowel movement frequency through intestinal contraction. The onset of action is six to 10 hours ([APPENDIX V – Oral Medication Dosages](#)).
 - Timed sitting and use of a stimulant laxative are not likely to work (timed sitting for a bowel movement is used by only 3% of those with SB, and less than half of those individuals have bowel continence doing this). If this approach is tried, it is appropriate to use it for less than two weeks if success is not achieved. A bowel cleanout likely would be needed before moving to the next program.
- Per rectum interventions. These interventions can be used for routine management or to alleviate acute concerns. The most rapid intervention will be rectal medications.
- **For routine management**
 - Liquid glycerin suppositories (Pedilax®): 2.8 g (4 mL) daily as needed. If the individual has weak external sphincter tone, caregivers may have to manually hold the buttocks cheeks together for better retention of the enema solution. ([APPENDIX XIX – Suppositories](#))
 - Enemeez®: Follow packaging directions for dosing
 - Enemeez® Plus: is a prepared mini-enema of 283 mg of docusate sodium AND 20 mg of benzocaine. The benzocaine anesthetizes the rectum and can be used in painful BMs, autonomic dysreflexia, or hemorrhoids. Enemeez® Plus is intended for those 12 years and older. Follow packaging directions for dosing.
 - Balloon or cone enemas: It is recommended to stop any of the oral laxative medications when starting a balloon/cone enema program (the addition of oral medications has been associated with decreased continence rates for enemas).⁽²⁶⁾
 - Transanal irrigation: It is recommended to stop any of the oral laxative medications when starting a balloon/cone enema program (the addition of oral medications has been associated with decreased continence rates for enemas).⁽²⁶⁾
 - MACE/Cecostomy: Surgical intervention may be needed. ([APPENDIX VII – Enema Basics](#))
 - Colostomy: Surgical intervention may be needed. ([APPENDIX XVII – Considerations for a Colostomy](#))

For acute constipation relief, see [APPENDIX II – Bowel Cleanouts](#).

Step 3: Suggested Monitoring and Follow Up

- The frequency of assessment for the effectiveness of any intervention should be carried out as recommended below:
 - When a new management intervention is initiated or adjusted, written instructions for dosing, schedule, and titration (if appropriate) should be given and explained to the caregivers.
 - Recommend having the individual complete the Kelly Pediatric Neurogenic Bowel Dysfunction Score(33) at each visit to objectively measure the patient’s neurogenic bowel symptoms to track progress and changes in symptoms. A score of 9 or higher is considered positive for neurogenic bowel dysfunction. This score is validated to be used from ages 6-18 years.
 - Adolescents or caregivers should complete a bowel diary ([Appendix VI – Bowel Diary](#)) for three consecutive days after starting a new intervention and again for three consecutive days before the next scheduled follow-up conversation. This diary should be shared with the provider to aid decision-making.
 - Frequent contact with the adolescent or caregiver is imperative to success and should occur ideally every other week during the first month after a new or adjusted management plan. Communication can be completed in person, via phone call, telehealth, or email.
 - After a change is made to a management plan, the individual should carry it out for two weeks without additional modifications. This allows time for the body to adjust. If goals are not achieved after two weeks, but significant improvement is being made, a program should remain unchanged for two to three more weeks to see if further improvement occurs. If goals are not achieved after two weeks,

- and there is little to no improvement, the bowel program should be changed.
- For balloon enema, cone enema, transanal irrigation, and surgical management, it can take two to three months until a regimen is stable and working. Careful, small changes in enema volume or frequency of the enema administration are generally needed rather than skipping to the next most invasive treatment at the first or second 2-week interval. Clinical judgment should be used in these cases. Suggestions on small changes that can be made are included in [APPENDIX VII – Enema Basics](#). Careful consideration of both the frequency and the consistency of the stool should be used to guide adjustments (i.e., the child has a good frequency of bowel movements twice a day, but bowel consistency is Type 1 or 2 on the Bristol Stool Chart⁽¹⁹⁾ or pellet-like, indicating a need to improve consistency of the stool).



SPINA BIFIDA
ASSOCIATION

**Lifespan Bowel Management Protocol
Chapter 11: Bowel Management (>18 years)**

Lifespan Bowel Management Protocol

Chapter 11: Bowel Management (>18 years)

Key Points

- More than 80% of individuals with Spina Bifida require a program to manage their bowels.(2) Adoption of a bowel management program and frequent reassessment of the program will likely allow most individuals with Spina Bifida to achieve bowel continence if desired.
- Sharing expectations of a bowel routine between adults, caregivers and clinicians is important. Identification of the adult's goals is vital. Their bowel health goals should be the driver of interventions. This increases their perception of things occurring for them rather than to them, which likely will improve compliance and communication. Clinicians should share the expectations with the adult and their caregivers, including time commitments, frequency of communication, and the importance of routine. These are necessary to establish a successful bowel management routine.
- Even with a successful bowel program, there may still be occasional accidents. Bowel programs may need to be changed or altered over time, even in adulthood.
- Bowel routines may need to alter slightly during menstruation for females as often their bowel habits change during different phases of their menstruation cycle. Charting by the individual and family will aid in this determination.
- Conversations should focus on the adult rather than the caregiver as development allows. Bowel management programs should be discussed at routine follow-up visits to ensure they are still meeting the needs of the individual.
- It is important to be aggressive about follow-up and moving to other management options if relief is not adequate on a management program.
- Appropriate bowel management can help to reduce other medical complications (See [Background](#) for more information).
- Optimizing continence will allow the individual the freedom to attend college, live independently, travel, or enter the workforce with the reduced worry of fecal incontinence.
- Not all adults are using a well-established bowel program. Clinicians should inquire about the bowel program and continence routinely. If a bowel management program is not established/or sufficient to meet the adult's goals, it should change. The ability for independence should be discussed with the adult. If independence is possible, consider which bowel management program is likely to result in independence. A balance of independence and continence is desirable. If there is difficulty achieving independence and continence, the adult should determine whether to prioritize independence or continence. Not all bowel programs can be managed entirely independently by everyone. Some may decide that a level of bowel dysfunction is preferable if the routine can be completed independently. Consider an occupational or physical therapy referral in conjunction with a bowel program if accommodations for independence are needed.
- More frequent follow-ups (phone, telehealth, email, in-person) may be needed during transition or difficult times in the adult's life. There is a risk of nonadherence, which may be minimized with an established relationship with a trusted healthcare provider.
- Bowel incontinence and the burden of some programs interfere with sexuality and sexual function.
- Body autonomy is important for all adults, especially those with Spina Bifida. This will allow them to take ownership of their body and functions. This may also increase the likelihood they will advocate for themselves if they feel they are in an uncomfortable situation that could lead to abuse. It is essential to empower adults about their ability to say no if they think they are in an uncomfortable position. Individuals with Spina Bifida may have altered sensation in the genitals. Awareness of the increased risk for sexual abuse and inappropriate touching should be clearly discussed. Adults with Spina Bifida are at a higher risk of maltreatment, including physical and sexual abuse. Clinicians should assess potential maltreatment and abuse and educate adults. The education will help ensure that individuals participating in intimate medical management, including bowel management, are trusted by the adult.

• Considerations to Increase Self-Management

- Talk about the bowel program using simple directions broken down into specific steps.
- Ask the individual to repeat the steps even if not performing. When the patient can articulate the steps of the bowel program, if assistance from an unfamiliar caregiver is needed, there will be less risk of errors during the bowel program.
- Have the individual write out the steps on notes that can be placed in order or hung on the wall as a reference. When appropriate, place the steps on a phone/computer.
- Review organization of supplies.
- Develop a step-by-step reminder.
- Talk about/review the steps for the program.
- Teach bowel accident management in a stepwise manner.
- Reward for the performance of tasks that should be done.
- Teach how and where to order supplies.
- Communicate using technology if possible.
- Explore the barriers they have that may reduce their ability to comply with the program and troubleshoot these with the individual. Discuss how employment may impact routine.
- Discuss the advantages of doing the program clearly with the individual: prevent unnecessary bowel cleanouts; avoid hospitalizations for cleanouts or shunt malfunction; reduce UTIs; avoid the embarrassment of an incontinent episode.

Goals

- Establish or maintain a bowel management routine. A bowel routine should become second nature, just like daily tooth brushing.
- Prevent constipation
- Maintain skin integrity
- Optimize continence
- Optimize independence
- Minimize the impact of neurogenic bowel on sexuality
- Identify adult clinicians who can offer bowel management advice when transitioning to adult specialty clinicians

Management

Step 1: Assessment

• History

- Determine current stool frequency, consistency, and amounts. The adult or the caregivers should use a bowel diary to record the time of day when a bowel movement (BM) occurs and the presence of BM urge or awareness. The bowel diary ([Appendix VI – Bowel Diary](#)) should be used for a minimum of three to five consecutive days to achieve a reliable assessment. If a bowel program is in use, the time between program initiation (i.e., suppository, enema) and when defecation occurs should be noted.
- Obtain an accurate history of prior bowel programs that have been attempted and facilitators and barriers to success.
- Determine the reasons for previously discontinued bowel programs. For example, a simpler plan should be designed if a program was stopped because it was too burdensome. If an enema program failed, determine the details regarding the types of enemas, the volume of fluid, additives, and frequency of use. This information will help providers to recommend a program most likely to succeed.
- Record medications the adult is taking, especially those with known side effects of constipation, such as anticholinergics, commonly used in individuals with Spina Bifida.

- It is important to evaluate different positive and negative signs in the medical history to determine if constipation is present in this age group. Using a time frame in which to expect a bowel movement can be difficult, so assessing for positive and negative signs may be more meaningful.
 - Signs that the bowel is working well (positive signs): eating well, formed stool (Type 4 on the Bristol Stool Chart⁽¹⁹⁾), no acute changes to voiding pattern.
 - Signs that the bowel may not be working well (negative signs): abdominal distension, irritability, poor intake/change in intake, change in stooling pattern, change in stool consistency, stools that are Type 1 or 2 on the Bristol Stool Chart,⁽¹⁹⁾ straining to have a bowel movement, bubbly liquid stool, sandy/grainy stool, vomiting, blood in the stool, and increased UTIs.
- **Physical examination**
 - Assessment of the abdomen. Using percussion and auscultation of bowel sounds to evaluate for constipation, obstruction, or pseudo-obstruction when a tympanic and hypoactive abdomen is identified. Palpation is used to assess sensation, tenderness, discomfort, and masses.
 - Perineal inspection for anal fissures, external hemorrhoids, and dermatitis.
 - Assessment of the anal sphincter for sensation, patulous anus, prolapse. Evaluation of anal sphincter tone with the use of a gloved finger. If anal sphincter tone is flaccid during exam this patient may benefit from a cone enema rather than a balloon catheter enema.
 - Digital rectal examination for the presence of a large rectal vault or presence of a fecal mass in the rectum.
 - Evaluation of the anocutaneous reflex (anal wink). Touch the perianal skin with a cotton swab such as a Q-TIP®.
 - Observe for the anal sphincter to contract or “wink.” Perform on both sides (right and left) of the buttocks/perianal skin. A positive contraction or “wink” may indicate intact motor and/or sensory innervation, reflexic bowel function, and is associated with urinary continence in children with Spina Bifida. ([See Background](#))

Knowledge from the history and physical will aid in determining which management should be initiated and the urgency that more invasive measures should be considered. For example, an adult with poor rectal tone and reduced sphincter control along with dermatitis may require additional interventions to maintain skin integrity. Interventions include zinc- or petroleum-based barrier pastes such as Calmoseptine®, Boudreaux Butt Paste®, iLEX®, and Critic-Aid® (see [APPENDIX XII – Diaper Dermatitis](#)). Additional wound care expertise may be needed and should be initiated when appropriate.

Step 2: Interventions

- **Preparation**
 - If a partner or caregiver is involved in bowel management, these individuals need to be trained in the bowel program.
 - The frequency of an assessment of the effectiveness of any intervention should be carried out as recommended below.
 - Educate caregivers that when changes are made to a bowel program, it can take multiple adjustments and several weeks to months for positive changes to occur and stabilize.

- **Building Good Bowel Habits**

These preparations are unlikely to achieve optimal bowel management on their own.

- Dietary – Encourage a healthy, balanced diet including fruits, vegetables, plenty of water, and limit constipating foods such as cheese and white rice. Fiber-rich foods may be beneficial to bulk up the stool and draw water from the colon to the stool, but inadequate fluid intake with increased fiber may make constipation worse. Fiber supplements may be especially more likely to increase constipation and should be used cautiously for those with neurogenic bowel. Recommendations for the amount of fiber

and water an adult should have can be referenced in [APPENDIX III – Recommended Dietary Fiber Intake](#) and [APPENDIX IV – Recommended Dietary Fluid Intake](#).

- Positioning – Several positions can help physically pass a bowel movement: placing the knees higher than hips; knees and hips bent in a typical squatting position. Feet should always be supported when sitting on the toilet, either by the floor or a stool.
- Consider using a probiotic (Culturelle®) for general improved gut health and microbiome biodiversity. Probiotics can result in increased bowel frequency and improved bowel consistency in adults. (36) For the most up-to-date information on specific probiotics and constipation consider checking this website: usprobioticguide.com

• Starting a Bowel Management Program

In general, interventions should be considered in a stepwise manner, with the goal of finding the least invasive intervention that balances stool consistency and frequency, thus optimizing continence ([APPENDIX I – List of Interventions from Least to Most Invasive](#)). Programs should be implemented for a minimum of two weeks consistently before altering the program. This time frame should be discussed with the family and past practices considered for barriers and facilitators.

If an individual is new to a bowel program or has had unclear adherence to a prior program, a bowel cleanout should be carried out. Bowel cleanouts before any program change should also be carried out. Cleanouts prepare the bowel for bowel management by reducing current stool burden/constipation (see [APPENDIX II – Bowel Cleanouts](#)).

• Oral supplementation

- Osmotic laxatives - used to improve consistency of hard stool
 - Polyethylene glycol 3350 powder (Miralax[®]): An osmotic laxative can improve hard stool consistency. The onset of action is 24-96 hours. This medication is not a stimulant. (Type 1 or Type 2 on the Bristol Stool Chart,⁽¹⁹⁾ see [APPENDIX V – Oral Medication Dosages](#)).
 - Linaclotide (Linzess[®]): An osmotic laxative capsule. Black Box warning for children under 2 years of age.
 - Lactulose (Kristalose[®], Constulose[®], Enulose[®], and Generlac[®]): An osmotic laxative can improve the consistency of hard stool (Type 1 or Type 2 on the Bristol Stool Chart,⁽¹⁹⁾ see [APPENDIX V – Oral Medication Dosages](#)). Success rates for Lactulose in adults may be lower than in children.
- Stimulant laxative - used to increase the frequency of a bowel movement
 - Sennosides-Docusate Sodium Oral or sennosides tablets (Ex-Lax[®], Senokot[®]): A stimulant laxative that can improve bowel movement frequency through intestinal contraction. The onset of action is six to 10 hours (see [APPENDIX V – Oral Medication Dosages](#)).
 - Timed sitting and use of a stimulant laxative are not likely to work (timed sitting for a bowel movement is used by only 3% of those with SB, and less than half of those individuals have bowel continence doing this). If this approach is tried, it is appropriate to use it for less than two weeks if success is not achieved. A bowel cleanout likely would be needed before moving to the next program.

Per rectum interventions. These interventions can be used for routine management or to alleviate acute concerns. The most rapid intervention will be rectal medications.

• For routine management

- Enemeez[®]: Follow packing directions for dosing.
- Enemeez[®] Plus: is a prepared mini-enema of 283 mg of docusate sodium AND 20 mg of benzocaine. The benzocaine anesthetizes the rectum and can be used in painful BMs, autonomic dysreflexia, or hemorrhoids. Enemeez[®] Plus is intended for those 12 years and older. Follow packing directions for dosing.

- Balloon or cone enemas: It is recommended to stop any of the above oral medications when starting a balloon/cone enema program because the addition of oral medications has been associated with decreased continence rates for enemas.⁽²⁶⁾
- Transanal irrigation: It is recommended to stop any of the above oral medications when starting a balloon/cone enema program (the addition of oral medications has been associated with decreased continence rates for enemas).⁽²⁶⁾
- MACE/Cecostomy: Surgical intervention may be needed ([APPENDIX VII – Enema Basics](#)).
- Colostomy: Surgical intervention may be needed ([APPENDIX XVII – Considerations for a Colostomy](#)).

For acute constipation relief, see [APPENDIX II – Bowel Cleanouts](#).

Step 3: Suggested monitoring and follow up

The frequency of assessment for the effectiveness of any intervention should be carried out as recommended below.

- When a new management intervention is initiated or adjusted, written instructions for dosing, schedule, and titration (if appropriate) should be given and explained to the caregivers.
- The Neurogenic Bowel Dysfunction Score⁽³⁷⁾ that has been validated for adults with neurogenic bowel should be used at each visit for a patient perspective of their symptoms and the effect on their quality of life. This can be used to track progress for an individual patient. The score should be interpreted as severe NBD 14; moderate NBD 10–13; minor NBD 7–9; very minor NBD 0–6.
- Adults or caregivers should complete a bowel diary ([Appendix VI – Bowel Diary](#)) for three consecutive days after starting a new intervention and again for three consecutive days before the next scheduled follow-up conversation. This diary should be shared with the provider to aid decision-making.
- Frequent contact with the adult or caregiver is imperative to success and should occur ideally every other week during the first month after a new or adjusted management plan; this can be done in person, phone call, telehealth, or email.
- After a change is made to a management plan, the individual should carry it out for two weeks without additional modifications. This allows time for the body to adjust. If goals are not achieved after two weeks, but significant improvement is being made, a program should remain unchanged for two to three more weeks to see if further improvement occurs. If goals are not achieved after two weeks, and there is little to no improvement, the bowel program should be changed.
- For balloon enema, cone enema, transanal irrigation, and surgical management, it can take two to three months until a regimen is stable and working. Careful small changes in enema volume or frequency of enema administration are generally needed rather than skipping to the next most invasive treatment at the first or second two-week interval. Clinical judgment should be used in these cases. Suggestions on small changes that can be made are included in [APPENDIX VII – Enema Basics](#). Careful consideration of both the frequency and the consistency of the stool should be used to guide adjustments (i.e., good frequency of bowel movements twice a day but bowel consistency is Type 1 or 2 on the Bristol Stool Chart⁽¹⁹⁾ or pellet-like, indicating a need to improve consistency of the stool).

Concerns for the Impact of Neurogenic Bowel on Sexuality

Qualitative research has shown that those with Spina Bifida often are under-educated regarding sexuality and the effect of bowel control on this. Clinicians should discuss sexuality with their patients to ensure accuracy of knowledge regarding fertility, genetic links to Spina Bifida, and sexual transmitted disease/ sexually transmitted illness risks. In addition, clinicians can guide patients in best practices for their sexuality and their bowel program to minimize the impact of bowel incontinence on this aspect of their life.

Recent research has identified that people with Spina Bifida report being perceived as asexual, lack resources for sex education, the need for Spina Bifida-specific sex education. Bowel and bladder incontinence are common during sexual activity, even in otherwise continent people, and have been shown to impact sexual satisfaction. Bowel incontinence is less common and less predictable but tends to be more bothersome, with some people avoiding sex altogether due to the fear of incontinence. Some people with Spina Bifida engage in anal sex due to increased sensitivity in the area, which promotes incontinence. The possibility of this should be considered when counseling patients. Tips for preventing bowel incontinence or diminishing its impact on satisfaction include evacuating the bowels immediately before intercourse or earlier in the day, being careful with one's diet on a day when sexual activity is expected and using bed protectors or chucks pads and having wipes handy in case of an accident. Patients should be encouraged to talk to their partner about the possibility of incontinence before having intercourse. This could decrease their embarrassment and the partner's surprise. Additionally, they may learn that it does not bother their partner, reducing their distress should incontinence occur. ([APPENDIX XVIII – Pregnancy Considerations](#))

Resources

- Gamé X, Moscovici J, Gamé L, Sarramon JP, Rischmann P, Malavaud B. Evaluation of sexual function in young men with Spina Bifida and myelomeningocele using the International Index of Erectile Function. *Urology*. 2006 Mar;67(3):566-570. doi: 10.1016/j.urology.2005.09.014. Epub 2006 Feb 28. PMID: 16504267.
- von Linstow ME, Biering-Sørensen I, Liebach A, Lind M, Seitzberg A, Hansen RB, Biering-Sørensen F. Spina Bifida and sexuality. *J Rehabil Med*. 2014 Oct;46(9):891-897. doi: 10.2340/16501977-1863. PMID: 25148270.
- Streur CS, Schafer CL, Garcia VP, Quint EH, Sandberg DE, Wittmann DA. "If everyone else is having this talk with their doctor, why am I not having this talk with mine?": The experiences of sexuality and sexual health education of young women with Spina Bifida. *J Sex Med*. 2019 Jun;16(6):853-859. doi: 10.1016/j.jsxm.2019.03.012. Epub 2019 Apr 19. PMID: 31010781; PMCID: PMC6582639.
- Johnsen V, Skattebu E, Aamot-Andersen A, Thyberg M. Problematic aspects of fecal incontinence according to the experience of adults with Spina Bifida. *J Rehabil Med*. 2009 Jun;41(7):506-511. doi: 10.2340/16501977-0373. PMID: 19543660.
- Streur CS, Schafer CL, Garcia VP, Quint EH, Wiener JS, Sandberg DE, Kalpakjian CZ, Wittmann DA. "I tell them what I can feel and how far my legs can bend": Optimizing sexual satisfaction for someone with Spina Bifida. *J Sex Med*. 2020 Sep;17(9):1694-1704. doi: 10.1016/j.jsxm.2020.05.026. Epub 2020 Jul 12. PMID: 32665213; PMCID: PMC7493719.
- Streur CS, Corona L, Smith JE, Lin M, Wiener JS, Wittmann DA. Sexual function of men and women with Spina Bifida: A scoping literature review. *Sex Med Rev*. 2021 Apr;9(2):244-266. doi: 10.1016/j.sxmr.2020.09.001. Epub 2021 Feb 17. PMID: 33608247; PMCID: PMC8049880.

References

1. Clayton DB, Tanaka ST, Trusler L, Thomas JC, Pope JC, Adams MC, et al. Long-term urological impact of fetal myelomeningocele closure. *J Urol*. 2011 Oct;186(4 Suppl):1581–1585.
2. Le JT, Mukherjee S. Transition to adult care for patients with Spina Bifida. *Phys Med Rehabil Clin N Am*. 2015 Feb;26(1):29–38.
3. Powers CJ, George T, Fuchs HE. Constipation as a reversible cause of ventriculoperitoneal shunt failure. Report of two cases. *J Neurosurg*. 2006 Sep;105(3 Suppl):227–230.
4. Martinez-Lage JF, Martos-Tello JM, Ros-de-San Pedro J, Almagro MJ. Severe constipation: an under-appreciated cause of VP shunt malfunction: a case-based update. *Childs Nerv Syst*. 2008 Apr;24(4):431–435.
5. Wide P, Mattsson GG, Drott P, Mattsson S. Independence does not come with the method--treatment of neurogenic bowel dysfunction in children with myelomeningocele. *Acta Paediatr*. 2014 Nov;103(11):1159–1164.
6. Ojetti V, Bruno G, Paolucci V, Triarico S, D'Aversa F, Ausili E, et al. The prevalence of small intestinal bacterial overgrowth and methane production in patients with myelomeningocele and constipation. *Spinal Cord*. 2014 Jan;52(1):61–64.
7. McClurg D, Norton C. What is the best way to manage neurogenic bowel dysfunction? *Bmj*. 2016 Jul 27;354: i3931.
8. Johnsen V, Skattebu E, Aamot-Andersen A, Thyberg M. Problematic aspects of fecal incontinence according to the experience of adults with Spina Bifida. *J Rehabil Med*. 2009 Jun;41(7):506–511.
9. Choi EK, Im YJ, Han SW. Bowel management and quality of life in children with Spina Bifida in South Korea. *Gastroenterol Nurs*. 2017 Jun;40(3):208–215.
10. Jinbo AK. The challenge of obtaining continence in a child with a neurogenic bowel disorder. *J Wound Ostomy Cont Nurs*. 2004 Dec;31(6):336–350.
11. Wiener JS, Suson KD, Castillo J, Routh JC, Tanaka S, Liu T, et al. Bowel management and continence in adults with Spina Bifida: results from the national Spina Bifida patient registry 2009-15. *J Pediatr Rehabil Med*. 2017 Dec 11;10(3–4):335–343.
12. Palit S, Lunniss PJ, Scott SM. The physiology of human defecation. *Dig Dis Sci*. 2012 Jun;57(6):1445–1464.
13. Krogh K, Christensen P, Laurberg S. Colorectal symptoms in patients with neurological diseases. *Acta Neurol Scand*. 2001 Jun;103(6):335–343.
14. Brookes SJ, Dinning PG, Gladman MA. Neuroanatomy and physiology of colorectal function and defaecation: from basic science to human clinical studies. *Neurogastroenterol Motil Off J Eur Gastrointest Motil Soc*. 2009 Dec;21 Suppl 2:9–19.
15. Krogh K, Nielsen J, Djurhuus JC, Mosdal C, Sabroe S, Laurberg S. Colorectal function in patients with spinal cord lesions. *Dis Colon Rectum*. 1997 Oct;40(10):1233–1239.
16. Leduc BE, Giasson M, Favreau-Ethier M, Lepage Y. Colonic transit time after spinal cord injury. *J Spinal Cord Med*. 1997 Oct;20(4):416–421.
17. Choi EK, Shin SH, Im YJ, Kim MJ, Han SW. The effects of transanal irrigation as a stepwise bowel management program on the quality of life of children with spina bifida and their caregivers. *Spinal Cord*. 2013 May;51(5):384–388.
18. Kilpatrick JA, Zobell S, Leeflang EJ, Cao D, Mammen L, Rollins MD. Intermediate and long-term outcomes of a bowel management program for children with severe constipation or fecal incontinence. *J Pediatr Surg*. 2020 Mar;55(3):545–548.
19. Lewis SJ, Heaton KW. Stool form scale as a useful guide to intestinal transit time. *Scand J Gastroenterol*. 1997 Sep;32(9):920–924.
20. Sanders C, Driver CP, Rickwood AMK. The anocutaneous reflex and urinary continence in children with myelomeningocele. *BJU Int*. 2002 May;89(7):720–721.
21. Weaver LT, Ewing G, Taylor LC. The bowel habit of milk-fed infants. *J Pediatr Gastroenterol Nutr*. 1988 Aug;7(4):568–571.
22. Gélinas P. Preventing constipation: a review of the laxative potential of food ingredients. *Int J Food Sci Technol*. 2013;48(3):445–467.

23. Coccorullo P, Strisciuglio C, Martinelli M, Miele E, Greco L, Staiano A. Lactobacillus reuteri (DSM 17938) in infants with functional chronic constipation: a double-blind, randomized, placebo-controlled study. *J Pediatr*. 2010 Oct;157(4):598–602.
24. Dicianno BE et al., Scientific methodology of the development of the guidelines for the care of people with Spina Bifida: an initiative of the Spina Bifida Association, *Disability and Health Journal*. <https://doi.org/10.1016/j.dhjo.2019.06.005>.
25. Sawin KJ, Thompson NM. The experience of finding an effective bowel management program for children with Spina Bifida: the parent's perspective. *J Pediatr Nurs*. 2009 Aug;24(4):280–291.
26. Kelly MS, Wiener JS, Liu T, Patel P, Castillo H, Castillo J, et al. Neurogenic bowel treatments and continence outcomes in children and adults with myelomeningocele. *J Pediatr Rehabil Med*. 2020;13(4):685–693.
27. Benninga MA, Buller HA, Staalman CR, Gubler FM, Bossuyt PM, van der Plas RN, et al. Defecation disorders in children, colonic transit time versus the Barr-score. *Eur J Pediatr*. 1995 Apr;154(4):277–284.
28. Kokke FT, Sittig JS, de Bruijn A, Wiersma T, Van Rijn RR, Limpen JL, et al. Starreveld scoring method in diagnosing childhood constipation. *Pediatr Radiol*. 2010 Nov;40(11):1789–1793.
29. Jackson CR, Lee RE, Wylie AB, Adams C, Jaffray B. Diagnostic accuracy of the Barr and Blethyn radiological scoring systems for childhood constipation assessed using colonic transit time as the gold standard. *Pediatr Radiol*. 2009 Jul;39(7):664–667.
30. Rofail D, Maguire L, Heelis R, Colligs A, Lindemann M, Abetz L. The impact of Spina Bifida on caregivers. *Neurol Ther*. 2012 Dec;1(1):4.
31. Rofail D, Maguire L, Kissner M, Colligs A, Abetz-Webb L. A review of the social, psychological, and economic burdens experienced by people with Spina Bifida and their caregivers. *Neurol Ther*. 2013 Dec;2(1–2):1–12.
32. Huang R, Hu J. Positive effect of probiotics on constipation in children: a systematic review and meta-analysis of six randomized controlled trials. *Front Cell Infect Microbiol*. 2017;7:153.
33. Kelly MS, Hannan M, Cassidy B, Hidas G, Selby B, Khoury AE, et al. Development, reliability and validation of a neurogenic bowel dysfunction score in pediatric patients with Spina Bifida. *NeuroUrol Urodyn*. 2016 Feb;35(2):212–217.
34. Yun HJ, Kim HS. Self-management behaviors of children With Spina Bifida. *J Neurosci Nurs J Am Assoc Neurosci Nurses*. 2017 Feb;49(1):15–21.
35. Psihogios AM, Kolbuck V, Holmbeck GN. Condition self-management in pediatric Spina Bifida: a longitudinal investigation of medical adherence, responsibility-sharing, and independence skills. *J Pediatr Psychol*. 2015 Sep;40(8):790–803.
36. Dimidi E, Christodoulides S, Fragkos KC, Scott SM, Whelan K. The effect of probiotics on functional constipation in adults: a systematic review and meta-analysis of randomized controlled trials. *Am J Clin Nutr*. 2014 Oct;100(4):1075–1084.
37. Krogh K, Christensen P, Sabroe S, Laurberg S. Neurogenic bowel dysfunction score. *Spinal Cord*. 2006 Oct;44(10):625–631.

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APPENDIX I – List of Interventions from Least to Most Invasive

As noted in the protocol, management should begin with the least invasive intervention appropriate and proceed to more invasive as needed.

Oral medications*
Digital rectal stimulation**
Suppositories**
Enemas**
Cone/balloon large volume enema
Transanal irrigation system (Peristeen®, Navina®)
Antegrade enemas (MACE, Cecostomy, other)
Pouched fecal diversion (colostomy/ileostomy)

*Studies have identified that oral agents alone generally don't improve continence but may assist with relieving constipation and improve stool consistency.¹

**These treatments are generally more effective in individuals with reflexic bowels since they take advantage of the anorectal reflex. Most individuals with spina bifida have areflexic NBD and will not find success with these treatments. See [Background](#) for more information on reflexic versus areflexic NBD.



Lifespan Bowel Management Protocol

APPENDIX II – Bowel Cleanouts

A bowel cleanout is often necessary before starting a new bowel program or when constipation or stool impaction is present. Starting a new bowel program such as an enema with a clean colon can improve the success and comfort of the bowel program. A cleanout can also “reset” a routine bowel management program when constipation occurs as a result of reduced effectiveness of the program or novel situations such as surgery, inactivity, dehydration, or irregular food choices. Cleanouts may also be advised before bowel surgeries (such as the MACE or cecostomy) or other surgeries such as a spinal cord detethering or spinal fusion, when there is a high risk of constipation due to anesthesia, pain medications, inactivity, and inability to maintain the bowel program while on bedrest.

Full Cleanouts

A full cleanout is usually warranted before starting a new bowel management program or when a patient is moderately or severely constipated. This process is similar to at-home preparations for a colonoscopy. See the chart below for recommendations on the time frame and amounts of oral medications to be used.

Advise the patient and caregivers that a cleanout may be messy and cause stool accidents. A less aggressive cleanout may not be as effective and may contribute to diaper dermatitis and skin breakdown. Increasing fluids will make the cleanout more effective and reduce the risk of dehydration. By the end of a cleanout, the stool should be light brown liquid like the color and consistency of tea.

Full bowel cleanout recommendations with polyethylene glycol 3350 powder (PEG)

Age	Recommendation
1-1 year 11 months	17g PEG three times a day for two days Two Ex-Lax® squares once daily for the same two days
2-3 years 11 months	17g PEG four times a day for two days Two Ex-Lax® squares once daily for the same two days
4-5 years 11 months	34g PEG three times a day for two days. Two Ex-Lax® squares once daily for the same two days
6-9 years 11 months	Mix 120 g (seven capfuls) of PEG in 32 ounces of fluid. Drink entire mixture over four hours. Take two Ex-Lax® squares or pills two hours after starting the PEG.
10-12 years 11 months	Mix 238g (14 capfuls) grams of PEG in 64 ounces of fluid. Drink 48 ounces over four hours. Take two Ex-Lax® squares or pills two hours after starting the PEG.
13 and older	Mix 238g (14 capfuls) grams of PEG in 64 ounces of Gatorade®. Drink entire mixture over four hours. Take two Ex-Lax® pills two hours after starting the PEG.

*The fluid used to mix the PEG can be any fluid the individual enjoys. Often, Gatorade® or similar beverages are preferred by patients. Please do not use a red drink to mix the Miralax® powder; this could make it difficult to note blood in the stool.

**The fluid volumes for the PEG to be mixed with may be difficult for some individuals to consume within the designated time frame. If this is a concern, please reduce the total ounces of fluid that the PEG is mixed in but keep the grams of PEG the same. Educate caregivers and individuals of the importance of trying to reach these fluid intake volumes shortly after they have the PEG to optimize its effect.

Full bowel cleanout recommendations with magnesium citrate*

Magnesium Citrate Prep Instructions:

The night before, take Dulcolax® or Senna as prescribed. In the morning, give magnesium citrate per below

Magnesium citrate dosing:

Children:

<6 years: 2-4 mL/kg given as a single daily dose or in divided doses

6-12 years: 100-150 mL

Children \geq 12 years and Adults: 150-300 mL

Weight 20-22 kg: 5 mg Dulcolax® OR 10 ml senna, magnesium citrate 2-4 ml/kg

Weight 23-30 kg: 10 mg Dulcolax® OR 15 ml senna, magnesium citrate 2-4 ml/kg

Weight 31-50 kg: 15 mg Dulcolax® OR 30 ml senna, magnesium citrate 2-4 ml/kg with maximum of 300 mls

Pour magnesium citrate over ice and drink within 30 minutes; once finished, please continue to give plenty of clear liquids throughout the rest of the day. The goal is to see clear liquid stools several times before resuming a regular diet.

Clear Liquid Diet

- Water
- Jell-O
- Juice
- Drinks without pulp
- Soda (clear soda only)
- Sports drinks (avoid red)
- Water ice
- Popsicles
- Broth
- Pedialyte®

Please limit the number of red fluids to no more than 1-2 servings. More than this can make it difficult to note if there is any blood in the stool.

*Disease-related concerns: in patients with kidney dysfunction, sodium- or magnesium-restricted diets, abdominal pain/nausea/vomiting or rectal bleeding develops, discontinue use and consult a health care provider. Use caution in patients with renal impairment; accumulation of magnesium may lead to magnesium intoxication.

Partial Cleanout

When someone already has a regular bowel management program but experiences mild to moderate constipation, they may be able to “reset” the bowel program without the burden of a full cleanout by performing their current program twice in one day for one to two days. If daily enemas are performed, recommend three enemas that are 12 hours apart (morning, night, morning), or two per day for two days. Extra ingredients may be added to the usual enema solution to assist with the cleanout, such as one to three doses of polyethylene glycol in the morning enema solution to soften stool and a phosphate saline enema in the nighttime solution to further stimulate the bowel. CAUTION: No more than one phosphate enema should be carried out in 24 hours.

Inpatient Cleanout

Cleanouts can usually be done safely and more pleasantly for patients at their home. Some surgeons may prefer an inpatient bowel cleanout before bowel procedures or other providers in cases of severe or life-threatening constipation. This usually requires GoLytely® (PEG) via nasogastric tube for 12-24 hours or until the stool is the color and consistency of tea or X-ray confirms a clean bowel. Patients and caregivers should be advised to seek emergency treatment for constipation when severely dehydrated, lethargic, vomiting excessively (or vomiting stool), or showing symptoms of shunt malfunction.

Lifespan Bowel Management Protocol

APPENDIX III – Recommended Dietary Fiber Intake

Encourage a healthy, balanced diet including fruits, vegetables, plenty of water, and limited constipating foods such as cheese and white rice. Fiber-rich foods have many health benefits. With stool, fiber may bulk up the stool and bring water into the stool to improve the consistency. Inadequate fluid intake combined with increased fiber can make constipation worse so it is very important to have adequate fluid intake. Fiber supplements are more likely to increase constipation than fiber rich foods so these should be used with caution.

The Academy of Nutrition and Dietetics Evidence Analysis Library suggests for adults with neurogenic bowel an initial fiber intake of 15 grams per day, with increases up to about 30 gm fiber per day as tolerated and as appropriate for each person.

The National Academy of Sciences Institute of Medicine fiber recommendations for adults are 25-30 gm/day for women ages 19-50 and men over 50, and 38 gm/day for men ages 19-50. If an individual is not currently meeting the recommended fiber amount and the decision is made to increase this it should be done slowly. To increase this slowly we recommend adding ~5g of fiber every 2-3 days until the total amount is met. It may take several weeks to reach the final fiber goal, and that is ok. Increasing fiber amounts too quickly can increase constipation or cause painful gas, cramping and diarrhea.

Patient Age	Recommended Dosage (g/day)	
0-12 months	Not recommended	
1-3 years	19 grams	
4-8 years	25 grams	
	Males	Females
9-13 years	31 grams	26 grams
14 years and older	38 grams	26 grams

Hydration

Hydration is essential to process increased fiber. Fiber without enough fluids can bulk the stool and increase constipation. Good hydration keeps the stool consistency soft enough that it can move through the colon at a good pace. Water is a best choice for hydration. ([APPENDIX IV – Recommended Dietary Fluid Index](#))

About Fiber

Fiber is a carbohydrate that comes from plant foods including fruits, vegetables, whole grains, beans and legumes, and nuts and seeds. Fiber is not something our bodies can digest, rather it moves through the

gastrointestinal system to bring in water into the stool and adding bulk to the stool. High fiber diets have been associated with other health benefits like blood sugar control and low cholesterol levels.

Types of Fiber:

- Soluble fiber. This form of fiber draws water into the colon, which softens stool and supports regular bowel movements. Soluble fiber is helpful in individuals with loose stool because it helps to form the stool into more solid pieces. For those with constipation it helps to keep the stool consistency soft by increasing the water content. Soluble fiber is also good at maintaining a healthy gut microbiome. Foods high in this type of fiber include black beans, brussels sprouts, avocado, sweet potato, pears, figs, oranges, oats and barley.
- Insoluble fiber. This type of fiber acts differently since it does not attract water like the soluble fiber does. This type of fiber adds bulk to the stool but doesn't increase the water content. This type of fiber encourages the body to move water into the colon independently and speeds up how quickly stool moves through the colon, which can improve constipation. Foods high in this type of fiber include cauliflower, green beans, potatoes, nuts, whole-wheat flour.

Tips for Patient Adding Fiber into Diet:

- Read food labels and include foods with at least 3-5 grams of fiber regularly
- Choose whole grain breads and cereals with 100% whole wheat, rye, oats, or bran as the first or second ingredient.
- Choose brown or wild rice
- Switch in whole grains you haven't tried, such as quinoa, millet, barley, farro, or bulgur.
- Make half your plate vegetables at lunch and dinner. The more colorful your plate the better!
- Eat fruits and vegetables rather than drinking them as juices
- Add nuts and seeds to your day. Include 2 tbsp. of mixed nuts with a snack, add 2 tbsp. of pumpkin seeds or sunflower seeds to a salad, or toss chopped almonds or walnuts onto oatmeal. Can add hemp seeds, chia seeds, flax seeds to oatmeal or salads or smoothies.
- Consider hummus as a dip for snacking with crackers or vegetables
- Certain foods may help soften stool or increase how fast stool moves through the intestines. Examples: prunes (5-6 per day), wheat bran or ground flax (1-2 tbsp/day), and kiwi (2 per day).
 - Note: Kiwis, avocados, and bananas are foods with a higher likelihood to cause an allergic reaction in people who are allergic to latex. Use caution with these foods and remove them from the diet if allergy symptoms occur. Some people choose to avoid these out of caution if they have a latex allergy.

References

Mosiello G., Safder S., Marshall D., Rolle U., & Benninga M. A. (2021). Neurogenic bowel dysfunction in children and adolescents. *Journal of Clinical Medicine*. 2021;10(8):1669.

McPherson AC., Chen L., O'Neil J., Vanderbom KA. Nutrition, metabolic syndrome, and obesity: Guidelines for the care of people with Spina Bifida. *J Pediatr Rehabil Med*. 2020;13(4):637-653.

University of Pittsburgh Medical Center. Nutrition for Spina Bifida and Healthy Bowel Movements. *Patient Information Sheet*. 2022.

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APPENDIX IV – Recommended Dietary Fluid Intake

Good hydration is an essential component of a successful bowel management program. Adequate fluid intake optimizes the effect of osmotic laxatives and fiber and is also necessary for bowel health overall.

Follow the following 24-hour period daily maintenance fluid requirements calculation:

- 100 mL/kg for the first 10 kg body weight
- + 50 mL/kg for the next 10 kg body weight
- + 20 mL for every kilogram of body weight over 20 kg

The chart below also provides ranges that can be used:

Patient Weight		Maintenance Fluid Intake Daily		
Kilograms	Pounds	Fluid Ounces	Millimeters	Cups
4.8-10	10.5-22	16-33.5	480-1000	2-4
10-20	22-44	33.5-50	1000-1500	4-6
15	33	41.5	1250	5
20-30	44-46	50-56.5	1500-1700	6-7
25	55	53	1600	6.5
30-40	66-88	56-63.5	1650-1900	7-8
40-50	88-110	63-70	1900-2100	8-9
>50	>110	72-80	>2100	9-10

Lifespan Bowel Management Protocol

APPENDIX V – Oral Medication Dosages

Lactulose (10g/15ml susp): 1.5-3 ml/kg/day divided BID; 1-2 g/kg/day divided BID. Maximum dose/day: 60 ml/day; 40 g/day. Response may require 24-48hrs.

Polyethylene glycol 3350 powder: Children \geq 10-19kg: 8.5g of powder mixed in 4oz of water daily; Children \geq 20 kg- adults 17g of powder mixed in 8oz of water daily. Not recommended in children less than 10 kg

Linaclotide: (72 mcg, 145 mcg, 290 mcg capsules): give >30 minutes before 1st meal

Sennosides-docusate sodium (8.8mg sennosides/5ml syrup; 8.6mg/50mg tablets):

Infants 1 month-2 years 1.25-2.5 ml qhs (2.2-4.4 mg sennosides); not to exceed 5 ml/day (8.8 mg/day). 2-5 years $\frac{1}{2}$ -1 tablet po QD-BID; max 1 tablet po BID; 2.5-5 mg once or twice a day.

6-11 years 1-2 tablets po QD-BID; max 2 tabs po BID; 7.5-10 mg/day.

12 years and older 2-4 tablets po qd-bid; 4 tabs po BID; 15-20 mg/day.

Milk of Magnesia: 2-5 years old: 0.4-1.2 g/day, once or divided BID; 6-11 years old: 1.2-2.4 g/day, once or divided BID; 12 and older: 2.4-4.8 g/day, once or divided BID

Bisacodyl²: 2-10 years old: 5 mg once per day; >10 years old 5-10 mg once per day

² Ikarashi N, Baba K, Ushiki T, Kon R, Mimura A, Toda T, et al. The laxative effect of bisacodyl is attributable to decreased aquaporin-3 expression in the colon induced by increased PGE2 secretion from macrophages. Am J Physiol Gastrointest Liver Physiol. 2011;301(5): G887-95.; Manabe N, Cremonini F, Camilleri M, Sandborn WJ, Burton DD. Effects of bisacodyl on ascending colon emptying and overall colonic transit in healthy volunteers. Aliment Pharmacol Ther. 2009;30(9):930-6.

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APPENDIX VI – Bowel Diary

When		Where			What			How		Why		
Date	Time	Toilet	Diaper	Pant	Hard	Soft	Loose	Strain	Urgent	Exercise	Food, Fluids	Meds

Lifespan Bowel Management Protocol

APPENDIX VII – Enema Basics

An enema is an installation of liquid into the rectum to evacuate stool. Although enemas are used most often for acute constipation for people with neurotypical bowels, enemas can be part of an effective regular bowel management program for people with neurogenic bowel.

Many people administer their enema at night before bed as part of a nighttime routine. This is when people typically have the time to sit on the toilet. If there is a bowel accident shortly after the enema, the risk of a socially inappropriate or unanticipated bowel accident is diminished because most individuals are home rather than out at work/school/social activities at this time. Others may prefer to incorporate the enema into their morning or after-school routines. Regardless of what time the enema fits best into an individual's schedule, it should occur at the same time each day.

Types of enema programs:

- Enemeez® is a prepared mini-enema of 283 mg of docusate sodium intended for those 12 years and older, and DocuSol® Kids is 100 mg and designed for ages 2-12. These lubricate and stimulate the rectum only. Insurance may or may not cover Enemeez®, so cost may be a factor if used regularly.
- Enemeez® Plus is a prepared mini-enema of 283 mg of docusate sodium and 20mg of benzocaine. The benzocaine anesthetizes the rectum and can be used in painful BMs, autonomic dysreflexia, or hemorrhoids. Enemeez® Plus is intended for those 12 years and older.
- Sodium phosphate enemas, typically known under the brand name Fleet, are convenient for cases of occasional constipation but are not appropriate for a daily bowel program. These enemas are low volume (60ml for ages 5-11 and 120 ml for ages 12+), and the soft silicone tip does not prevent the fluid from immediately leaking back out in the case of a loose anal sphincter, common with Spina Bifida. The Fleet Enema kit is not meant to be administered daily due to the risk of an electrolyte imbalance secondary to the phosphate in the solution. They are not safe for anyone with severe kidney issues or megacolon. Long-term daily use can cause narrow, hyperactive colon and signs of colitis due to chronic irritation and decreased kidney function. Although the Fleet box states the solution is a “saline” enema solution, it is a “phosphate saline” enema solution. The recommendation for only intermittent use is supported by Fleet® and an FDA warning regarding the risk of electrolyte imbalance with routine or daily use. Read the recommendation here:
 - [Drug Safety Communication: FDA warns of possible harm from exceeding recommended dose of over-the-counter sodium phosphate products to treat constipation | FDA](#)
 - [Fleet® link to FDA recommendation](#)
- Bulb syringe enemas are used for smaller volume enemas in older infants and young toddlers. The bulb is inserted into the anus, and 60-90 ml of warm water can be instilled. This is an inexpensive option for families as the bulbs can be purchased at most pharmacies. The family should be educated to purchase a latex-free or silicone bulb syringe.
- Balloon enemas use a 24 F Foley catheter to administer a high-volume rectal enema. The individual usually must lay down with the catheter balloon inflated inside the rectum to have the enema administered and then transfer to the toilet to deflate the balloon and evacuate. The catheter's balloon needs to be inflated to approximately 50ml of air or water. This amount is more than is recommended on the catheter but is necessary for the balloon to stay in the rectum while the fluid dwells. The solutions used on balloon enemas vary based on individual needs (see the [Enema Solutions](#) section).
- Cone Enemas use an irrigation system to administer high-volume rectal enemas. The cone tip where the fluid meets the body must be held in the anus during administration to block the fluid from releasing, and it can be entirely done on the toilet or involve transferring from the floor to the toilet. The solutions used in cone enemas vary based on individual needs (see the [Enema Solutions](#) section). These can be done using irrigation bags, and the solution enters the body by gravity or using a pump system as with the Wellspect® Navina cone irrigation system.

- Transanal irrigation systems (Peristeen®, Coloplast®, and Navina, Wellspect®) were designed to increase independence in bowel management. These irrigations may also take less time to administer than other high-volume enemas (cone and balloon). These are retrograde enemas that use a catheter in the rectum that is designed to stay in without assistance, and the enema is released via a pump system and not by gravity flow. Those with loose rectal tone may need to hold the catheter in during administration to prevent expulsion from the rectum. Not all insurance policies cover it, but coverage is expanding.
- Antegrade enemas (MACE, Monti, Chait, and cecostomy) are surgical procedures that create a channel from the abdomen to the bowel to allow for antegrade enemas. Many teens and adults can administer their antegrade enemas independently. The cecostomy channel is an artificial tube with a “button” on the abdomen to access it. The MACE (Malone Antegrade Continence Enema) channel is fashioned from the appendix with a stoma on the abdomen to access it; a Monti works similarly to the MACE but uses a piece of bowel and not the appendix to create the channel.
- Colostomies are surgeries that bring the large intestine to the abdomen’s surface to form a stoma. Stool is collected in an external bag worn by the patient around the stoma. This is a last resort surgery for neurogenic bowel patients.

Enema Solutions

For continence enemas, success is often dependent on what solution and additives are in the enema. Finding the right recipe may require significant trial and error and frequent communication between individuals and clinicians.

Volume

For enemas that do not come in a pre-filled bottle or bag, a general recommendation for small children is to start with 10-20 ml of water or saline per kilogram of the child’s weight. For patients over 50 kg, consider starting at 500 ml saline or water. The maximum amount of water is 1,500 ml, no matter the weight. It is believed that keeping the total volume of fluid used in an enema as low as possible to achieve goals will reduce the risk of megacolon. In some cases, using an additive in addition to the water or saline will allow for reduced overall solution volume.

Water/Saline

All enemas that do not come pre-filled with a specific solution should be first initiated with plain tap water or saline. Well water is not recommended for irrigations, and home water softening systems can also alter the chlorine and sodium content of the water and should not be used for irrigation due to the risk of hyponatremia and hypochloremia.³ Bottled water may be substituted when the tap water is unsafe.

Saline is a preferred solution by some clinicians and individuals, as it more closely resembles body fluids and is less likely to be absorbed in the colon.⁴ Bottled saline can be ordered and may be covered by insurance. Saline solution can be made at home by mixing 1000 ml (4 cups or 1 liter) of distilled water or tap water and 1.5 teaspoons table salt. It is important to stress the need to carefully measure water and salt with patients and caregivers using homemade solutions. Hyponatremia and hypochloremia should be monitored in cases where a homemade solution is being used due to errors in the measurement of the salt additive.⁵

Bottled saline is preferred over homemade mixtures.⁶ However, if using the tap water/salt mixture, it is recommended that the saline solution be stored in the refrigerator and warmed before the next use. There is a risk of bacterial contamination in homemade solutions, but this risk is significantly reduced when the solution is refrigerated. If refrigerated, solutions have been shown without bacterial growth up to 4 weeks.

³ Yerkes EB, Rink RC, King S, Cain MP, Kaefer M, Casale AJ. Tap water and the Malone antegrade continence enema: a safe combination? *J Urol*. 2001 Oct;166(4):1476-1478. PMID: 11547116.

⁴ Hyde SJ, Coulthard MG, Jaffray B, Vallely ME, Harding SM. Using saline solutions for ACE washouts. *Arch Dis Child*. 2008 Feb;93(2):149-150. doi: 10.1136/adc.2007.123489. Epub 2007 Sep 19. PMID: 17881423

⁵ Hyde SJ, Coulthard MG, Jaffray B, Vallely ME, Harding SM. Using saline solutions for ACE washouts. *Arch Dis Child*. 2008 Feb;93(2):149-150. doi: 10.1136/adc.2007.123489. Epub 2007 Sep 19. PMID: 17881423.

⁶ Hardy, E. T., Stringer, S. P., O’Callaghan, R., Arana, A., Bierdeman, M. A., & May, W. L. (2016, February). Strategies for decreasing contamination of homemade nasal saline irrigation solutions. In *International forum of allergy & rhinology* (Vol.

Additives

Water or saline alone may be sufficient for an enema program. But if someone is not successful with only water or saline, additives can make the enema more effective. Examples include:

- Baby soap: Many people start with 5-10 ml baby soap, such as Johnson & Johnson, and then increase up to 20 ml. Baby soap is gentle but effective, especially for small children or those not prone to constipation, because it contains glycerin as an ingredient.
- Glycerin USP Grade⁷: If baby soap is not adequate, the next step is pure glycerin. Glycerin is a non-toxic, gentle, thick liquid used to make soap and other products but is also used as a stimulant laxative. Most people start with 15-20 ml and increase to 40-50 ml or more if needed. Often, adding glycerin can decrease the water or saline volume.
- Castile soap: Castile soap is also safe and can be easier to find than glycerin, but it is considered “stronger” than glycerin or baby soap. It can be started in 10 ml increments. Castile soap can also be added to the glycerin management to make it stronger for especially stubborn colons. For example, a 40 kg child may use 400 ml saline, 40 ml glycerin, and 10 ml castile soap.
- Other: There are various other options to include in the enema. Some use one or more doses of Miralax® in the enema instead of, or in addition to taking it orally. Phosphate saline enema solution may also be used occasionally to help clear constipation but should not be used regularly ([APPENDIX VII – Enema Basics](#)).

Oral Medications and Enemas

It is recommended to stop oral medications when starting an enema program. The addition of oral medications has been associated with decreased continence rates for enemas⁸, but for a particular individual, it may be helpful. Some people continue taking Miralax® or stool softeners when they start an enema program, some can decrease the amount, and most can discontinue them altogether if the enema is effective. Breakthrough accidents may occur between enemas if the stool is too loose from osmotic laxatives. Taking stimulant laxatives often works against a continence enema program as it stimulates the bowels to move outside of enema time.

⁶, No. 2, pp. 140-142); Fellows, J., & Crestodina, L. (2006). Home-prepared saline: a safe, cost-effective alternative for wound cleansing in-home care. *Journal of Wound Ostomy & Continence Nursing*, 33(6), 606-609.

⁷ Chu DI, Balsara ZR, Routh JC, Ross SS, Wiener JS. Experience with glycerin for antegrade continence enema in patients with neurogenic bowel. *J Urol*. 2013 Feb;189(2):690-693. doi: 10.1016/j.juro.2012.08.209. Epub 2012 Oct 8. PMID: 22986031; PMCID: PMC5453718

⁸ Kelly MS, Wiener JS, Liu T, Patel P, Castillo H, Castillo J, Dicianno BE, Jasien J, Peterson P, Routh JC, Sawin K, Sherburne E, Smith K, Taha A, Worley G. Neurogenic bowel treatments and continence outcomes in children and adults with myelomeningocele. *J Pediatr Rehabil Med*. 2020;13(4):685-693. doi: 10.3233/PRM-190667. PMID: 33325404; PMCID: PMC8776357.

Bulb Syringe Enema



A bulb syringe enema is used for smaller volume enema in older infants and young toddlers. The bulb does not hold as much fluid as an enema bag but can be a little easier to set up and administer. The bulb holds about two to three ounces (60-90 ml). The bulb can be bought at most pharmacies and where infant items can be purchased. It is usually used for nasal suctioning with infants, so you may need to look in the infant section of a store. The bulb is not to be used in children less than three months of age, and the bulb needs to be non-latex!

Fluid volume calculation: 10-20 ml/kg

Note: Larger bulbs may be available to purchase online. In addition, an emptied Phosphate enema bottle could be used. These bulbs do not create a seal around the anus, so the enema solution will often leak around the bulb.

Alert: The bulb section can harbor mold and bacteria if it remains damp. Proper cleaning or replacement is required. Do not store the bulb in a sealed container, as this will promote growth. Patients should empty the bladder before bowel management.

Steps for bulb syringe enema

Supplies:

- A urine collection cup (or similar container) to mix irrigation solution if baby soap/shampoo (Johnson & Johnson or generic is fine too) is used.
- Diaper or absorbent pad or towel for protection
- A potty seat (unless you prefer to skip the sitting time and let them go in their diaper) most families recommend the Graco® Clean Contour Potty Ring, Green because you can access the anus from the back of the toilet seat.

Steps:

1. Lay a waterproof pad or towel/liner down wherever you do the enema (preferably near the toilet or in an adjacent room).
2. Get a diaper, bed/chucks pad, towel, or something that will absorb the enema water.
3. Squirt baby shampoo (a "squirt" or about a teaspoon) in a urine collection cup or a measuring cup, using the lines to measure out. You could also just try the warm water only at first and see if the child stools with only the warm water. The child will probably need the baby shampoo as a stimulant/irritant.
4. Add warm water from the faucet (nice and warm to the touch, but not hot).
5. Put the lid on the cup and shake gently to mix (if you added the baby shampoo).
6. Fill the bulb syringe with the solution, squirting back out any remaining air and filling until there is no air space in the bulb. You can start with two to four ounces.
7. Lay your child on their left side with knees bent to a 90-degree angle to relax the pelvic floor. Place the diaper under them.
8. You can either put lubricant on the end of the bulb or simply add a dab of the baby soap.
9. Gently place the bulb tip into the rectum until the bulb portion is firm against the rectum and fully inserted. You can put pressure against the rectum to block any back-flow; it shouldn't hurt them.
10. Grab the butt cheeks with your other free hand and squeeze them together tightly as you squeeze the bulb into the rectum.
11. Keep pressure on the bulb as you're emptying it; you do NOT want to let go and suck stool/water back into the bulb.
12. When you have emptied it as much as you possibly can, keeping pressure on the bulb and not letting it expand, gently pull it out while you continue to squeeze the butt cheeks firmly.

13. Keep holding the butt cheeks for five minutes if possible. If the child does not sit on the toilet, make sure they are well diapered.
14. If you have the child stool on the toilet, wait up to five minutes or until they feel the urge to push or begin stooling; cup the diaper over the bottom and quickly transfer them to the toilet and remove the diaper. This can be tricky and messy. Keep the child's knees bent higher than the hips for the best emptying position. Sitting time will vary based on what the child can handle. Try to have the child sit for up to 20 minutes and make sitting on the potty very fun.

Cone Enema

Usually used to flush a colostomy, a cone irrigation system has become a popular tool to administer high-volume rectal enemas for children who have decreased sphincter tone. The cone acts as a stopper to prevent the enema from immediately leaking out.



Many families can get cone enema supplies through their DME company, and most insurances cover them. Supplies can also be purchased from Amazon.com or an online medical supply retailer. A search for “cone irrigator” results in several options in the \$40 range. One kit can be washed and reused for six months or more, but it may be helpful to have a backup kit on hand. Water-based lubricant for the cone is also needed. See the [Enema Solutions](#) section for suggestions for what to put in the enema.

Often parents are afraid when they see how large the cone is. With lubricant, it should not hurt the child, and it will not permanently stretch out the rectum. It should be inserted deep enough to make a good seal, so the solution does not leak out, and many are surprised to see the cone goes in far enough that the base is flush with the buttocks.

Pictured above: Visi-Flow® Irrigator with Stoma Cone (Courtesy of ConvaTec Inc.) Available from multiple medical distributors and companies.

Pictured right: Navina irrigation set with a cone tip. Not intended for children under two years of age.

This type of cone enema acts similarly to the one above, except it does not rely on gravity to instill the solution but rather a pump system which is thought to decrease the amount of time it takes to complete the enema. Since this device can also be used with a catheter tip, as mentioned in [APPENDIX VII – Enema Basics](#), utilizing this device earlier may increase comfort with more invasive programs if needed.



Nurses are available by phone for Navina support by calling 1-877-456-3742.

Fluid volume calculation: 10-20 ml/kg of tap water or saline. Maximum of 1500ml regardless of weight.

Note: Insurance requires training before starting this program.

Alert: Hemorrhage with or without pain suggests a possible bowel perforation, which should be assessed as a potential medical emergency.

- Contraindications: Do NOT use Navina Systems if you have one or more of the following:
- Known anal or colorectal stenosis
- Active inflammatory bowel disease
- Acute diverticulitis
- Colorectal cancer
- Ischemic colitis
- During the spinal cord shock phase
- Complex diverticular disease
- You are within three months of anal or colorectal surgery
- You are within four weeks of previous endoscopic polypectomy

As the list may not be exhaustive, health care professionals will always consider individual user factors as well. Patients should empty the bladder before bowel management.

Steps for Cone Enema by Gravity

Step 1: Gather a potty seat (if being used), lubricant, and irrigation set. Mix the solution and place the prescribed amount into the bag. Using the roller on the tubing, lock the tubing, so the solution doesn't begin to pour out. Hang the bag of fluid from a Command hook on the wall, shower curtain hook, showerhead, or a clothes hanger, depending on the bathroom configuration. The bag should be hung high enough that fluid flows freely down the tubing. Some caregivers prefer to wear non-latex gloves while administering the enema. Flush the line with the irrigation solution to remove air from the tube so trapped air does not cause discomfort, then roll the lock into place again to prevent further drainage until you are ready.

Step 2: There are two ways to administer the enema. Some parents have the child lie on the floor on their left side (on a towel, mat, pad, etc.) to instill the enema, and then transfer the child to the toilet. Lifting the child to the toilet while holding in the cone can be messy and physically difficult, especially as the child grows.

Others administer the enema while the child is sitting on the toilet, leaning forward. This is a benefit of the cone enema that it can be administered on the toilet to avoid mess and lifting, compared to some other types of enemas. With the child sitting on the toilet, the person giving the enema can sit on their knees, chair, or step stool in front of the child and reach around or through the legs to hold in the cone. Or they can sit beside the child on a chair, bathtub edge, etc., with the child leaning on the caregiver's knees or a TV tray. Some children sit backward on the toilet, making it easier for the caregiver to hold the cone in place during the instillation of the enema solution.

Step 3: Let the water/solution flow in. Some people prefer to turn the roller clamp to wide open, so it flows as quickly and forcefully as possible, but some children cannot tolerate a fast flow, and it must be adjusted with the roller valve to a comfortable flow. If cramping or discomfort occurs, you can pause the irrigation and wait for the discomfort to resolve before the rest of the irrigation occurs. After all the solution empties the bag, the caregiver can hold the cone in for up to 10 minutes to get a more effective flush. Then they lean the child back onto the toilet seat while swiftly removing the cone. This can be messy at first but will get better with practice.

Step 4: The child sits on the toilet to let all the stool and water come back out, usually 30 to 60 minutes. It is good for the child to "push" a few times during the enema, especially right at the end. Some children do not know what pushing feels like, but caregivers can show them how to bear down, grunt, yell, laugh, blow bubbles, stretch, etc. When the enema seems complete, clean the child with toilet paper, wipes, or a Bidet. The cone can be washed with soap and water and stored with the roller clamp open to drain. Each irrigation set can usually be reused for six months before needing replacement. If the integrity of the tubing is compromised, replace it sooner.

Steps for Navina Cone Enema

The Navina Cone catheter is limited to use for those ages 2-21 years.

Preparation

1. Fill the container with water to the level given by your health care professional.
2. + max 200 ml extra for activating the cone surface (making it slippery).
3. Connect the water container tube between the water container and the control unit (dark blue).
4. Connect the cone tube between the control unit and the cone (light blue/white).

Note: Follow color-coding and symbols. Use lukewarm and clean water only. Make sure the safety valve on the lid is not blocked during the procedure.

Activation

1. Make sure the water symbol is shown on the central switch.
2. Pump water with the dark blue pump until it covers 3/4 of the cone, making it slippery.
3. Close water flow.

Note: Do not add additional lubricant.

Instillation

1. Find the best position for the child; this can be bending over with knees bent or sitting on the toilet, or crouching.
2. Carefully insert the cone, without any force, into the rectum until the cone fits comfortably, as instructed by your health care professional. Hold it in place during the procedure.
3. Open water flow.
4. Instill the water volume, as indicated by your health care provider, using the dark blue pump.
5. Stop or pause the instillation at any time by releasing the pump and closing the water flow.
6. Monitor the child's face during instillation for signs of distress or discomfort. Stop or pause if it is uncomfortable for the child.
7. Close water flow.

Note: Never insert cone with force. If experiencing resistance, remove the cone and follow see instructions in the [Troubleshooting](#) section below. If resistance continues, stop using irrigation and seek help from a health care professional.

Evacuation

1. Remove the catheter gently.
2. Allow bowel to empty. If needed to start emptying, relax for 10-15 minutes, lean forward, cough, or massage abdomen.

Disassembly

1. Open the water flow and let the remaining water in the container flow through the system by elevating the water container above the level of the catheter.
2. Open water container lid.
3. Disconnect tubes from the control unit.
4. Empty water from tubes.
5. Empty water from the control unit.
6. Disconnect cone and dispose of in the household waste.
7. Disconnect tube from the water container and empty water.
8. Rinse, clean, and dry the system.

Note: Check a box in the usage calendar (see instructions for use) after each use to track when to exchange the water container and tube set.

Troubleshooting:

- If water flows around the cone, it may be that it is not pushed in far enough. More likely, the solution is hitting stool inside the rectum. This means the initial cleanout wasn't complete, or they have become constipated over time and need to do a partial cleanout.
- If constipation occurs regularly, make the enema solution stronger (see the [Enema Solutions](#) section).
- If stool accidents consistently occur before the next day's enema, this usually indicates the solution is not strong enough. Assess for constipation to determine whether a partial cleanout is needed and increase the strength of the solution (see the [Enema Solutions](#) section).
- If cramping or pain occurs, make sure the water/saline used is warm (approximately 96-100F). Speed of fluid flowing into body can also cause cramping, pausing instillation and continuing when cramping subsides more slowly may alleviate this. Otherwise, pain and cramping may indicate constipation or sometimes a solution that is too strong.
- If no stool is evacuated after an irrigation, repeat irrigation or split irrigation into two consecutive episodes repeated 10-15 minutes apart and using half the irrigant at a time. Check for constipation and treat if needed (may need a laxative).

Balloon Enema

A balloon enema requires a latex-free 24 F foley catheter hooked to a gravity feeding bag or syringe. Once lubricated, inserted in the rectum, and inflated, the catheter prevents the water/solution from immediately leaking out. Supplies can be prescribed through a DME company and paid for by insurance or purchased out of pocket from online medical supply retailers. Catheters can be washed and reused, and the bags or syringes also usually last a few weeks.

See the [Enema Solutions](#) section for suggestions for what to put in the enema.

Fluid volume calculation: 10-20 ml/kg of tap water or saline

Alert: It is believed that the balloon can accommodate 60-90cc of air or fluid before bursting. Some balloons may rupture before that volume. Rupture is often very loud and can be distressing but is not dangerous to the colon. Some children can expel the balloon while the enema is occurring while it is inflated. This is generally a sign of potential constipation or the need to progress to a different management technique. Patients should empty the bladder prior to bowel management.

Steps for Balloon Enemas

Step 1: Gather the potty seat, footstool, TV tray, and/or other supplies. Mix the solution and fill the syringe or hang the bag of fluid from a Command hook on the wall, shower curtain hook, showerhead, or a clothes hanger, depending on the bathroom configuration. The higher the bag hangs, the easier the fluid will flow in. Some caregivers prefer to wear non-latex gloves while administering the enema. Flush the line to remove air from the tube so trapped air does not cause discomfort.

Step 2: Unlike the cone enema, which can be administered either on the floor or on the toilet because it is manually held in, the balloon enema is almost always administered while the child is lying on the floor to prevent the balloon from popping out. The child can lie on a mat, towel, pad, etc., with their bottom raised in the air if possible, or laying on their left side, or sitting on a toilet. A caregiver inserts the catheter into the rectum about 4 inches, inflates the balloon, and opens the valve on the gravity bag for fluid to start flowing into the rectum.

Step 3: The caregiver must hold the catheter taut to form a seal while the water flows in. Some people prefer to turn the roller clamp to wide open so it flows as quickly and forcefully as possible, but some children cannot tolerate a fast flow and it must be adjusted with the roller valve to a comfortable flow. If cramping or discomfort occurs, you can pause the irrigation and wait for the discomfort to resolve before the rest of the irrigation occurs. It is best to have the child continue to lie down for about 10 minutes after the water is instilled, with the catheter still held taut and the roller clamp closed.

Step 4: The child must then be transferred to the toilet with the catheter still inflated and held taut. Depending on the child's weight and abilities, they may need to be lifted to the toilet, they may assist with standing and transferring, or some can independently stand up and back up to the toilet. Once the child is sitting on the toilet, the balloon can be deflated and the catheter removed. Next, the child sits for usually 30-60 minutes to empty the bowel. It is a good idea for the child to "push" a few times during the enema, especially right at the end. Some children do not know what pushing feels like, but caregivers can show them how to bear down, grunt, yell, laugh, blow bubbles, stretch, etc. When the enema seems to be complete, clean the child with wipes. The catheter can be washed with soap and hot water.

Troubleshooting:

- If the inflated balloon consistently pops out, the balloon may need to be inflated more than the intended 30cc. Many people inflate it with 40cc, 50cc, or even more air or water to prevent it from popping out due to low rectal tone. The maximum inflation should be 60-90cc.
- The balloon popping out episodically when it has held consistently before may be a sign of constipation.
- If water flows around the balloon, make sure it is pulled taut to form a seal. The solution could be hitting stool inside the rectum, which might mean the initial cleanout wasn't complete, or they have become constipated over time and need to do a partial cleanout.
- If constipation occurs regularly, see the [Enema Solutions](#) section for ways to make the enema solution stronger.
- If stool accidents consistently occur before the next day's enema, this usually indicates the solution is not strong enough. Assess for constipation to determine whether a partial cleanout is needed, and increase the strength of the solution (see the [Enema Solutions](#) section).
- If cramping or pain occurs, make sure the water/saline used is warm. Otherwise, pain and cramping may indicate constipation or sometimes a solution that is too strong.
- There is anecdotal evidence that pain with balloon enemas may be due to rectal spasm. Rectal spasm during balloon enemas may be an indication that the patient is not a candidate for the Peristeen system.

Transanal Irrigation* (e.g.: Peristeen®, Navina)



A transanal irrigation system works by pumping fluid into the colon rather than using gravity flow of fluid into the colon to evacuate stool that cone or balloon enemas use. The system consists of a semi-rigid catheter attached to pump tubing that attaches to a bag or container, filled with warm water. After priming the tubing and hydrophilic catheter, the catheter is inserted into the anus, the balloon is inflated, then the parent or patient pumps air into the water-filled bag, which is then pressurized so water flows through the tubing and out of the catheter. This can be done while the patient sits on the toilet. There is no dwell time: once the prescribed volume is delivered, the balloon is deflated and the fluid and stool are expelled. The patient should sit for 30-45 minutes to evacuate the water and the stool. It is recommended that patients begin with daily irrigation. Once soil-free for 30 consecutive days, they may consider switching to every-other-day

irrigations. Transanal irrigation often requires prior authorization through the patient's insurance company with a specific prescription, letter of medical necessity, and office notes regarding bowel management.

* Contraindicated in known anal or colorectal stenosis, colorectal cancer, radiotherapy to the pelvis, recent abdomino-perineal surgery, active inflammatory bowel disease, diverticulitis and ischemic colitis, chronic and complex diverticular disease, abdominal, anal or colorectal surgery within the last three months, within four weeks of endoscopic polypectomy, recent colonic biopsy, recent endoscopic mucosal resection (EMR) and recent endoscopic sub-mucosal dissection (ESD), severe autonomic dysreflexia or during spinal cord shock phase, and in patients who are pregnant and have not used the system before. Since the list is not exhaustive, the health care professional should always consider individual patient factors as well.

Fluid volume calculation: 10-20 ml/kg of tap water

Note: NO ADDITIVES are recommended by the manufacturers. Training is required by a clinician prior to use. Patients should empty the bladder prior to bowel management.

Alert: Although it is unlikely, bowel perforation can occur. Rates of this occurring are 2/1 million irrigations.

Symptoms include: Severe abdominal or back pain, large amount of blood from rectum. If this occurs, the patient and family should understand that this is an emergency, and they should go directly to the emergency room.

Steps for Peristeen®

1. Gather supplies: Water bag, pump (set on blue ~ balloon) & rectal catheter and any activity planned for sit time.
2. Open the catheter package and attach the catheter to the pump tubing (blue to blue).
3. Attach gray tubing connector to the gray lid.
4. Fill the water bag with warm water to the "0" mark or the very top.
5. Close the lid properly and place the bag on the floor or surface where it can easily be seen to view the numbers on the bag.
6. Turn the dial on the pump to water (white) and pump gently until water coats the hydrophilic catheter. This will lubricate the catheter within 30 seconds.
7. Turn the pump to the balloon (blue) symbol to stop the flow of the fluid.
8. The patient should sit on the toilet, leaning forward to insert the catheter into the anus up to the hub (thin blue horizontal line), this should go easily, if it does not check to see if there is hard stool obstructing the way and remove any hard stool.
9. Inflate the balloon by giving the prescribed pumps to create a water seal.
10. Turn the dial on the pump to the water (white) symbol and begin to gently pump water into the colon while your child is sitting back. No more than 1 pump each second. May stop by turning to balloon (blue) symbol to rest as needed.
11. Once you have pumped in the prescribed amount, deflate the balloon by turning the pump to the Go (green) symbol. The air will come out of the balloon and the catheter will slip out of the rectum. Water should begin to come out followed by stool. Turn the dial back to balloon (blue) to stop the flow of water.
12. Encourage the patient to cough, gently massage the abdomen or lean forward to assist in evacuation of stool.
13. The patient should sit for a minimum of 30 minutes after releasing the balloon to ensure evacuation of all fluid and stool from the colon. During the sit time, encourage activities such as screen time, coloring, homework or other activities that help the time pass.
14. Once the irrigation and sit time are completed, the bag will need to be emptied by disconnecting the tubing from the bag and the catheter. The catheter is disposed of in the trash. The pump control is then turned to water (white) setting and all water is pumped out of the tubing. The bag can then be hung upside down along with the tubing with pump control on storage (orange) to allow to dry.
15. Patients and caregivers should keep track of progress on diaries.

Steps for Navina Catheter Enema

The Navina Small Rectal Balloon catheter is limited to use for adolescent (12 - <18 years old) and transitional adolescent (18 - < 21 years old) patients and adults. The Navina Regular Rectal Balloon catheter is limited to use for adults.

Preparation

1. Fill the container with water to the level given by your health care professional + max 200 ml extra for activating the catheter surface (making it slippery).
2. Connect the water container tube between water container and control unit (dark blue).
3. Connect the catheter tube between control unit and catheter (light blue/white).

Note: Follow color-coding and symbols. Use lukewarm and clean water only. Make sure the safety valve on the lid is not blocked during the procedure.

Activation

1. Make sure water flow is opened.
2. Pump water with the dark blue pump until it covers 3/4 of the catheter tube, making it slippery.
3. Close water flow.

Note: Do not add additional lubricant.

Instillation

Find the position that is best for the child, this can be bending over with knees bent or sitting on the toilet or crouching.

1. Carefully insert rectal catheter according to the health care professional's instruction.
2. Inflate balloon with light blue pump.
3. Never use more than two pumps when using the small catheter.

Note: Monitor the child's face during inflation and instillation, for signs of distress or discomfort. Stop or pause if it is uncomfortable for the child. If repositioning of catheter is needed, deflate balloon completely first. The balloon should not be inflated more than two times.

1. Gently pull catheter slightly down to seal the rectum.
2. Open water flow.
3. Instill the water volume, as indicated by your health care provider, using the dark blue pump.
4. You can stop or pause instillation at any time by releasing the pump and closing the water flow.
5. Close water flow.

Note: Never insert catheter with force. If experiencing resistance, remove catheter, and follow the instructions in the next [troubleshooting section](#). If resistance continues, stop using irrigation and seek help from a health care professional.

Evacuation

1. Deflate balloon by pressing black button.
2. Remove catheter gently.
3. Allow bowel to empty. If needed to start emptying, relax for 10-15 minutes, lean forward, cough or massage abdomen.

Disassembly

1. Open the water flow and let the remaining water in the container flow through the system by elevating the water container above the level of the catheter.
2. Open water container lid.
3. Disconnect tubes from control unit.
4. Empty water from tubes.
5. Empty water from control unit.
6. Disconnect cone and dispose in household waste.
7. Disconnect tube from water container and empty water.
8. Rinse, clean and dry the system.

Note: Check a box in the usage calendar (see instructions for use) after each use to keep track of when to exchange the water container and tube set.

Troubleshooting Navina and Peristeen:

- If the inflated balloon consistently pops out, experiment with inflating the balloon more or fewer pumps and both child and adult catheters. Some people find they must always hold the catheter in due to low rectal tone.
- The balloon popping out episodically when it has held consistently before may be a sign of constipation.
- If stool accidents consistently occur before the next day's enema, more water may be needed. Assess for constipation to determine whether a partial cleanout is needed before increasing.
- If cramping or pain occurs, make sure the water/saline used is warm. Otherwise, pain and cramping may indicate constipation. May also stop irrigation temporarily to see if cramping decreases and if it does continue instilling more water until desired volume is reached.
- It can often take three months of experimentation to develop a working program.

MACE (Malone Antegrade Continence Enema), ACE (Antegrade Continence Enemas), Chait and Cecostomy

These procedures are surgical solutions for bowel management.

The MACE/ACE involves the surgeon fashioning a channel from the appendix or ileum to a stoma on the abdomen so the patient can insert a catheter into the channel and flush fluids through it. Many teens and adults can administer these bowel flushes independently. Studies have found that continence rates are equal in retrograde enemas (TAI, and cone) to antegrade enemas (MACE, cecostomy) (80 percent success in retrograde and 81 percent in antegrade).⁹ ([APPENDIX XV – Independence](#))

Often a surgeon can use the appendix for both the MACE and Mitrofanoff, so the surgeries are regularly done at the same time. The MACE can sometimes be done laparoscopically or robotically for an easier recovery. Some choose the MACE/ACE because it is usually aesthetically less obtrusive than the Chait/Cecostomy since there is no permanent device that is on the skin.¹⁰ The main drawback is for those who experience stomal stenosis.¹¹ About 20 percent of MACE patients experience stomal stenosis.¹² In some cases, this can be solved by leaving a catheter or stent in the stoma for a prolonged period. If a catheter cannot pass through at all, it may require surgical revision. If the patient has recurring stomal stenosis, the surgeon may recommend inserting a MIC-KEY button, MiniACE®, or Chait Trapdoor™ in the MACE.

For a Cecostomy, the surgeon inserts an artificial tube from the outer abdomen through to the cecum. A couple weeks after the procedure, the surgeon, or Interventional Radiology places either a Chait Trapdoor, MIC-KEY button, or mini-ACE/ONE enema button. These must be replaced usually every 3-12 months, with or without sedation, by the surgeon or Interventional Radiology.

⁹ Velde SV, Biervliet SV, Bruyne RD, Winckel MV. A systematic review on bowel management and the success rate of the various treatment modalities in spina bifida patients. *Spinal Cord*. 2013 Dec;51(12):873-881. doi: 10.1038/sc.2013.123. Epub 2013 Oct 15. PMID: 24126852.

¹⁰ Kelly, "Malone Antegrade Continence Enemas vs. Cecostomy vs. Transanal Irrigation-What Is New and How Do We Counsel Our Patients?"

¹¹ Routh JC, Joseph DB, Liu T, Schechter MS, Thibadeau JK, Chad Wallis M, Ward EA, Wiener JS. Variation in surgical management of neurogenic bowel among centers participating in National Spina Bifida Patient Registry. *J Pediatr Rehabil Med*. 2017 Dec 11;10(3-4):303-312. doi: 10.3233/PRM-170460. PMID: 29125521; PMCID: PMC5891120.

¹² Velde SV, Biervliet SV, Bruyne RD, Winckel MV. A systematic review on bowel management and the success rate of the various treatment modalities in spina bifida patients. *Spinal Cord*. 2013 Dec;51(12):873-881. doi: 10.1038/sc.2013.123. Epub 2013 Oct 15. PMID: 24126852.

Some choose the Cecostomy because it can have a shorter recovery than the MACE, it is reversible, and there is no risk of stomal stenosis as with the MACE. Or they may choose the Cecostomy so they do not have to use the appendix—if the patient’s appendix has already been removed or used for a Mitrofanoff, or if the surgeon wants to save the appendix for a later Mitrofanoff. Some people note the downside that a button is more outwardly visible than a stoma, increased risk of skin breakdown and the tube must be replaced routinely. Many parents choose surgical intervention for bladder and bowel in the upper elementary years for independence. By then, parents know more about their child’s bowel and bladder, children are able to have (limited) input, and young people usually adapt better to changes in routine. Some younger children, such as preschoolers, have these surgeries to avoid incontinence in school if rectal enemas and other bowel programs have not been successful. One good reason to wait is if it is not known what bladder surgery will be needed, if any. The appendix is usually the easiest material to use for both the MACE and Mitrofanoff, and surgeons like to try to use it for both procedures at once. Teenagers can be resistant to the idea of an elective procedure and to changing their routine, and the recovery can be more difficult for adults. Adults with Spina Bifida may also have challenges finding doctors who are familiar with the surgeries.

Two types of enema fluid practices are commonly followed, one uses tap water and the other uses normal saline. Both have been documented in the literature with success. It is largely up to the surgeon/clinical practice which is utilized. In addition to differences in the fluid used for irrigation variation exists regarding the amount of fluid to be used. We will provide some guidance here to help guide practice patterns but further research in regards to these variations is needed to improve patient outcomes and ensure patient safety. All enemas should be started once daily and after a minimum of two to six weeks, if the individual is not having episodes of fecal incontinence they can move to once every other day. It is rare that individuals can achieve continence and do enemas less frequently than every other day but, in some cases, this can be achieved and trial and error is the best way to decipher this.

If tap water is used it should be room temperature water that is bottled or tap. Tap water should not be softened or well water. During the inpatient post-operative phase, we recommend starting with normal saline until the patient has been discharged home, once there is no sign of surgical complications (fistulas, rupture) a switch to tap water can be carried out.

If saline is used it can be purchased or made at home. If made at home, follow the instructions above to do so and be cautious as variations in concentration are commonly noted and can cause secondary medical complications.

Many providers will start with low-volume solutions with an irritant, such as glycerin. One example that has been published is 30ml of glycerin and 50ml of tap water with increases of tap water to 90ml readily if needed to achieve bowel movements within an hour of doing the enemas and without incontinence afterward. Reported continence rates with this method have been up to 95 percent.¹³ The use of glycerin is recommended as an irritant to promote contraction and stimulation to have a bowel movement as it is easy and inexpensive to purchase and has been studied in the setting of large and small volumes of fluid.^{14,15} Other stimulants that have been used are 1-3 drops of castile soap, mineral oil, or polyethylene glycol 3350 powder. These are commonly used but have less evidence published to back the practice.

¹³ Experience with glycerin for antegrade continence enema in patients with neurogenic bowel. J Urol. 2013 Feb;189(2):690-693. doi: 10.1016/j.juro.2012.08.209. Epub 2012 Oct 8. PMID: 22986031; PMCID: PMC5453718.

¹⁴ Schletker J, Edmonds T, Jacobson R, Ketzer J, Hall J, Trecartin A, Peña A, Bischoff A. Bowel management program in patients with Spina Bifida. Pediatr Surg Int. 2019 Feb;35(2):243-245. doi: 10.1007/s00383-018-4403-5. Epub 2018 Nov 7. PMID: 30402681.

¹⁵ Bani-Hani AH, Cain MP, King S, Rink RC. Tap water irrigation and additives to optimize success with the Malone antegrade continence enema: the Indiana University algorithm. J Urol. 2008 Oct;180(4 Suppl):1757-1760; discussion 1760. doi: 10.1016/j.juro.2008.04.074. Epub 2008 Aug 21. PMID: 18721951.

Larger volume enemas are often used and are considered large when the volume is greater than 250 ml.^{16,17,18} Many find that using 10-20 ml/kg of fluid, similar to other enemas, is needed for success. There has been thought that chronic use of large volume irrigations may cause enlarged colons, which can cause other health effects, but little has been published on this topic. If large volume enemas are the technique, you will practice or recommend, it is recommended to start in the postoperative period with smaller volumes and work the patient up to the final large volume. Starting with 50 ml of water is often used and then increments of 50 ml added nightly until the final volume is achieved.

Due to the various options for maintaining an antegrade enema, it is recommended to follow a stepwise approach in your practice, aligned with our least to more invasive techniques. This would be starting with daily irrigations of tap water and glycerin in small quantities (e.g., 30 ml glycerin, 50 ml water) then increasing the water to 90 ml water. If this is not sufficient, changing techniques to a large volume enema, starting with 10-20 ml/kg of water would be the next option. If the increased volume was insufficient for outcomes, then glycerin would be the first recommended additive, followed by castile soap, mineral oil, and lastly, Miralax®.

If tap water is causing concerns with plasma osmolarity then changing to normal saline would be appropriate.

¹⁶ Ayub SS, Zeidan M, Larson SD, Islam S. Long-term outcomes of antegrade continence enema in children with chronic encopresis and incontinence: what is the optimal flush to use? *Pediatr Surg Int.* 2019 Apr;35(4):431-438. doi: 10.1007/s00383-018-4416-0. Epub 2018 Nov 13. PMID: 30426223.

¹⁷ Schletker J, Edmonds T, Jacobson R, Ketzer J, Hall J, Trecartin A, Peña A, Bischoff A. Bowel management program in patients with spina bifida. *Pediatr Surg Int.* 2019 Feb;35(2):243-245. doi: 10.1007/s00383-018-4403-5. Epub 2018 Nov 7. PMID: 30402681.

¹⁸ Bani-Hani AH, Cain MP, King S, Rink RC. Tap water irrigation and additives to optimize success with the Malone antegrade continence enema: the Indiana University algorithm. *J Urol.* 2008 Oct;180(4 Suppl):1757-1760; discussion 1760. doi: 10.1016/j.juro.2008.04.074. Epub 2008 Aug 21. PMID: 18721951.

Lifespan Bowel Management Protocol

APPENDIX VIII – Helping Parents and Caregivers Prepare to Start a Bowel Program

Providers should be mindful that their patients' family and child self-management ability and success with their bowel programs are significantly impacted by parents' and children's feelings about the transition and the program. Parents may experience grief that their child will not potty train typically, frustration at trying different programs unsuccessfully until finding the right one, and stress due to adding another major caretaking duty to an already full schedule. Children may be fearful that the program will be painful, resistant to a change in routine, and nervous about accidents. Although a bowel program can greatly increase a patient's and family's quality of life, starting a program is usually stressful.

It will be helpful to get to know parents' and children's goals and concerns to best choose a bowel program that fits their needs, answer their questions, and address any misconceptions. Some parents feel more comfortable starting a bowel program if they can talk to other parents, either locally or online, who do the same and can give them support and practical tips.

Parents' attitudes impact a child's perspective on starting a new program. Whether parents appear sad and afraid, or positive and confident, children will follow suit. Good advice for parents is to not apologize to their children about having to do a bowel program. Everyone has to stool; they just do it a little differently. Many parents present a bowel program to their child as a "big kid" activity rather than a Spina Bifida-related chore. "I'm so excited you'll be pooping on the big potty like Mommy!" is a more helpful approach than "I'm so sorry, I wish you didn't have Spina Bifida and could poop like everyone else, but the doctor said we have to do this."

To help children transition to a new program, experienced parents recommend making potty time a "party in the bathroom," at least at first. Offer special treats and privileges the child normally may not get, like extended screen time, new coloring books, toys that can only be used during bathroom time, the promise of ice cream after it's finished, plans to watch a movie to celebrate the first week done, and lots of company from parents and siblings in the bathroom if desired. Over time, these positive reinforcements can fade as the child gets used to the routine, but it sets them up for a positive outlook about their bowel program.

It is also important for providers and caregivers to acknowledge and validate the child's feelings and frustrations and give them as much power in the situation as possible and appropriate. If the child refuses to do the program, ask questions to find the root cause of the refusal. If the cause is discomfort, the enema solution may need to be changed. If the cause is missing out on fun activities, the timing of the program could change. If the child resents having to do a program his or her friends or siblings do not have to do, it may be helpful to introduce the child to other children on bowel programs.

The child can be involved in the process as much as they are capable, to increase their independence as well as compliance. They can help set up the supplies, or at least choose the movie and press play. Give children as much control and choice as possible in how it is done, but whether or not to do the program is not negotiable, or they will beg to not do it every night.

Over time, families find ways to work the bowel program into their schedules. Sitting on the toilet for an extended period of time is an ideal chance to do homework. Parents may take that time to bathe another child, or eventually get other household tasks done as the child is more comfortable in the bathroom on their own. After some time, it just becomes part of the daily routine.

Some make up code names for bathroom time to make it more fun and so they don't have to talk about personal specifics in front of people outside the immediate family. (One boy calls it "Hulk time" because he acts like the Hulk when pushing at the end of his enema.) Age-appropriate privacy is important, but so is having more than one person know how to help the child with their bathroom program. A parent can burn out or be

overly restricted if they are the only person who can help the child with the bowel program, and it puts the child at risk if that parent cannot do it for any reason.

Prepare families that the process may be frustrating and messy at first, but to give it some time. Just like with the other procedures they have had to learn, after a couple weeks they will be pros. Keep the end goal in mind. Even when a bowel program gets difficult, it is well worth it for the child to be healthy and socially continent for stool.



Lifespan Bowel Management Protocol

APPENDIX IX – Timed Sitting

Parents can start a timed sitting – toilet training program with their child with SB as early as two years of age. When starting a program, it's important to assess the child's level of mobility, hand dexterity, and core strength, which allows them to balance while sitting on the toilet. Each are key components to independence and success.

In order for children to eventually become independent with their bowel management, it is important for them to practice getting to the bathroom, pulling down their pants and underwear (or pull up), sitting well balanced on the toilet, performing hygiene, and getting off the toilet safely. Building these habits and skills is a learning process that takes time.

When beginning a timed sitting program, it is important to understand that it is not expected that simply by sitting on the toilet the child will have a bowel movement. This builds consistency towards a bowel program.

- Timed sitting is often done after a meal to take advantage of the gastro-colic reflex; evenings work best for most children
- Start with a well-fitting potty seat
- Use a footstool under the feet so the child has a firm foundation and feels secure and stable while sitting on the potty; positioning the knees above the hips assists with better emptying
- Use distracting activities such as reading books, using tablets or phones to play games or watch videos
- Doing timed seating in the bathroom rather than in other rooms in the home promotes normal bathroom practices
- Start with short periods of time for sitting, from 3-5 minutes
- Try to do this at the same time every evening
- Make sure to check for any pressure sores on the skin after each timed seating
- Slowly increase the timed sitting by adding 1-2 minutes every month until the child is able to sit for 30-45 minutes
- Once your child is able to sit for 30-45 minutes, they are ready to begin an enema program

As the child becomes more independent with sitting, it is important to consider how clothing can help or hinder this learning process:

- Pants should be easy to pull down
- Shirts or dresses may be rolled up or a clothespin can hold the garment up and out of the way
- Pull ups or underwear may be easier to manage than a tabbed diaper

It is important to teach good hygiene after sitting on the toilet:

- How much toilet paper should be used
- Wiping from front to back.
- Using a Bidet toilet attachment if available
- If tissue is soiled and there is more wiping to do, drop the soiled tissue in the toilet and start over with clean tissue or a wet wipe
- Flushing the toilet

If the child has decreased lower extremity mobility, it is important to make sure the child can move about the bathroom and easily sit on the toilet if they are using crutches. If the child uses a wheelchair in the home, it is important they are able to transfer from wheelchair to toilet safely and back to the wheelchair when complete. These activities of daily living can be reviewed during Physical Therapy or Occupational Therapy sessions.

Lifespan Bowel Management Protocol

APPENDIX X – Potty Seats and Adaptive Equipment Recommendations

With time and experimentation, families find equipment and products that make their bowel management programs easier. Below are some tried and true, family-recommended products.

Potty Seats

Small floor potties are often not large enough to hold the volume of fluid involved in enemas, and children should be encouraged to do their bowel programs in the bathroom from the start for privacy. The potty seat should be comfortable for sitting long periods and should not leave red marks on the legs long after potty time.

A very popular potty seat for small children is the Prince Lionheart® WeePOD Toilet Trainer. The Graco® Clean Contour Potty Ring is not especially soft but has a hole in the back where a parent can fit their hand to administer the enema. For larger children who outgrow toddler potty seats, a popular option is the Special Tomato Portable Potty Seat. It comes in round or elongated shapes to fit either type toilet seat and is often purchased at Adaptivemall.com. Some use a Folding Bedside Commode over the toilet (removing the catch bucket) to lift the seat high enough over the toilet to allow a caregiver's hand underneath. The height may cause more splash mess. The arms of the commode also help children who need more stability. A potty ring is still needed on the bedside commode.



The Rifton Toileting System may benefit children who need trunk support or help with balancing on the toilet. Parents also like it for the cone enema because it makes it a little easier for them to get their hand underneath the child. Often, insurance will cover this equipment. Encourage the family to ask their rehabilitation provider or physical or occupational therapist for proper device guidance and insurance information. A letter of medical necessity may be needed.



Other Adaptive Equipment

A footstool is also helpful for proper stooling positioning. Feet that are allowed to dangle for prolonged periods often lose circulation. Stepstools can be found in many stores and price ranges. One popular footstool is the Squatty Potty.





In addition, many people bring a TV tray into the bathroom to lean on during enema administration and for homework, coloring, or movies during the sitting time. The Table Mate II Folding TV Tray is a favorite.

A bidet attachment on the toilet can be useful for cleaning up after the enema. It is especially helpful for children to become more independent at cleaning themselves.



Rectal/Anal Plugs

A rectal/anal plug is a device placed in the rectal vault to prevent incontinent episodes. ([see APPENDIX XVI - Anal Plugs](#))

Buying Bulk Glycerin

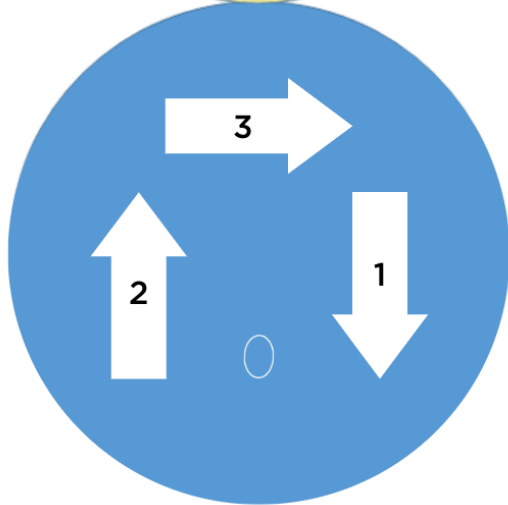
A frequently asked question is where to buy glycerin and what type to use for enemas. Those new to glycerin may want to pick up a small bottle found in the Walmart® Pharmacy section, but for long term use it is more economical to purchase by the gallon online. Any food grade/USP grade glycerin is fine. For those who use gallons of glycerin, a tip to reduce the mess of pouring and spilling is to purchase a pump for gallon containers. Measure how many pumps it takes to reach the amount needed to eliminate measuring each night. For castile soap, a popular brand is Dr. Bronner's unscented castile soap, but generic brands are also fine. It can be found in many grocery stores and pharmacies, often in the health, natural products, or beauty section. Some of the stores that carry castile soap are Whole Foods Market and Target.



Lifespan Bowel Management Protocol

APPENDIX XI – Infant Abdominal Massage for Constipation

1. Form an “I” shape on the left of the baby’s belly (your right). You start on the top left side of the baby’s belly to theoretically stimulate peristalsis or movement of contents of the colon starting in the area of the descending colon.



2. Draw an upside down “L-LOVE” going from your left to right across the top of your baby’s belly, above the belly button or in the area of the ascending colon.
3. Form an upside-down “U-YOU” again from your left to right. Moving from the area of the ascending colon across the transverse colon and down the descending colon.
4. You can use a lotion or an oil to help with reducing friction of your fingers against your baby’s skin.
5. For the best effectiveness, massage should be done routinely (every day), for several minutes.
6. Visit this link to view a short video on YouTube which demonstrates the infant abdominal massage technique for constipation, or search for “I LOVE YOU (baby massage)” posted by Andrius Jovaisas.

Massage the infant in the direction of the arrows.

References

- Choi, H., Kim, S. J., Oh, J., Lee, M. N., Kim, S., & Kang, K. A. (2016). The effects of massage therapy on physical growth and gastrointestinal function in premature infants: A pilot study. *Journal of Child Health Care*. 20(3), 394-404.
- Sinclair, M. (2011). The use of abdominal massage to treat chronic constipation. *Journal of Bodywork and Movement Therapies*. 15(4), 436-445.
- Turan, N., & Atabek Aşti, T. (2016). The effect of abdominal massage on constipation and quality of life. *Gastroenterology Nursing*. 39(1), 48-59.

Lifespan Bowel Management Protocol

APPENDIX XII – Diaper Dermatitis

The best intervention of diaper dermatitis is prevention. Prevention includes frequent diaper changes – every two hours for newborns/young infants due to frequent wetting and every three to four hours for older infants. Frequent diaper changes reduce the skin exposure to the harshness of urine and stool. Don't use harsh cleansers or soaps. The pH of the soap used on an infant's skin should be seven or less (a neutral pH). Fragrance-free and alcohol-free diaper wipes that include an emollient are often better than plain water and a washcloth. Air exposure can also reduce the time of contact of a diaper to the infant's skin.

Infants who have sensitive skin, reddened skin, or skin breakdown need a barrier cream. A barrier cream (more water) or ointment (less water) protects the skin and provides a moisture barrier. There are many different types of barrier products. Your infant or previous children may have responded better to one than another; try a product that has worked on yourself or other children in your family. It is best to try a product for a few days rather than changing day to day to another product unless your infant's skin is worsening. A product that contains zinc oxide or petrolatum is most beneficial. The barrier product should be applied to the skin as thick as cream cheese or like frosting on a cake, not a thin layer.

The care of the skin is often more important when managing diaper dermatitis than the type of barrier product. When the infant's diaper is changed, the remaining barrier cream doesn't need to be removed as the rubbing and friction can cause further skin irritation. During the diaper change and bathing, the infant's skin should be patted dry, not rubbed. This can be difficult, but there should be as little rubbing as possible against any damaged or at-risk skin. The diaper dermatitis should improve within a few days.

Suggested barrier products:

- Hello Bello - Walmart®
- Comforts – Kroger
- Calmoseptine
- Stoma Powder
- A&D
- Cavilon Spray
- Boudreaux's Butt Paste®
- Aquaphor and antifungal
- Critic-aid
- Coloplast Moisture Barrier Cream
- iLEX®
- "Riley" Butt Cream
- Sudocrem
- Vaseline over iLEX®
- Neosporin/Bacitracin
- Medihoney
- Desitin
- Purple Desitin
- Triple Paste
- Browned Flour
- Bag Balm
- Corona Ointment

References

- Heimall, L. M., Storey, B., Stellar, J. J., & Davis, K. F. (2012). Beginning at the bottom: evidence-based care of diaper dermatitis. *MCN: The American Journal of Maternal/Child Nursing*. 37(1), 10-16.
- [Bowel Management for Spina Bifida Facebook group](#). (n.d.). May 5, 2021

Lifespan Bowel Management Protocol

APPENDIX XIII – Digital Rectal Sweep/ Digital Stimulation

A digital rectal sweep can check the rectal vault for any stool impaction or any stool contents that may block flow of enema fluid or effective use of a suppository. A digital rectal sweep can also ensure the rectal vault is empty after a bowel program.

It is best to visually note the location of the anus prior to finger insertion into the anus and rectum. Positioning the child on their side with the knees and hips flexed assists in visualizing the anus. A well-lubricated gloved pointer finger (or little finger for infants) is gently inserted to the rectum approximately one to two inches or the first or second knuckle. A slow 360° circular sweep should be performed. If any stool is present, it can be gently digitally removed. Sometimes hard stool may need to be gently broken up before it can be removed or expelled from the rectal vault. If the stool is hard and constipation is present, rectal bleeding may occur with the digital sweep due to vascularity of the rectum and the dryness of the hard stool. Exceptional care and gentleness is important if an impaction or hard stool are present.

References

- Pediatric Rectal Exam: Why, When, and How (Orenstein). *Curr Gastroenterol Rep.* (2016) 18:4 DOI 10.1007/s11894-015-0478-5
- <https://www.medscape.com/answers/928185-185101/which-rectal-exam-findings-are-characteristic-of-pediatric-constipation>

Lifespan Bowel Management Protocol

APPENDIX XIV – Bowel Program Complications

Defecation Syncope

Defecation syncope¹⁹ is a phenomenon where during defecation, the person may exhibit a range of typical syncopal symptoms such as nausea, dizziness, sweating, low blood pressure, and fainting. Although the phenomenon is well documented in adults, the description in the Spina Bifida population is lacking. Defecation syncope has been described though in Spina Bifida social media pages both by patients and caregivers.

Defecation syncope has also been termed vasovagal syncope, although it may be considered more of a situational syncope.²⁰ The pathophysiology of general vasovagal syncope and situational syncope may be similar although not entirely certain.²¹ The etiology of defecation syncope can include constipation, dehydration, straining (Valsalva), abdominal cramping and abdominal pain. It may be that when a person with Spina Bifida and altered lower extremity circulation is in the sitting position while on the toilet, blood pools in the lower extremities and leads to relative hypovolemia during the bowel program and subsequent evacuation.

Management of defecation syncope includes knowledge of triggering factors, bowel program regularity, prevention of constipation, monitoring of enema fluid temperature and volume, use of a footstool to provide support to the lower extremities, squatting position, or even raising the lower extremities to prevent blood pooling. As well, gripping a ball and squeezing tightly until reduction in symptoms, holding the hands together and tightly pulling until symptom reduction, or crossing the legs and squeezing tightly (for those who have greater lower extremity function) have been recommended to reduce symptoms.²²

Autonomic Dysreflexia

Autonomic Dysreflexia²³ (AD) is well documented in the spinal cord injury literature and is most often seen in people with a lesion level around T6 and above. The signs and symptoms of AD can include a pounding headache, sweating above the level of the lesion, sudden high blood pressure, flushed skin above the level of the lesion, stuffy nose, goosebumps, and/or bradycardia. AD related to a bowel program can be due to constipation, impaction, bowel pain, or hemorrhoids. AD is a medical emergency and needs to be treated promptly as it can result in stroke.

The cause of AD is the interruption of the signals of the autonomic nervous system that prevent the parasympathetic nervous system signals to dampen the sympathetic nervous system signals. The sympathetic nervous signals are unable to turn off due to the block in the spinal cord and cause the typical symptoms.

The immediate management of AD includes raising the head and lowering the legs and loosening any tight clothing. Patients should be supplied with a blood pressure cuff. Blood pressure should be taken every two to five minutes until the episode has resolved. The cause of the AD must be alleviated and in the case of constipation, the bowel program needs to occur. Use of lidocaine around the anus and rectum prior to manual

¹⁹ Komatsu, K., Sumiyoshi, M., Abe, H., Kohno, R., Hayashi, H., Sekita, G., & Daida, H. (2010). Clinical characteristics of defecation syncope compared with micturition syncope. *Circulation Journal*, 0912140559-0912140559.; Sikirov BA. Cardio-vascular Events at Defecation: Are They Unavoidable. *Medical Hypotheses* (1990); 32:231-233

²⁰ Adkisson WO, Benditt DG. Pathophysiology of reflex syncope: A review. *J Cardiovasc Electrophysiol*. 2017 Sep;28(9):1088-1097. doi: 10.1111/jce.13266. PMID: 28776824.

²¹ Adkisson WO, Benditt DG. Pathophysiology of reflex syncope: A review. *J Cardiovasc Electrophysiol*. 2017 Sep;28(9):1088-1097. doi: 10.1111/jce.13266. PMID: 28776824.

²² Runser, L. A., Gauer, R., & Houser, A. (2017). Syncope: Evaluation and differential diagnosis. *American family physician*, 95(5):303-312.

²³ Acute Management of Autonomic Dysreflexia, https://pva-cdnendpoint.azureedge.net/prod/libraries/media/pva/library/publications/cpg_autonomic-dysreflexia.pdf

removal of stool or enema is acceptable as well as ample lubricant. Also, medication management includes nitrate paste or sublingual nitrates to reduce blood pressure that is >150mmHg systolic (dependent on baseline) in adults or >120mmHg in children <5 years of age, 15mmHg above baseline in children five to 13 years, and 15-20mmHg above baseline for teenagers.

Rectal Prolapse

Rectal prolapse²⁴ is the phenomenon of extrusion of the rectal tissue and mucosa outside of the anus. Although this is generally uncommon in children, it can be observed in children with Spina Bifida due to weak anal and rectal musculature. Frequent episodes of constipation can also contribute to rectal prolapse as well as straining during defecation. Caregivers often notice the prolapse during or after the bowel program. At times the prolapsed tissue may bleed slightly due to friable surface vessels.

If a prolapse is observed, the caregiver should be instructed to reduce the tissue as soon as possible. This is done by laying the child down and positioning the knees to the chest. A lubricated, gloved finger should be gently inserted into the rectum and with gentle pressure the tissue should be guided back into the rectal vault. If the prolapse is difficult to reduce, sugar can be dusted over the tissue to reduce edema (via osmosis). The buttocks can be taped (if necessary) to ensure reduction.

Other management strategies include a bowel cleanout if constipation is present, reduction of straining during the bowel program by propping the feet on a bench where the knees are higher than the hips, or performing the bowel program lying down (although this is not an ideal long-term solution). Also increasing the frequency or effectiveness of the bowel program may be necessary.

The more often the prolapse occurs, the more likely manual reduction will not reduce the prolapse. If the prolapse continues or worsens, a referral to general surgery is recommended for further management that can include sclerotherapy or surgery.

Rectal Bleeding

Rectal bleeding can occur in anyone whether they are using a bowel program or not.

Anal Fissures: A small amount of rectal bleeding may come from an anal fissure or a crack in the skin around the anal opening. These fissures occur when bowel movements are extremely large and hard to pass. Most patients or families will notice bright red blood on the toilet paper or wipes. Most fissures heal on their own with good bowel management and passage of softer, smaller caliber stools.

Bowel Perforation: a bowel perforation or hole in the bowel can occur in any patient who performs a bowel program per rectum. Patients with Spina Bifida have very little sensation at the rectal/anal level, which puts them at risk. Bowel perforation may present as a large amount of bright blood from the anus/rectum with severe lower back pain or abdominal pain. This is a surgical emergency and the patient should be seen in the emergency room.

Glycerin and Risk of Colitis

There is some evidence that glycerin that is added to the enema solution can cause ischemic colitis.²⁵ It is theorized that the colonic and rectal mucosa may become irritated by the glycerin and cause inflammation of the lining of the colon. The adult population has been studied and the occurrence was extremely low (.23 percent) and occurred more often in the most elderly patients. The evidence in the pediatric literature in children with Spina Bifida suggests that glycerin in the enema solution is safe and in the correct amount results

²⁴ Rentea, R. M., & St Peter, S. D. (2018). Pediatric and Congenital Colorectal Diseases in the Adult Patient: Pediatric Rectal Prolapse. *Clinics in colon and rectal surgery*, 31(2), 108. Segal J, Waheed A, Tavarez MM. Rectal Prolapse. In: *StatPearls*. StatPearls Publishing, Treasure Island (FL); 2019. <https://europepmc.org/article/NBK/NBK532308>

²⁵ Sheibani S, Gerson LB. Chemical colitis. *J Clin Gastroenterol*. 2008;42(2):115-121.

in timely and more complete evacuation. It would be very important for caregivers to follow the provider advice for appropriate glycerin additive amounts. The amount of glycerin which has been studied in children with Spina Bifida is 30 ml of glycerin in school-aged children. If larger amounts of glycerin are used, the person should be monitored for different from normal abdominal pain during the enema and any rectal bleeding.

Lifespan Bowel Management Protocol APPENDIX XV – Independence

The current rates of independence for individuals in the National Spina Bifida Patient Registry for the following types of management are below:²⁶

		Percent (%) independent		
Selected management	Overall, regardless of age (%)	5-11 year-olds	12 - 19 year-olds	20 years old and older
Suppositories	23%	6%	34%	58%
Standard rectal enemas	26%	<10%	38%	38%
Cone/balloon large volume enemas	21%	10%	37%	45%
Peristeen® transanal irrigation	13%	<5%	<25%	<65%
Antegrade enemas	49%	22%	54%	69%

²⁶ Kelly MS, Wiener JS, Liu T, Patel P, Castillo H, Castillo J, Dicianno BE, Jasien J, Peterson P, Routh JC, Sawin K, Sherburne E, Smith K, Taha A, Worley G. Neurogenic bowel treatments and continence outcomes in children and adults with myelomeningocele. *J Pediatr Rehabil Med.* 2020;13(4):685-693. doi: 10.3233/PRM-190667. PMID: 33325404; PMCID: PMC8776357.

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APPENDIX XVI – Anal Plugs

The anal plug or tampon is a device which blocks stool from being expelled from the rectum. The anal plug is not used as a primary device/method to prevent incontinence. An anal tampon is a device that is inserted in the rectal vault to reduce the risk of unanticipated defecation. An anal tampon may be used during a situation when an unanticipated bowel accident would be unacceptable such as during a swim outing or a job interview or while traveling. Use of the anal plug has been studied and successfully used in children four years of age and older in other countries. The anal plug has not been approved for use by the FDA in the United States. However, anal plugs may be available for online purchase from other countries.

There are different types of anal plugs which have differing levels of success. The vaginal tampon for feminine hygiene has been used successfully as an anal plug. The Coloplast Company (maker of the Peristeen System) makes the Peristeen Anal Plug. There is also an anal insert. The correct insertion of the anal plug is important for success. The plug is inserted beyond the rectal sphincter and into the rectal vault. Both types of anal plugs (feminine hygiene tampon and Peristeen anal plug) are removed by pulling the string that is external to the anus.

References

Shoshan L, Ben-Zvi D, Katz-Leurer M. Use of the anal plug in the treatment of fecal incontinence in patients with meningomyelocele. *J Pediatr Nurs*. 2008 Oct;23(5):395-399. doi: 10.1016/j.pedn.2006.09.006. Epub 2008 May 2. PMID: 18804021.

Bond C, Youngson G, MacPherson I, Garrett A, Bain N, Donald S, Macfarlane TV. Anal plugs for the management of fecal incontinence in children and adults: a randomized control trial. *J Clin Gastroenterol*. 2007 Jan;41(1):45-53. doi: 10.1097/MCG.0b013e31802dcba5. PMID: 17198065.

Further information and pictures of anal plugs are available at

<https://www.continenceproductadvisor.org/faecaldevices>

A reliable personal review of the anal tampon is available at

<https://www.incontinencesupport.org/phpBB3/viewtopic.php?f=31&t=2503>

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APPENDIX XVII – Considerations for a Colostomy

A colostomy is generally considered the last option for bowel management. Recent studies identified only about 2% of individuals with Spina Bifida manage their bowels with a colostomy with the majority being adults.²⁷ But for many this may be an option before they proceed through the recommended list that has been described due to personal rationales such as independence, dexterity, severe pressure ulcers or sacral wounds or personal preference. This surgical option brings a piece of colon to the anterior surface of the abdomen where a bag can be attached to collect stool as its endpoint. The bag needs to be changed and emptied periodically by an individual or a caregiver. Complications such as skin breakdown, colostomy hernia are relatively common (20%-30%) and patients should be referred to a specialist for counsel on this surgical procedure and ideally a wound care nurse or practitioner who can provide proper follow-up and management techniques to optimize this management.

References

- Ahn, Y., Hong, G. S., Lee, J. H., Lee, C. W., & Kim, S. O. (2020). Ischemic colitis after enema administration: incidence, timing, and clinical features. *World Journal of Gastroenterology*. 26(41):6442–6454. <https://doi.org/10.3748/wjg.v26.i41.6442>
- Chu, D. I., Balsara, Z. R., Routh, J. C., Ross, S. S., & Wiener, J. S. (2013). Experience with glycerin for antegrade continence enema in patients with neurogenic bowel. *The Journal of Urology*. 189(2):690–693. <https://doi.org/10.1016/j.juro.2012.08.20>

²⁷ Wiener et al., “Bowel Management and Continence in Adults with Spina Bifida: Results from the National Spina Bifida Patient Registry 2009-15.”

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APPENDIX XVIII – Pregnancy Considerations

Pregnancy and Bowel Management

Pregnancy can increase the incidence of constipation in women with Spina Bifida. It is recommended to continue the routine bowel program but as the uterus gets larger, especially during the second trimester, the flushes may be less successful and increased flushes as well as changes to the solution may be necessary. It is also important to prevent constipation if a shunt is present in the presence of an enlarged uterus, which can progress to shunt malfunction.

There is also the risk of skin breakdown at the site of a cecostomy/Chait tube or Mic-Key button for bowel flushes. This is noted more often during the second trimester and beyond. And finally, it is important that if the woman has an augmented bladder or cecostomy or MACE, the urologist and surgeon may possibly need to be present at a cesarean birth. This is to address any complications or anatomic issues that may arise during the procedure due to the proximity of the uterus to the MACE channel, cecostomy channel, bladder augmentation, or appendicovesicostomy.

References

- Sivarajah K, Relph S, Sabaratnam R, Bakalis S. Spina Bifida in pregnancy: A review of the evidence for preconception, antenatal, intrapartum and postpartum care. *Obstet Med.* 2019;12(1):14-21. doi:10.1177/1753495X18769221
- Whiteley I and Stewart P. "Antegrade continence enema (ACE) in adults: a review of long-term outcomes and complications from a single institution." *Australian and New Zealand Continence Journal*, Vol. 26, No. 4, Summer 2020, 90-97
- Macdonald, MC, Garner, JP, Selby, KF, & Nelson, R. (2009). Successful pregnancy and delivery following a Malone antegrade continence enema procedure. *Techniques in Coloproctology.* 13(4):337.
- Arata M, Grover S, Dunne K, Bryan D. Pregnancy outcome and complications in women with Spina Bifida. *J Reprod Med.* 2000 Sep;45(9):743-748. PMID: 11027084.

Lifespan Bowel Management Protocol

APPENDIX XIX – Suppositories

A Guide for Proper Use of a Liquid Glycerin Suppository

Gather your supplies:

- Liquid Glycerin Suppository
- Water-soluble lubricant
- Chucks Pads
- Potty chair with arms (if needed)
- Step stool for toilet
- Book to read, tablet or music

Tips:

- Pick a convenient time during the day (evenings are often best)
- Same time every day after a meal
- Chart your results on a calendar until your child has established a good emptying pattern
- All supplies should be LATEX-FREE

Giving the suppository:

- Have your child lay in the “Knee/Chest” position or on their left side to allow gravity to assist in preventing leakage
- Place the Chucks pad under your child’s bottom
- Hold the glycerin suppository ampule upright
- Twist off and remove cap
- Lubricate tip (some brands come pre-lubricated but if you are reusing the bulbs, please remember to lubricate prior to insertion)
- Insert the tip of the glycerin suppository into the rectum until the large bulb is against the anal opening
- Squeeze the glycerin to empty the contents and continue to squeeze while in the rectum for 2-10 minutes to prevent aspiration of glycerin or stool back into the bulb
- Check to see that fluid is not leaking out, but is staying in the rectum
- Pinch your child’s buttocks together to prevent leakage
- Remove the bulb
- Have your child sit upright with a diaper on (infants) or on the potty chair/toilet with feet flat on the floor or a stool under their feet
- Chart results