



# A Bowel Management Perspective

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Your cell phone rings and you glance down at the number displayed on the screen. It is the call you dread and yet comes all too often. Your child's school is calling for the second time this week to inform you that you need to come pick him up, as he/she has had another stool accident. You leave work early, yet again, and pull into the school parking lot and heading to the school office you can see your "baby's" tear stained face through the window. So many emotions crossing through you of frustration, sadness, worry and you know your child is suffering from sadness and embarrassment after much ridicule from classmates after each stool accident.

Fecal incontinence can be devastating to the child, the parent, and often the entire family who suffers from it. It often is a barrier of being socially accepted, which in turn can result in long term psychological consequences. In order to treat fecal incontinence it is important to understand the potential causes.

First and foremost, your child needs to have an in depth evaluation to determine which of 3 categories he/she fits into; Pseudo-Incontinence, True Fecal incontinence with Diarrhea, or True Fecal Incontinence with Constipation. Once the true cause of the fecal incontinence is determined, the treatment can then be carefully tailored to meet the needs of your child. Although there are some specific guidelines that must be followed, it also is much trial and error and close monitoring until the exact treatment needed to be successful is determined. The goal is to have your child socially clean and to ensure proper emptying of the colon.

## Fecal incontinence (pseudo incontinence) due to severe constipation

This group of children has good prognosis for having bowel control. This type of constipation may or may not be associated with another diagnosis. Regardless, if the constipation is not well managed, it may result in pseudo incontinence. Thousands of children suffer from many degrees of constipation. Through our experience, we have noticed that a mild form of constipation can often be managed by a stool softener; however, the more severe case of constipation needs to be treated with a true provocative laxative. We find that a senna based laxative provides the best response increasing bowel

peristalsis, thus resulting in a bowel movement. The amount of senna needed to provoke the colon to contract varies greatly from child to child and colon to colon. The exact amount that is required is determined during a qualified bowel management program that expands over a week timeframe. Throughout this week of close monitoring, including radiologic evaluation, the goal would be for your child to have one to two voluntary bowel movements in every 24hr period that is soft, well formed, able to be felt is controlled, and in conjunction with x-ray evidence of proper emptying of the colon. This should result in voluntary bowel movements without embarrassing accidents in the underwear.

There are many cases in which the amount of senna required for the colon to be adequately stimulated is such a high dose that it results in loose or urgent stools, thus inhibiting fecal control. In this situation it requires the addition of a 100 % water soluble fiber supplement. The two supplements that we have found to produce the best outcomes are Pectin (a product used for making jelly) and Citrucel Smart Fiber. A diet high in fiber may also be helpful. We suggest that if a high fiber diet is required it should be done under the guidance of a Licensed Registered Dietician, who is familiar with your child's diagnosis. It is also important to make good diet choices that will help minimize the constipation and will encourage the colon to move.

See table below for reference on food choices:

<b>High-Fiber Foods</b>	<b>Low-Fiber Foods</b>
<b>Fruits:</b> Pears, berries, apples with skin, citrus fruits, bananas, skin of fruits, etc.	<b>Fruits:</b> Applesauce, apples without skin
<b>Vegetables:</b> Green leafy vegetables, broccoli, peas, spinach, potatoes with skin, corn, etc.	<b>Vegetables:</b> Iceberg lettuce, white potatoes without skin
Whole wheat or whole grain-based bread, bagels, pasta, cereal, and English muffins	White flour-based bread, bagels, pasta, crackers and English muffins
Brown rice	White rice
Oats and oat bran	Meat, chicken, fish, and eggs
Barley	Dairy products such as yogurt, milk and cheese
Popcorn	Fruit juice
Beans and legumes	Candy
Nuts and seeds	Oils and butter

#### True fecal incontinence with constipation

We have determined that this group of children have a poor prognosis for having bowel control and a slow moving colon. This group of children will need a bowel management

program that consists of a daily enema that will clean the colon once per day. The enema must be tailored to the specific child so that the colon is mechanically emptied at a controlled time of day/evening and then the colon remains quiet in between enemas. This allows the child to stay completely clean in underwear for 24 hours. This group of patients often needs a larger enema with additives to “irritate” the colon and promote the colon to empty. Common irritants consist of a saline based enema with the addition of glycerin and/or castile soap. The use of sodium phosphate in enemas should be limited to once per day and avoided if your child has any kidney damage or failure. Diet and fiber plays a minimal role in this population. However it is still important to offer a nutritional well balanced diet.

### True fecal incontinence with diarrhea

This group of children we have determined has poor prognosis for having bowel control and a fast moving colon, or short piece of colon, thus resulting in diarrhea. This is the hardest type of condition to manage. This will often require a small daily enema with little to no additives and a very strict diet of constipating foods, limiting laxative type foods/drink and daily medication to slow or paralyze the colon between enemas. In accordance with the table above, these children should have foods on the constipating list and limit foods on the laxative list. We do recommend that being strict on the diet at first is important to achieve a clean child, but then offer one food at a time back into the diet to see if the child remains clean or not. If the child remains clean, this is a food item he/she can have without limitation. For these children it is a good idea to provide a daily multi-vitamin. Sugar can be very problematic for these children and in extreme cases, sugar based medications may need to be altered in order to keep the colon quiet throughout the day. This group may also benefit from the addition of a fiber supplement as listed above to help keep the stool bulked and optimize control.

There are additional supplements and products that may be trialed if the child is still not doing well. Again, these products should only be trialed in collaboration with your colorectal doctor and under close observation through a bowel management program. Some of the products we have trialed in the past with varying results include:

- Imodium (Loperimide), first line antidiarrheal
- Lomotil, (a mild narcotic, should be closely titrated under your colorectal doctor’s guidance.)
- Cholestyramine ( a drug normally used to reduce cholesterol, also used to bulk stool, if used, needs replacement of vitamins ADEK-levels need to be monitored ongoing)
- Luvos (a natural medicinal clay, results not yet determined and should not be used unless under the guidance of your colorectal physician).

Again, there are specific protocols for dosing, titrating, and combining these medications that should only be done under close monitoring, a reputable bowel management program, and your colorectal physician.

#### Independence with bowel management

As a parent, you worry first about your child being clean at a young age as they enter school. Then becomes the worry about how they will maintain this as they get older and need, or want, to become more independent? There are options to support independence for those patients for whom it has been determined daily enema is needed to remain clean. Surgical and non-surgical options are available. A common surgical option includes the Malone procedure in which the appendix or piece of bowel is used to create a channel from the colon to a small opening at the belly button. This opening allows the independent child/young adult to be able to sit on the toilet and administer the enema on their own.

A non-surgical option would be the use of [Peristeen®](#). This is a rectal enema kit that is designed for the patient to be able to self-insert the rectal catheter and then infuse the enema using a conveniently placed hand dial. This system has been used widely in Europe for a long time and is more recently FDA approved in the United States. Our experience suggests that the results vary and you should discuss with your clinical team if your child would benefit from this product or not.

#### Other alternatives for fecal incontinence

A newer and growing option for trying to obtain fecal continence is the use of Sacral Nerve Stimulation, or Sacral Neuromodulation delivered via the InterStim® System by Medtronic, Inc. It is a minimally invasive treatment we offer when other therapies have failed. There is a trial period to assess if the child is a successful candidate for permanent implantation. The therapy involves surgical placement of a probe into the sacral space to provide stimulation of the nerves between the pelvic floor, sphincters and colon, to the brain. It works in a similar fashion to a pacemaker. Medtronic Bowel Control Therapy uses a device that provides gently electrical stimulation to help correct this communication problem.

There is another type of therapy we are trialing which includes the injection of Solesta. Solesta injections are usually used for those children who present with a wide open (patulous) anus and continued fecal incontinence. Injections of Solesta into the anus act as “a filler” to bulk up the tissue of the anal canal and assist in being able to hold the stool. Our experience shows varying results, and we suggest you discuss this further with your bowel management team.



### Concerns about ongoing bowel management

In reviewing our data for over 20 years, the only long term side effects that we have found with the use of long term senna is a benign effect. The senna may produce a discoloration or darkened color (freckling appearance) of the colon that may be seen during a colonoscopy. This has no clinical significance as far as we know.

For those children who require a high enough dose of senna that they are unable to tolerate the medication, they may have side effects of ongoing nausea, vomiting, or daily abdominal cramping. If these symptoms are NOT COMPATIBLE WITH QUALITY OF LIFE, there may be other options available to discuss with your health care team.

There is data reporting that when young children unintentionally ingested (large amounts) of senna it potentially caused severe diaper rash, blisters, and skin sloughing (similar to a chemical burn) and that this was seen more often in children wearing diapers. Note, that this was not reported in the population of children who were provided therapeutic doses given by parents or caregivers. In our experience we have seen 3 such cases of these burns out of the thousands of children we treat with senna.

Accidental consumption of large amounts of senna, especially by young children, puts them at risk for diarrhea and dehydration. This is why we stress the use of senna under the guidance of your bowel management team.

Supplemental fiber may cause some bloating or loss of appetite due to "feeling full". If this occurs, it may need to be taken in smaller amounts of food or fluid, depending on how your child tolerates it. It is often given in 2-4 oz. of fluid or 1-2 Tablespoons of food followed by a regular meal with good daily fluid intake.

Enemas, laxatives, and supplements, are not addicting. Rather, the child was born with a condition that requires assistance with bowel management routine and may need adjustments as the child grows and enters different stages of life.

### Conclusion

Remember that bowel management is all about quality of life. Quality of life is determined by the patient and the caregiver. Treatment must be feasible to both the child and the family's lifestyle. It is important for the child and family to understand the implications of the bowel management needs. As the child grows and becomes more mature, it may be easier for the child to take more responsibility for this aspect of their treatment. Ongoing bowel management is a life-long commitment and should be provided under the supervision of a good colorectal center and physician to determine the best outcomes.



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