Bowel Management Programme

FOLLOW-UP AND MANAGEMENT OF CHILDREN OPERATED ON FOR AN ANORECTAL MALFORMATION

Bowel Management Programme

FOLLOW-UP AND MANAGEMENT OF CHILDREN OPERATED ON FOR AN ANORECTAL MALFORMATION

by Dalia Aminoff

Associazione Italiana per le
Malformazioni Anorettali - AIMAR
Italian parent's organization
with children born with ARM

It is knowledge
that influences
and equalizes the
social condition
of man

Benjamin Disraeli

Those of us who deals with anorectal anomalies owe a special debt to many people.

In particular, we would like to acknowledge the remarkable work of Dr. Alberto Peña in this field, and his collaborator Kathleen Guardino O'Connor for having written this paper, Dr. Marc Levitt and Dr. Antonio Zaccara for their contributions as editors, Daria Violani for the graphics, and Vincenzo Toma for printing the copies we sent to the USA for the Colorectal Club 2004.

Our gratitude to all of those who have generously donated their expertise in order to publish this text.

In 1996, I was in Long Island NY, and I listened to a presentation by Kathleen O'Connor Guardino on the topic of Bowel Management. It was the first time I ever heard the words "bowel management" and these two words gave me hope that our children could be kept and remain artificially clean.

When I returned to Italy I wanted others to share in the hope that we have a way to improve the quality of life for our children. Hence, the gathering of the written material and its translation into Italian.

In the intervening years, the Italian booklet on bowel management has been used in many pediatric surgery departments throughout Italy. As a result many children and their families, doctors and nurses continue to benefit from the philosophy of support which is behind it.

Today, I feel that I have come full circle in my wish to share hope. Once again I hope the English booklet will help others and give all of our children the hope for a good life.

Dalia Aminoff
(mother of Emanuele dob 14-2-90)

Fecal incontinence represents a devastating problem for all who suffer from it. It often prevents a person from becoming socially accepted which in turn, provokes serious psychological sequelae. This is a problem which affects more children than previously thought.

Operations designed to treat fecal incontinence are still controversial and render variable results. That is why at our Institution, we have developed a Bowel Management Program specifically designed to help individuals with this problem.

The Bowel Management Program basically consists in teaching the patient or his/her parents how to clean the colon once daily so as to stay completely clean in the underwear for 24 hours. We do this by keeping the colon quiet in between enemas. The program, although essentially simplistic, is implemented by trial and error over a period of one week. The patient is seen each day and an x-ray film of the abdomen is taken so that we may monitor on a daily basis, the amount and location of any stool left in the colon as well as the presence of stool in the underwear. We then decide whether the type and/or quality of the enemas should be modified as well as diet and/or medication.

As children grow older, they want to be more independent and do not like their privacy infringed on by adults helping them with their bowel management. When a child begins to feel this way and they have been successful with the bowel management, we offer them a "continent appendicostomy" (also known as a Malone or ACE procedure). This is an operation consisting in creating a small orifice in the umbilicus (belly button) through which the patient can pass a small catheter into their colon and administer the enemas themselves while sitting on the toilet. It allows the child to be more independent and further improved his/her quality of life.

We have treated over 500 patients and have been successful 95% of the time. As you can imagine, it is a rewarding experience to witness the dramatic change in the quality of life of the children subjected to this program.

Dr. Alberto Peña
Chief of Pediatric Surgery
Schneider Children's Hospital
Long Island – New York

Fecal continence is one of the most important achievements in a child's development. Ability to control passage of stool is one of the first manifestations of independence by which interaction with parents and environment is exerted by the child.

Fecal continence which is usually reached by the age of 2-3 may be partially or entirely compromised in children born with some anomalies of the large bowel (anorectal anomalies and Hirschsprung's disease) or anomalies of the innervation of the pelvic organs such as spina bifida.

Fecal incontinence may have a significant social impact regardless of the age it arises.

Moral conditioning which is usually associated with toilet training leads to a close association between stool and something "dirty" and negative.

It is not difficult to imagine what kinds of difficulties a child can go through when he/she are not able to hold the stool.

Nowadays, much can be done for children with fecal incontinence. An accurate evaluation along with an appropriate follow up program can have an enormous impact on psychological and social consequences of being incontinent. Treatment of incontinence should be regarded as a “care” aiming at raising a child in a normal context with a normal lifestyle.

Bowel Management is a treatment program which has been purposely conceived for children born with imperforate anus: however, it can be applied to all children with fecal incontinence.

FECAL INCONTINENCE

The medical definition of fecal incontinence is simplistic, in fact it is defined as “the incapacity to voluntarily hold the feces”. Usually, we can divide fecal incontinence into two categories: 1) real fecal incontinence, and 2) pseudoincontinence.

Real fecal incontinence

In this case, the normal mechanism of the bowel control is damaged. An alteration of the muscles which surround the anorectal canal along with poor sphincters (those muscles which control the anus) are responsible for fecal incontinence in children operated on for anorectal malformations with bad prognosis. The innervation (supply of nerve connections) of these muscles are important for their correct function. In addition, colonic motility is seriously abnormal in anorectal malformations and spina bifida. A deficit of the innervation occurs in anorectal anomalies as well as in other conditions. For example, in cases of spina bifida, the contraction and relaxations of the muscles, as well as sensation are both deficient. Thus the presence and the passage of stool, and the perception of the difference between solid and liquid stool and gas is interrupted.

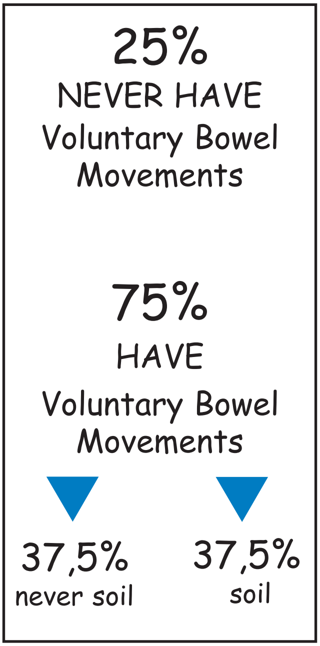
Pseudo-incontinence

In this situation the child behaves like he/she is fecally incontinent. Further study, however, shows that he/she suffers from severe constipation and fecal impaction. Amazingly, when the disimpaction is treated and the patient receives enough laxatives as to avoid constipation, be/she becomes continent.

It is extremely important to distinguish between real incontinence and pseudoincontinence in order to identify the origin of the problem and consequently to plan the best treatment.

FECAL INCONTINENCE AND ANORECTAL MALFORMATIONS

From recent studies it is found that 75% of all children with anorectal malformations who have undergone a correct and successful operation, have voluntary bowel movements after the age of 3. About half of these children soil their underwear occasionally. Those episodes of soiling are usually related to con-



stipation. When the problem is treated properly, the soiling frequently disappears. Thus, approximately 40% of all children have voluntary bowel movements and no soiling. In other words, they behave like normal children. There is a long way to go and a lot to do to improve the quality of life of a significant number of children. Children with good bowel control still may suffer from temporary episodes of fecal incontinence, especially when they experience severe diarrhea. Some 25% of all children suffer from fecal incontinence, and they must receive some form of bowel management to keep them clean.

Despite a good operation to correct a child's anorectal defect, there are many children who do not achieve bowel control or suffer from different degrees of fecal incontinence.

It is important to know the three specific factors that play a role in achieving fecal continence:

1) the child needs to have sensation (within the rectum)

2) the child needs to have good motility of the colon

3) the child needs to possess good voluntary muscles or sphinteric mechanism

Sensation within the rectum

Most children born with anorectal malformation lack the intrinsic sensation to feel stool or gas passing through their rectum. Therefore, many times the child may unknowingly soil, become accustomed to the smell of stool, which upsets the entire family and anyone around him/her.

Motility of the colon

The rectosigmoid is that portion of the bowel that acts as a natural reservoir of the feces. It is physiologically important in order to accumulate and “store” the feces between every other bowel movement.

Normally, the rectosigmoid remains quiet for periods of 24 to 48 hours (time necessary to accumulate the feces); then a massive peristaltic wave allows the complete emptying of it and then to remain quiet again. If the rectosigmoid is slow, the stool stays stagnant, hence, constipation occurs, the child may suffer from overflow incontinence and will thus soil. On the other hand, if a child has no rectosigmoid (no reservoir) he/she will be passing stool constantly, which we call colonic hypermotility.

Muscles

These muscles, or voluntary sphincter, normally surround the rectum and anus and are considered fundamental for the control or continence. Children with anorectal malformations suffer from different degrees of lack of development of these muscles and therefore incapacity to hold the stool.

The new surgical technique introduced by Dr. Alberto Peña at the beginning of the 1980s, has an enormous advantage compared to the previous operations to position the rectum exactly within the limits of the sphincteric mechanism responsible for continence.

Unfortunately, the sphincter (muscles) are frequently not normal: the more complex the defect, the less developed the muscle complex.

The surgeon is able to predict in advance which children may have good functional prognosis and which children may have poor prognosis.

After the main repair and after the colostomy closure it is possible to establish the functional prognosis.

The tables below shows the most common indicators of good and poor prognosis and the prognostic signs.

INDICATORS OF GOOD PROGNOSIS FOR BOWEL CONTROL	INDICATORS OF POOR PROGNOSIS FOR BOWEL CONTROL
■ Normal sacrum	■ Abnormal sacrum
■ Prominent midline groove (good muscles)	■ Flat perineum (poor muscles)
■ Some types of anorectal malformations:	■ Some types of anorectal malformations:
● Rectal atresia	● Rectobladderneck fistula
● Vestibular fistula	● Cloacas with a common channel <3 cm
● Imperforate anus withouta fistula	● Complex malformations
● Cloacas with a common channel <3 cm	
● Less complex malformations: perineal fistula	

GOOD PROGNOSIS SIGNS	POOR PROGNOSIS SIGNS
■ Good bowel movement patterns: 1 - 2 bowel movement per day - no soiling in between	■ Costant soiling and passing of stool
■ Evidence of sensation when passing stool (pushing, making faces)	■ No sensation (no pushing)
■ Urinary control	■ Urinary incontinence, dribbling of urine

Functional prognosis in relation to the type of malformation

Parents must be realistically informed as to their child's chances for bowel control avoiding needless frustration later on. It is imperative to establish the functional prognosis of each child as early as possible in order to avoid creating false expectations for the parents. Since we are dealing with a spectrum of defects, we should expect a spectrum of results.

TYPE OF DEFECT	sex	voluntary bowel mov.	soiling	voluntary bowel mov. *never soiling*	constipation
Perineal fistula	F/M	100%	0%	100%	26%
Anal atresia or stenosis	F/M	100%	16%	84%	80%
Vestibular fistula	F	94%	38%	71%	64%
Bulbar fistula	M	88%	65%	32%	59%
ARM without fistula	F/M	85%	41%	71%	47%
Cloaca C. Ch.<3 cm.*	F	83%	78%	27%	32%
Prostatic fistula	M	76%	78%	28%	50%
Real vaginal fistula	F	75%	100%	0%	25%
Cloaca C. Ch.>3 cm.*	F	59%	89%	22%	53%
Bladder-neck fistula	M	28%	100%	0%	29%

* C. Ch.= common channel

Once the diagnosis of the specific defect is established, the functional prognosis can be predicted. If the child's defect is of a type associated to good prognosis – such as a vestibular fistula, perineal fistula, rectal atresia, rectourethral bulbar fistula, or imperforate anus with no fistula – one should expect that the child will have voluntary bowel movements by the age of 3. These children will still need supervision to avoid fecal impaction, constipation and soiling.

If the child's defect is of the type associated with a poor prognosis – for example, a very high cloaca with a common channel longer than 3 cm or a recto-bladder-neck fistula, parents must be informed that their child will most likely need a bowel management program to remain clean and socially acceptable. This should be implemented when the child is 3 or 4 years old, before he/she begins spending a great deal of time away from home. Children with rectoprostatic fistulas have an almost equal chance of having voluntary bowel movements or being incontinent. In these children, an attempt should be made to achieve toilet training by the age of 3. If this proves to be unsuccessful, bowel management should be immediately implemented so that the child can remain clean and avoid psychological sequelae. However since the child has significant possibilitier to be toilet trained; every summer vacation we stop the bowel management and try to train him/her.

Urinary incontinence occurs in male children with anorectal malformations only when they have an extremely defective or absent sacrum or when the basic principles of surgical repair are not followed and important nerves are damaged during the operation. Thus, the overwhelming majority of male children with anorectal malformations who are properly treated have urinary control.

This is also true for female children with all anorectal malformations, except cloacae. A significant number of children who have undergone repair of a cloaca require intermittent catheterization in order to empty the bladder. This happens in 69% of children with a high cloaca, defined as a common channel longer than 3 cm, and 20% of children with a low cloaca, defined as a common channel shorter than 3 cm. The bladder neck in most girls with cloaca is competent, and therefore, they remain completely dry when treated with intermittent catheterization. If catheterization is not performed, urinary overflow incontinence will occur.

DIFFERENT TYPE OF FECAL INCONTINENCE IN CHILDREN WITH ANORECTAL MALFORMATION

As previously seen, 75% of children operated on for an anorectal malformation will have voluntary bowel movements. Out of them, half will not soil and their parents are encouraged to prevent constipation; while the other half may soil. However, treating the constipation makes the soiling disappear. Occasionally these children require bowel management when the soiling is troublesome.

Children candidates for a reoperation

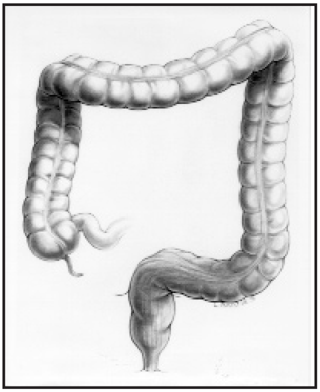
These are children who were previously operated on for an imperforate anus and now have fecal incontinence. A second operation with the hope of obtaining good bowel control can be performed if the following conditions are met:

1. The child was born with a good sacrum, good sphincter mechanism and a malformation with good functional prognosis.
2. There is evidence that the rectum is completely mislocated
3. The child has the full length of his/her colon.

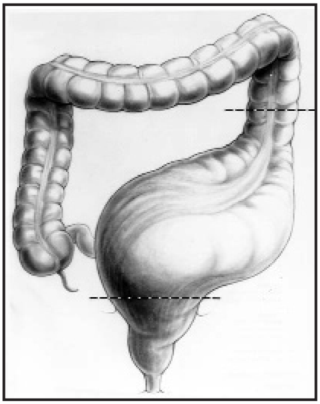
A posterior sagittal anorectoplasty can be performed and the rectum can be relocated within the limits of the sphincter mechanism. In this case, approximately 50% of the children operated on under these circumstances have a very significant improvement in bowel control to the point that they do not require bowel management to remain clean.

Children with pseudo-incontinence

Most of these children suffer from different degrees of dilatation of the rectum and sigmoid, a condition defined as megarectosigmoid (constipation). There is also evidence that these children suffer from a hypomotility



- normal colon



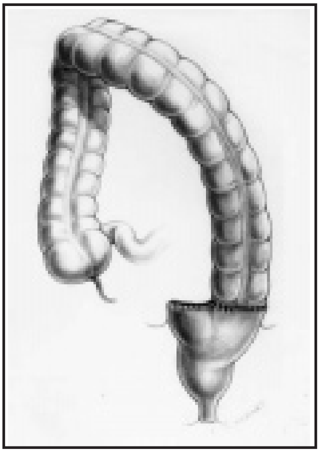
- megarectosigmoid

disorder that interferes with complete emptying of the rectosigmoid. These children are born with a good prognosis type of defect and underwent a technically correct operation, but did not receive appropriate treatment for constipation. They therefore developed fecal impaction and overflow pseudo-incontinence.

The fecaloma needs to be removed with enemas and colonic irrigations (usually an aggressive program of enemas) to clean the megarectosignoid. Subsequently the constipation is treated with the administration of large doses of laxatives. The dosage of the laxative is increased daily until the right amount of laxative is reached in order to empty the colon completely every day.

Once the constipation is treated adequately, if the child cannot control the stool, then we conclude that he/she suffers from real incontinence and constipation. He/she cannot be treated with laxatives but rather needs the bowel management for fecal incontinence that will be described here.

On the other hand, once the constipation is treated adequately, if it becomes evident that the child is actually continent we then conclude that he/she suffers from overflow pseudoincontinence. If medical treatment proves to be extremely difficult because the child has a severe megasigmoid and requires an enormous amount of laxatives, the surgeon can offer a surgical alternative consisting of a resection of the sigmoid colon.


- resected colon

Before offering these children a sigmoid resection it is mandatory to confirm that they are suffering from overflow pseudoincontinence rather than real fecal incontinence with constipation. Failure to make this differentiation may lead to an unnecessary operation; a fecally incontinent constipated child subjected to this operation would be changed to one with diarrhea, who is much more difficult to manage.

As a result of this operation, the laxatives required to treat these children can be significantly reduced or even abolished.

Children who are candidates for a Bowel Management

Children who suffer from fecal incontinence after the repair of an imperforate anus are usually those born with a bad prognosis type of defect and severe associated defects (defect of the sacrum, poor muscle complex). However, children who were born with a poor prognosis type of defect may still enjoy a good quality of life when treated with a bowel management program.

Children operated on for imperforate anus who suffer from fecal incontinence can be divided into two well defined groups that require individualized treatment plans:

Children with constipation (colonic hypomotility)

In these children the motility of the colon is significantly reduced. The basis of the Bowel Management is to teach the parents **to clean the child's colon once a day** by the use of a suppository, an enema or a colonic irrigation. No diet or medication is necessary in these cases. The fact that they suffer from constipation (hypomotility) guarantees that they will remain clean in between enemas. The real challenge is only to find out the enema capable of cleaning the colon completely.

Soiling episodes or severe "accidents" occur by an incomplete cleaning of the bowel with feces that progressively accumulates into it.

25%
NEVER HAVE
Voluntary Bowel
Movements
(incontinence)

▼ hypo-motility
▼ hyper-motility

Children with loose stools and diarhea

The great majority of children who suffer from this kind of problem have been operated on before 1980, which means before the introduction of the PSARP (posterior sagittal anoplasty) technique. In those years the techniques frequently included resection of the rectosigmoid (reservoir).

Therefore, this group of children have an overactive colon. Rapid transit of stool results in frequent episodes of diarrhea. This means that even when an enema cleans their colon rather easily, stool keeps on passing fairly quickly from the cecum to the descending colon and the anus. To prevent this, a constipating diet and/or medications to slow down the colon are necessary.

Eliminating foods that further loosen bowel movements will help the colon to move slowly. Some children, however, may have in addition an "irritable" colon which makes the management more challenging.

BOWEL MANAGEMENT

As we have seen, almost 60% of children operated on at birth, for an anorectal malformation, even when they received a technically correct operation will suffer from functional bowel problems of different types.

The main goal of the Bowel Management Program is to improve the quality of life of these children. The good or bad quality of life in every child must be defined by each child and by their parents. Therefore, every child must be free to make a choice after he/she learns about the alternatives offered.

For instance a child that is completely fecally incontinent in whom, an operation is not indicated, has the following alternatives:

1. To remain incontinent and use diapers permanently
2. To try the bowel management program
3. To have a permanent colostomy

The key of success of a Bowel Management program is dedication, timing and sensitivity from the medical team and the nurse, and for them to be authentically interested in the patient. If the elements of sensitivity, authentic interest and dedication are missing, the chances of success of the bowel management are very low.

What is the Bowel Management Program?

The basis of the bowel management program is to clean the colon with the use of enemas once a day and to decrease the motility of the colon with medication or diet to keep the patient clean for the following 24 hrs.

- BOWEL CLEANING (enemas, micro-enemas)
- MODIFICATION OF THE DIET (if necessary)
- MEDICATIONS (if necessary)

There are some medications that are able to slow the motility of the colon. The use of these specific medications such as Lomotil or Immodium must be decided on with the physician.

The program is an ongoing process that is responsive to individual patient and differs from child to child. The success of this program is usually achieved within a week of a process of trial and error and requires a lot of dedication. More than 90% of the children who follow this program are artificially clean and dry for the whole day, can carry out a completely normal life and have a new sense of self esteem and confidence based on an improved quality of life.

It is unacceptable to send a child with fecal incontinence to school in diapers when his classmates are already toilet trained. Children who require diapers or who have accidents while in school because of fecal incontinence are exposed to ridicule from their peers that can lead to adverse psychological sequelae.

The first step is to perform a contrast enema study* in order to learn about the patient's type of colonic motility (hypomotility – constipated or hypermotility type). The bowel management program is then implemented according to the patient's type of colon and the results are evaluated every day. Daily changes in the volume and content of the enemas are made until the colon is successfully cleaned. For this, one should take an x-ray film of the abdomen every day to see whether the colon is empty.

*The contrast enema in children with ARM is performed with hydrosoluble material (Hypaque) and without a previous bowel preparation. The study should never be done with barium; it is important to obtain a picture after the evacuation of the contrast material.

ENEMAS

Equipment needed

1. Enema bag
2. Water soluble lubricant
3. Catheter

A catheter of 20-22 CH. Sometimes it is useful to use a Foley catheter (22 or 24 french) with a 30cc balloon.

4. The determined enema (i.e. Fleet, Ped. Fleet etc.)

There are different types of solutions to use for enemas: there are some ready solutions that can be bought in a drugstore or solutions that can be prepared at home based on water and salt.

The use of the solutions have to be indicated by the physician who is following your child.

The use of phosphate enemas (Fleet) is most convenient since it is already a prepared vial. However, pure saline enemas are often just as effective and some families find it easier and less expensive. Occasionally, children will complain of cramping with the Fleet enema but will have no complaints with the saline one. Children older than 8 years of age or heavier than 65lbs (30 kg) may receive one adult phosphate enema daily. Children between 3 and 8 of age or between 35 and 65lbs (15 and 30 kg) may receive one pediatric phosphate enema a day. Children should never receive more than one phosphate enema a day because of the risk of phosphate intoxication. Children with impaired renal function should use Fleet enemas with caution, or as directed by their doctor.

The phosphate enema administered on a regular basis should result in a bowel movement followed by a period of 24 hours of complete cleanliness. If one enema is not enough to clean the colon (as demonstrated by an x-ray, plus the fact that the child keeps on soiling), then the child requires a more aggressive treatment, and a saline enema is added, in addition to the phosphate. If the addition of the saline enema still results in inadequate results, then high colonic washings are indicated with a Foley catheter attached to an enema bag (see section on enemas using a Foley catheter).

The following table shows how to make a saline solution at home:

WATER	SALT
250 c.c.	1 tsp.
500 c.c.	2 tsp.
750 c.c.	3 tsp.
1000 c.c.	4 tsp.

*Do not exceed 4 tsp salt in 1000 cc. It has been noted children have had serious side effects with over dosage of salt.

These values are just an indication of the amount of salt and water to be used.

As mentioned previously the Bowel Management program is an individual ongoing process and “no magic formula” exists to find out what is the right amount of enema solution necessary for your child. Therefore, a larger volume of saline solution is necessary in those children who have hypomotility as compared to those who have hypermotility and tend to empty their colon in rapidly.

The quantity of salt varies from each child: a large amount of salt can provoke cramps.

The “right” saline enema is the one that can empty your child’s colon and can let him stay clean for the following 24 hours. This can be achieved only by trial and error and learning from previous lack of success.

The solution of the enema should be body temperature to decrease cramping.

Since the program is very personalized, the parents and children learn to look at the consistency and the amount of stool obtained after the enema to determine whether it was effective. After a period of time, parents will know when the enema was not effective and when they need to repeat it with a saline solution. Suppositories very occasionally may be sufficient to stimulate a full bowel movement.

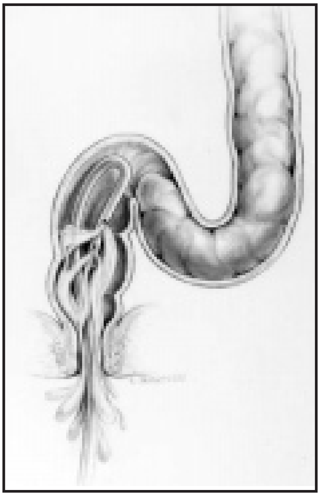
Administering the enema

a) Gather all your equipment

b) Position your child (see section on positioning)

c) Lubricate the catheter tip

d) Gently insert the catheter into the anus as high as possible. The catheter is flexible so parents can maneuver it into the colon. If any resistance is met you may need to instill a small amount of fluid to dislodge some stool. Occasionally leakage occurred with this technique, resulting from kinking of the catheter.



- a kinked catheter

e) Attach the catheter to the enema bag

f) Instill the enema at this time, the higher the bag is held the faster the flow, the lower the bag is held the slower the flow. Giving the enema should take about 5 –10 minutes, if there are cramps you should slow down the flow, by lowering the enema bag to help decrease cramping.

g) Once the enema is instilled you may remove the catheter and hold the buttock cheeks together, trying to retain the fluid for at least 5 minutes if possible.

h) After the retention time is up, you should now ask your child to sit on the toilet for about 30-45 minutes for optimal results. Check the results of the enema, look into the toilet. If no stool or minimal stool, report these findings to your doctor. Your child may require a different or larger enema.

Use of the Foley catheter

The Foley catheter is used as an alternative to the normal catheter and when the enema solution administered leaks.

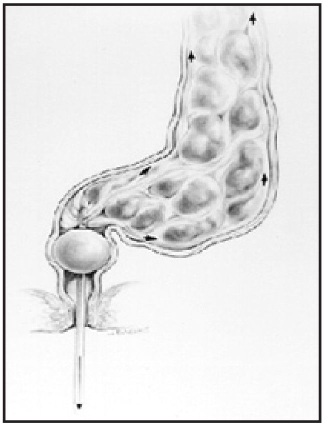
The goal of this procedure is to use a balloon to act as a plug to avoid leaking during the enema process.

Administering the enema:

a) the enema as previously described

b) Lubricate 20 to 24 F Foley catheter and gently introduce it through the anus 4 to inches.

c) Using a 20cc syringe fill it with warm water, attach the syringe to small port and instill 15cc of the water to inflate the baloon then pull back on the catheter. If the balloon comes out, push the catheter back and in-



- Foley catheter

still the remaining 5 cc of water then pull back again. You may continue this process up to the full 30cc. Remember, never to inflate the balloon in the anus or push the catheter in more than 5 inches

d) While keeping tension on catheter, to avoid leaking, proceed with the enema as before.

e) When the enema is complete, clamp the end of the catheter, then detach bag, this will allow the solution to remain for optimal effect.

f) When retention time is up, place your child on toilet and at this point you may deflate the balloon allowing the catheter to slip out, and continue as previously described.

To make sure you are administering the enema in the right way, the nurse or physician should administer the first enema with the parent present. This will clarify any questions the parent may have regarding the technique, positioning or amount of solution to be given.

At what age should the B.M. be started?

First of all, a child who suffers from fecal incontinence is basically a happy child during the first part of his life when he/she is still in diapers because he/she is not different from other children. The problem with these children begin when they have to separate from their protective figures (parents) and start to socialize by themselves in an environment where all their classmates are already wearing normal underwear, whereas the child is still in diapers (2 to 3 years of age). That is the moment when the real problems (discrimination and ostracizing) start, potentially having very serious deleterious psychological effects.

Toilet training for stool is a long-term goal for children with anorectal malformations, although this is not always possible. In children born with a good prognosis type of defects parents should be encouraged to use the same strategies for toilet training as in children with normal anatomy. Between 2 and 3 years of age the parents are instructed to sit the child on the toilet after every meal.

The parents are encouraged to do it as a game and not as a punishment. The child can sit in front of a little table and play with his/her favorite toys.

The parents should sit with the child and not argue or force the child to remain seated. However, if the child gets up, the parents should put the toys away. The child should be rewarded for a bowel movement or voiding while on the toilet.

If the child is not successfully toilet trained by school age, there are two alternatives: 1) do not send the child to school for one more year and continue attempts at toilet training or 2) try the Bowel Management program hopefully on temporary basis. Therefore it is advisable to start the bowel management at approximately 3 years of age. At this age most of the children do not wear diapers.

It is important to stress that the choice of when and how to start the bowel management is something that each parent has to decide. At the same time the child should be conditioned to wearing normal underwear so when he/she goes to school he/she will be like the rest of their classmates who are already toilet trained.

Why use an enema and not a micro-enema?

Administration of a micro-enema to a child that is severely constipated only cleans the last part of the rectum, leaving the colon full of stool which softened by the micro-enema will leak in an easier way thus allowing episodes of soiling.

Obviously there are some exceptions since this is not a rigid rule and there are some children who benefit from the use of microenemas and suppositories. In this case if the goal is reached and the child is clean, there is no point in changing this regimen.

When to administer an enema?

The timing of when to give the enema may also play a role in how efficiently it cleans the bowel. The recommendation is to give an enema after the main meal of the day so as to take advantage of the gastrocolic refex (this reflex happens after each meal).

It is therefore advisable to give the enema every day at the same time in order to create a “routine”. It is also important to consider that if the enema is given every other day the child is expected to expel the amount of stool for two days. Never wait more than 48 hours to give an enema.

How to make the procedure more pleasant for the child?

Success of the enemas depends on making the procedure unpleasant. The child should be encouraged to take his or her time when toileting. To reach this goal it is advisable to make the toilet comfortable. The child should be at ease and use this time for homework, special reading, or a favorite TV program.

How to keep a child quiet while giving the enema?

This is something that requires a lot of creativity and patience from a parent. It can be useful for instance, to play only with certain toys or reading a “special” book which can be read only on this particular occasion. Some parents make the toilet more comfortable by putting a TV or a personal computer with which their children can play.

It is very important to understand what are the best strategies in relation to the age of your child. It is also important to involve siblings and the family in this issue thus not segregating the child to the “enema time”.

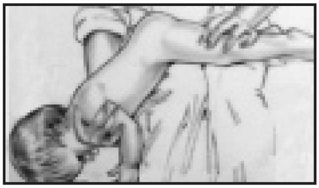
If the child does not want to have the enema administered, there is no point to insist. It is really important to transform a negative experience into a positive one, reinforcing all the positive aspects such as: being clean, wearing underwear, no diapers, the use of a bathing suites, and the possibility to change garments in front of other children.

Which is the best position for administering an enema?

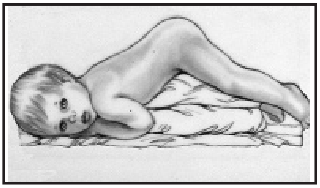
The position of a child is important in determining the efficiency of the enema.

The child should be in a position that would facilitate delivery of the fluid as high up into the colon as possible.

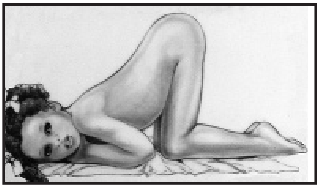
If this is a small child, this can be done by placing the child on the parent's lap with the head down and the buttocks on the lap.



The older child may lie on a bed with his/her buttocks on the bed and a pillow under their abdomen.



Another position for the older child or adolescent is in a knee-chest position with the buttocks in the air.



Adolescents who are trying to achieve independence with the self administration of these enemas may also try the knee-chest position while lying on their sides.

After the administration of the enema

The enema fluid should be retained as long as possible and this depends on the child and the quantity of fluid introduced.

After administration of the enema, the child should sit on the toilet for as long as necessary (usually between 30 to 40 minutes) to allow for emptying of the colon.

It is very important to be sure that the child empty his/her colon otherwise a more aggressive enema is necessary. For the child it is a “torture” to repeat the enema and not benefit from its advantages. Again it is worthwhile repeating that parents learn from trial and error: this is the only way to obtain the maximum benefit from this program.

Parents become experts and know if the amount of stool was enough or insufficient and therefore if the enema achieved the desired effect.

What are the long terms effects of daily enemas?

The bowel management program has been implemented for only the last 20 years. We are not aware of any medical secondary effects that can be attributed to the use of enemas or colonic irrigations. However, we do not know what the consequence could be 20-30 years from now.

It is important to remember that there are several kinds of enemas that can be administered. A Fleet enema is a phosphate enema and can be toxic when given in excess. If the specific recommendations of the manufacturer are followed, problems of phosphorus intoxication or hypocalcemia (low calcium) have not been seen. Many children receive colonic irrigations or enemas with saline solution which is not different from the liquid that integrates throughout our body in terms of the concentration of electrolytes and therefore any secondary effects from the use of these enemas have not been seen.

Seizures (convulsions) have ocurred immediately after the administration of a saline enema, prepared in a careless way. Excessive salt resulted in absorption of sodium and seizures.

Many parents frequently express a common misconception. They think that giving enemas may interfere with nutrition and absorption of nutrients. It is very important for the parents and families to remember that when giving enemas we are only washing the colon and the colon only has stool in it, which is waste. The main absorption of nutrients occurs in the small bowel and our enemas do not wash that part of the intestine. We are really only washing out the waste.

CHILDREN WITH LOOSE STOOL AND DIARRHEA

Children with tendency to diarrhea have an overactive colon and most of the time they are missing part of their colon, in other words they do not have a reservoir. This means that even when an enema cleans their colon rather easily, the stool passes fairly quickly from the cecum to the descending colon and the anus. To prevent this, a constipating diet and/or medications to slow down the colon (such as Loperamide) is recommended. Eliminating foods that further loosen bowel movements will help the colon to move slowly.

Parents are provided with a list of constipating type of foods to be promoted and a list of laxative foods to be avoided. The diet is very rigid: banana, apple, baked bread, white pasta, rice with no sauce, boiled or broiled meat or fish. No fried foods and dairy products. Most parents know which meals provoke diarrhea and which constipate their child. To determine the right combination, the treatment start with enemas, a very strict diet, and a high dose of loperamide (Immodium). Most children respond to this aggressive management within 24 hours. The child should remain on a strict diet until clean for 24 hours for 2 to 3 days in a row.

Then the child can choose one new type of food every 2 to 3 days observing the effect on his/her colonic activity. If the child soils after eating a newly introduced food, eliminate that food from the diet on a permanent basis. However, find the most liberal diet possible for the child. If the child continues to be clean with a liberal diet, gradually the dose of the medication is reduced to the lowest dose effective to keep the child clean for 24 hours.

Again, this is found by trial and error. This strict diet does not need to last forever. After about 2 months in which the child has remained clean for 24 hours, they may have one of their “black list” foods that they have been craving. If the child soils after eating that food, the children know they must stay away from it. They must only introduce one new food a week and observe the bowel movement pattern.

Failure

If incontinence appears again it means that something has changed in the child’s habit and a meticulous evaluation is needed.

The first thing to question is whether the enemas are still effective. The questions are “is my child emptying himself/herself properly?” “is she/he emptying the colon less successfully than before?”

To understand this, it is necessary to have an x-ray of the abdomen taken and analyze the quantity of stool present in the colon.

If the x-ray shows a large amount of stool in the colon after the enema, it means that the enema needs to be adjusted (increase volume and/or concentration) to the new needs of the child and after a week of trial and error in which a daily x-ray is taken in order to understand if the child is clean.

On the other hand, if the plain radiograph shows a clean colon, the “accidents” had to be due to increased motility and therefore it is necessary to introduce some medications to slow the colon as described previously, as well as to observe a more strict diet.

An important issue is to evaluate the consistency of the stool: feces which remain in the colon for a long time becomes harder and stickier, therefore it is necessary to carefully evaluate both the stool quantity and consistency.

The change of a child’s habits plays an important role: changes in the diet, on certain occasion like birthdays, holidays, etc., may have repercussions especially on children with hypermotility. In the same way, other factors can play a role on the bowel function (moving from one’s house, divorces, changes of school, etc.).

In some adolescents the circumstances are predictable in which changes may influence the bowel function, such as exams, school stress, alcohol, etc..

In this case it is possible to give the child the day before an exam a medication such as Imodium to slow down his/her bowel motility.

WHAT IS THE FUTURE?

CONTINUE WITH THE B.M.?

In those cases of children who have a successful bowel management program (enemas), the parents frequently ask if this program will be needed for life. The answer is “yes” for those patients born with a poor prognosis type of defect. However, since we are dealing with a spectrum of defects, there are children with some degree of bowel control; they are subjected to the bowel management program in order not to be exposed to occasional embarrassing accidents of uncontrolled bowel movements. However, as time goes by the child becomes more cooperative and more interested and concerned about his/her problem. It is conceivable that later in life, a child may stop using enemas and remain clean, following a specific regimen of a disciplined diet with regular meals (3 meals per day and no snacks) fiber and sometimes laxatives to provoke bowel movements at a predictable time.

However there are some preliminary conditions to be followed before trying that:

1) the child has to be completely clean with the bowel management followed until now. This means that parents (or the child) are able to understand if they had a proper bowel movement.
2) the child is cooperative. The child has to be aware of his/her problem and motivated to experiment with new strategies to avoid enemas.

How to proceed

Every summer, the children with some potential for bowel control can try, on an experimental basis, (by trial and error) to find out how well they can control their bowel movements without the help of enemas. This is done during the summer vacations to avoid accidents at school at the time that they can stay home and try some of the strategies. Some of the fundamental points include:

A) Reduced socialization
it is expected that parents and child will stay at home and socialize very little

B) Regular diet with a regular schedule
Since the child is not going to school it is easier to control his/her diet. It is very important that the child will have regular meals at a regular time in order to take advantage of the gastrocolic reflex.

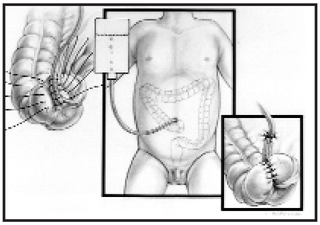
C) The child must sit on the toilet after every meal and try to pass stool.

D) He/She must remain alert all day while trying to learn to discriminate the feeling of an imminent bowel movement.

E) If the child belongs to the “constipated” group, it is advisable to give him/her a laxative every day in a single dose, to try to provoke an effect as controlled as possible; ideally that is a single bowel movement per day. The dose of the laxative is adjusted by trial and error. It is best to first try the less aggressive and natural types of laxative, and then, depending on the child’s response, use medications with more active ingredients. The first choice, of course, must be a laxative type of diet; the next one is either a bulking forming type of product or else a stool softener. If this medication does not work, a laxative with an active ingredient is indicated. After a few days or weeks, the family and child are in a position to decide whether they want to continue with the new regimen or go back to the bowel management program (enemas). This decision is up to the family and the child and is based on the quality of life experienced with each type of method.

ADDITIONAL STRATEGIES: THE ACE OR MALONE PROCEDURE

Most preschool and school-age children enjoy a good quality of life while undergoing the bowel management program. However, when they reach puberty, many express a high degree of dissatisfaction. They feel that their parents are intruding on their privacy by giving them enemas. It is feasible but rather difficult for them to administer the enema themselves. For this specific group of children, an operation called a continent appendicostomy or a Malone procedure has been designed.



It is important to stress that the Malone procedure is just another way to administer an enema. Before implementing the Malone procedure some preliminary conditions need to be met:

- The child has to be perfectly clean with his/her regular bowel management

It does not make sense to operate on child who is not successful with the bowel management in order to create another route to administer the enema.

- The child has to be absolutely motivated

  Both in terms of the operation and the administration of the enemas as well as for his/her ability to evaluate the effects.

The operation consists of connecting the cecal appendix to the abdominal wall (usually at the belly button) and creating a valve mechanism that allows catheterisation of the appendix but avoids leakage of stool through it. If the child has lost his/her appendix, it is possible to create a new one from the colon. This is called a continent neo-appendicostomy.

This procedure allows the child to administer an enema, inserting a small catheter into the orifce on the belly button while sitting on the toilet. The enema infusion enters the bowel pushing the stool forward. It is very easy and comfortable for any child.

As you can see, Bowel Management does not mean “just giving an enema” or following a prescribed diet or taking a medication. There is no a miraculous recipe. However, through a methodical combination of enemas, colonic irrigations, suppositories, diet and medication following a specific rationale, it is possible to help children born even with a very bad prognosis type of malformation to remain artificially clean.

The success of any of these strategies requires collaboration among the family, the child and the health care team.

There are many variations depending on the child’s needs: it takes dedication, determination, consistency and love by everyone involved.

Children who have completed the bowel management program and remain clean for 24 hours experience a new sense of confidence based on an improved quality of life.

AIMAR (Italy)
www.romacivica\aimar
aimar@romacivica.net

APMAR (Portugal)
www.mundo.iol.pt/apmar/saude
apmar@iol.pt

NFO (Norway)
www.analatresi.no
op-h@online.no

Pullthru (Usa)
www.pullthrough.org
info@pullthrough.org

So.MA (Germany)
www.soma-ev.de
info@soma-ev.de

Verening Anusatrisie (Holland)
www.anusatresie.nl
info@anusatresie.nl

Imperforate Anus Family Association
(Taiwan)
www2.mmh.org.tw
mmhss@ms2.mmh.org.tw

Israelian Parent's Organization (Israel)
erd@bezeqint.net