

## **Spina Bifida:**

*Your Guide to  
a Healthy Life*



**SPINA BIFIDA  
ASSOCIATION**

# Bowel Function & Care

For ages 0-18+

***Adapted from Guidelines for the Care of  
People with Spina Bifida, 2018***

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# Introduction

Managing bowel function can be one of the biggest and most important challenges accompanying the diagnosis of Spina Bifida. Spina Bifida results in neurogenic bowel, meaning not having control of bowel movements. Higher Spina Bifida lesion levels make it difficult for the bowel to empty, resulting in constipation or impaction. Lower lesions result in difficulty containing stool, leading to incontinence.

The importance of bowel management goes beyond constipation and incontinence. These problems contribute to urinary incontinence, urinary tract infections (UTIs), shunt malfunction, potential for skin breakdown, hemorrhoids, anal fissures, loss of social and work opportunities, and decreased quality of life. Staying on top of bowel management using approaches that are realistic for parents and adults with Spina Bifida can greatly improve quality of life.

A successful bowel management program must meet an individual's needs. The following guidelines are intended to help achieve the goal of bowel continence without constipation, starting with the least invasive approach and moving toward more invasive techniques. These guidelines should be followed with the help of a health care professional with expertise in bowel management in Spina Bifida.



# Guidelines

## 0-11 Months

1. Monitor your baby's stool frequency, consistency, and amounts.
2. Breastfeeding, if possible, is preferred as breastmilk is easier to digest and helps restore the baby's beneficial gutbacteria after surgery.
3. Before using any oral laxatives, you should first try to manage constipation through diet (plenty of fiber and fluids) and/or rectal stimulants (glycerin suppositories).
4. Use barrier creams (creams with zinc oxide) to protect the diaper area from rashes or skin breakdown (Integument (Skin) Guideline).

## 1-2 Years

1. It is strongly recommended that you set a goal of bowel continence for your child. Your child's health care provider can help you work on toilet training.
2. Toilet training may include fiber intake, fluids, exercise, and timed bowel movements after meals.
3. At this age, your child may need a combination of diet (fiber and fluids) oral medication (sennoside or polyethylene glycol, commonly known as Miralax®) and "bottom up" intervention in the form of suppository, mini enema or enema to meet the goal of bowel continence without constipation.
4. Use barrier creams (creams with zinc oxide) to protect the diaper area from rashes or skin breakdown (Integument (Skin) Guideline).
5. A Spina Bifida clinic or specialist with expertise in bowel management in Spina Bifida can provide guidance.



## 3-5 Years



1. Keep in mind that constipation and bowel incontinence can lead to other problems, including shunt malfunction, UTIs, skin breakdown, and social isolation.
2. Bowel management should include fiber intake, fluids, exercise, and timed bowel movements after meals.
3. Your child may need a combination of diet (fiber and fluids), oral medication (sennoside or polyethylene glycol, commonly known as Miralax®) and rectal intervention in the form of suppository, mini enema or enema to meet the goal of bowel continence without constipation.
4. Use barrier creams (creams with zinc oxide) to protect the diaper area from rashes or skin breakdown (Integument (Skin) Guideline).
5. A Spina Bifida clinic or specialist with expertise in bowel management in Spina Bifida can provide guidance.

## 6-12 Years

1. Keep in mind that constipation and bowel incontinence can lead to other problems, including shunt malfunction, UTIs, skin breakdown, and social isolation.
2. Focus on developing independent bowel management skills to minimize and manage bowel accidents.
3. Your child may need a combination of diet (fiber, fiber supplements, and fluids) oral medication (sennoside or polyethylene glycol, commonly known as Miralax<sup>®</sup>) and rectal intervention in the form of suppository, mini enema or enema to meet the goal of bowel continence without constipation.
4. Consider working with school staff to track bowel accidents and assist with self-management. The school nurse can play a vital role in helping your child reach educational and health goals.
5. Use barrier creams (creams with zinc oxide) to protect the perineal from rashes or skin breakdown (Integument (Skin) Guideline).
6. Consider using a bowel habit diary with your child to better understand what triggers bowel accidents and establish an effective routine. This diary can include medications, diet, bowel management technique (timed toileting, suppository, enema, etc.), and whether there have been bowel accidents, constipation, or loose stools. There is an example of a bowel habit diary at the end of this guideline.
7. Bowel management may include fiber intake, fluids, exercise, and timed bowel movements after meals.
8. Discuss other options for treatment if the above have failed, including a cone enema routine (Fig. 1) or transanal irrigation system (such as Peristeen<sup>®</sup> in Fig. 2). Surgical options may include a cecostomy, which is a tube implanted in the start of the large intestine to help clear stool as in Fig. 3, or a Malone Antegrade Continence Enema (MACE), in which an opening called a stoma is created in the lower abdomen allowing the enema to be given directly into the colon.
9. A Spina Bifida clinic or specialist with expertise in bowel management in Spina Bifida can provide guidance.

## 13-17 Years

1. Keep in mind that constipation and bowel incontinence can lead to other problems, including shunt malfunction, UTIs, skin breakdown, and social isolation.
2. Focus on developing independent bowel management skills to minimize and manage bowel accidents (Self-Management and Independence Guideline).
3. Bowel management for your child may include a combination of diet (fiber, fiber supplements, and fluids), exercise, and timed bowel movements after meals. In addition, oral medication (sennoside or polyethylene glycol, commonly known as Miralax<sup>®</sup>) and rectal intervention (suppositories, enemas) may be necessary to meet the goal of bowel continence without constipation.
4. Use barrier creams (creams with zinc oxide) to protect the perineal area from breakdown (Integument (Skin) Guideline).
5. Consider using a bowel habit diary with your child to better understand what triggers bowel accidents and establish an effective routine. This diary can include medications, diet, bowel management technique (timed toileting, suppository, enema, etc.), and whether there have been bowel accidents, constipation, or loose stools. There is an example of a bowel habit diary at the end of this guideline.
6. Discuss other options for treatment if the above have failed, including a cone enema routine (Fig 1) or transanal irrigation system (such as Peristeen<sup>®</sup> in Fig. 2). Surgical options may include a cecostomy, which is a tube implanted in the start of the large intestine to help clear stool as in Fig. 3, or a Malone Antegrade Continence Enema (MACE), in which an opening called a stoma is created in the lower abdomen allowing the enema to be given directly into the colon.
7. A Spina Bifida clinic or specialist with expertise in bowel management in Spina Bifida can provide guidance.
8. Your child should develop a plan with care providers to handle personal hygiene in case of a bowel accident (such as cleaning up, changing clothes, and other strategies).



## 18+ Years



1. Keep in mind that constipation and bowel incontinence can lead to other problems, including shunt malfunction, UTIs, skin breakdown, and social isolation.
2. Focus on developing independent bowel management skills to minimize and manage bowel accidents (Self-Management and Independence Guideline).
3. Talk with your provider about how your bowel program may impact sexual relations.
4. Use barrier creams (creams with zinc oxide) to protect the perineal area from breakdown (Integument (Skin) Guideline).
5. Consider using a bowel habit diary to better understand what triggers bowel accidents and establish an effective routine. This diary can include medications, diet, bowel management technique (timed toileting, suppository, enema, etc.), and whether there have been bowel accidents, constipation, or loose stools. There is an example of a bowel habit diary at the end of this guideline.
6. Bowel management may include a combination of diet (fiber, fiber supplements, and fluids), exercise, and timed bowel movements after meals. In addition, oral medication (sennoside or polyethylene glycol, commonly known as Miralax®) and rectal intervention (suppositories, enemas) may be necessary to meet the goal of bowel continence without constipation.
7. Discuss other options for treatment if the above have failed, including a cone enema routine (Fig. 1) or transanal irrigation system (such as Peristeen® in Fig. 2). Surgical options may include a cecostomy, which is a tube implanted in the start of the large intestine to help clear stool as in Fig. 3, or a Malone Antegrade Continence Enema (MACE), in which an opening called a stoma is created in the lower abdomen allowing the enema to be given directly into the colon.
8. A Spina Bifida clinic or specialist with expertise in bowel management in Spina Bifida can provide guidance.
9. Develop a plan with care providers to handle personal hygiene in case of a bowel accident (such as cleaning up, changing clothes, and other strategies).

# Example of a Bowel Habit Diary

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

**Figure 1.  
Cone Enema  
Irrigation System**



**Figure 2.  
Peristeen®  
Transanal  
Irrigation System**



**Figure 3.  
Cecostomy  
Tube**

