



The Bowel Management Movement:

Principles and Advances in Modern Bowel Care in Spina Bifida

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SBA Lifespan Bowel Management Protocol:



#2 updates

- Importance of starting early and keeping tabs
- Bowel program options and updates
- Tips for starting and keeping a program going
- Considerations for females
- Common problems and potential solutions

In the beginning ...

Parents are:

- in denial (especially those of us who had fetal surgery)
- relieved their baby is peeing and pooping “on their own”
- not ready to handle long-term implications

Mindset shift for parents

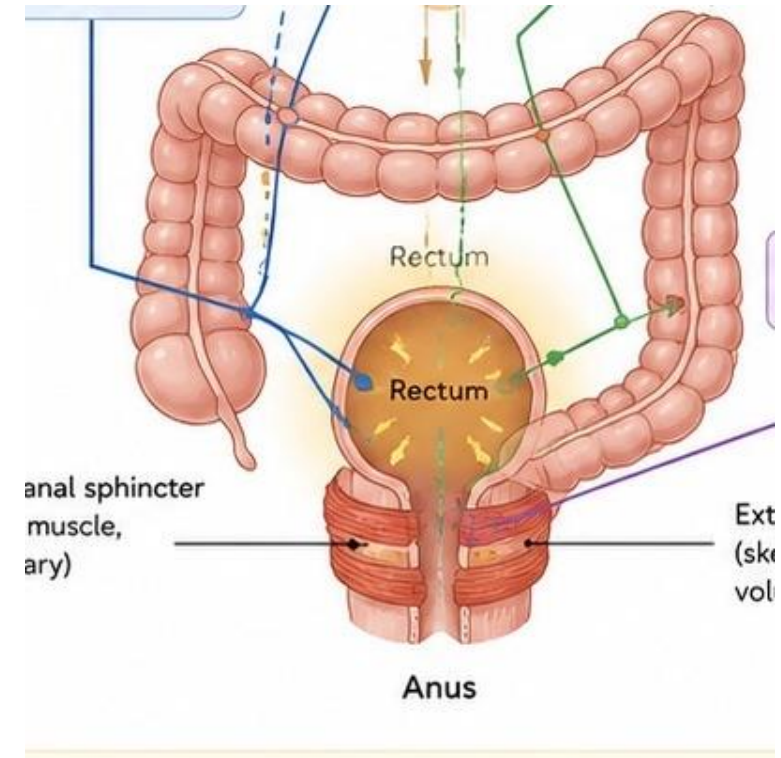
- Lots of people have bowel/gut issues, and it interferes with life. Nerve damage from SB just means higher likelihood and impact.
- Interventions are not the enemy. We want to avoid health and social issues, not the tools it takes to get there.
- Long-term goal: healthy, happy kid (and later, adult) who is not negatively impacted by neurogenic bowel. To get there, we need to be proactive so it's not harder for them later.

Brief, high-level, not-scary overview for parents

1. **Infants** poop all day. This isn't permanent. Need a good diaper cream.
2. **Babies** starting solids = starting constipation. Common for all babies, but we take it extra serious with SB. Make a plan, then enjoy starting solids.
3. **Toddlers** can start potty sitting! Very low pressure; reward for sitting, not results. This gets them used to potty sitting and gives us data.
4. **Preschoolers to Kindergarteners** can work toward continence alongside their peers. The process may look different, but we are interested in similar results.
5. **Big kids and teens** will work on independence with their bowel and bladder management.

Infants & Toddlers

- Starting early
 - Development of Bowel Continence
- Key Points/Goals
 - Prevent constipation
 - Stabilize stooling frequency
 - Prevent skin breakdown
 - Promote family communication



Neurological Control of Bowel

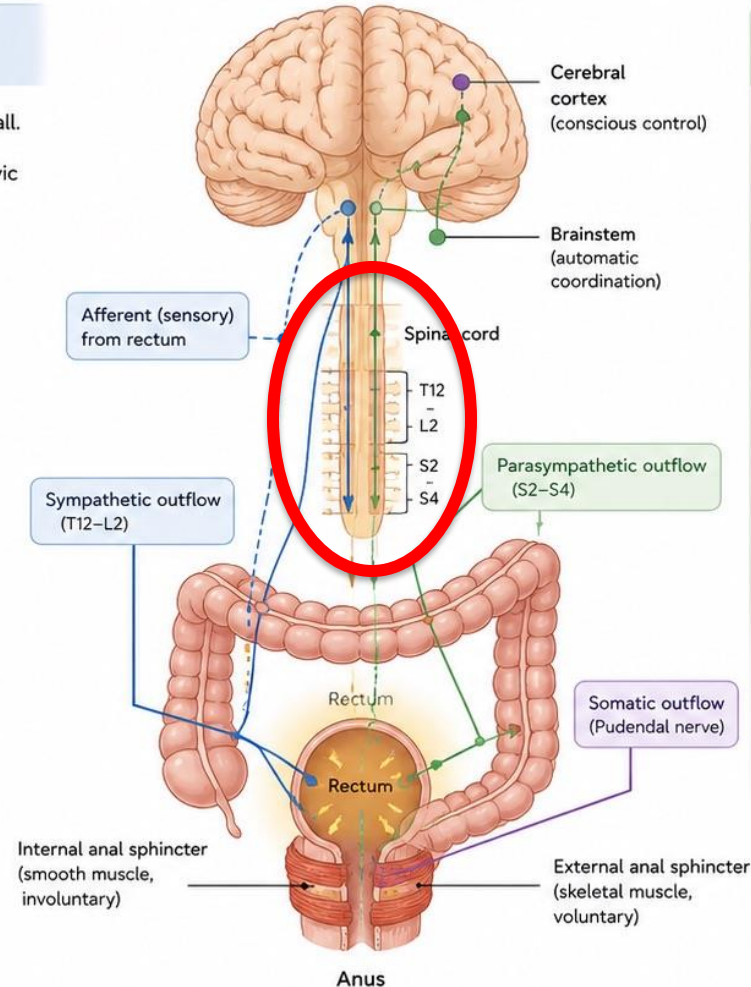
Bowel control is coordinated by the brain, spinal cord, and enteric nervous system.
It involves a balance between storage (continence) and defecation (emptying).

STORAGE / HOLDING (continence maintained)

- 1 Stool in rectum stretches the rectal wall.
- 2 Stretch receptors send signals via pelvic nerves to the spinal cord (S2–S4) and to the brain.
- 3 Brain (cerebral cortex) recognizes that the rectum is full.
- 4 If it is not the right time, the brain sends signals to **KEEP STOOL** in.
- 5 Sympathetic nerves (from T12–L2) and somatic pudendal nerve increase anal sphincter tone.
 - Internal anal sphincter (involuntary, smooth muscle) stays contracted.
 - External anal sphincter (voluntary, skeletal muscle) contracts.
- 6 Peristalsis in the colon is reduced, so stool remains stored.

Key nerves in storage

- Afferent (sensory)
- Efferent – sympathetic
- Efferent – somatic



DEFECATION / EMPTYING (bowel movement occurs)

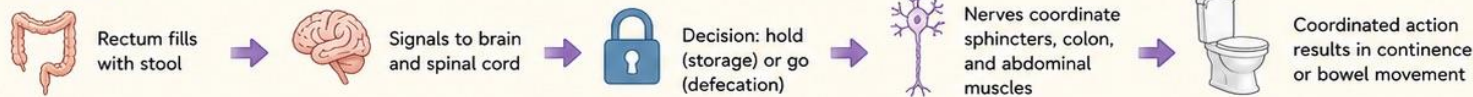
- 1 When it is appropriate, the brain (cerebral cortex) sends signals to allow defecation.
- 2 Signals descend to the spinal cord (S2–S4, sacral parasympathetic center).
- 3 Parasympathetic nerves (pelvic splanchnic nerves) are activated.
 - Contraction of colon and rectum increases.
 - Internal anal sphincter relaxes.
- 4 The pudendal nerve relaxes the external anal sphincter.
- 5 Abdominal muscles and diaphragm contract, increasing intra-abdominal pressure.
- 6 Stool is expelled.

Key nerves in defecation

- Efferent – parasympathetic
- Efferent – somatic (relaxation)

- Upper motor neuron – tight (above L1)
- Lower motor neuron – loose (below L1)

In summary



NEUROLOGICAL DEVELOPMENT OF BOWEL CONTROL

FROM NEONATE TO 5 YEARS OF AGE

AGE	NEURAL CONTROL (PATHWAY MATURATION)	BRAIN DEVELOPMENT (STRUCTURES & FUNCTION)	BOWEL PHYSIOLOGY & BEHAVIOR	CLINICAL MILESTONES
NEONATE (0–1 MONTH) 	Spinal reflexes only - Defecation occurs via intraspinal reflexes - No voluntary control - Parasympathetic (S2–S4) mediates rectal contraction - IAS relaxed reflexively	Immature brain - Brainstem & spinal cord mediate reflexes - Cortex, basal ganglia and PFC (prefrontal cortex) immature - Minimal cortical involvement	Automatic emptying - Frequent, spontaneous stools - Meconium in first days, then variable frequency - No stool withholding ability	No control - Reflexive bowel movements - No awareness
INFANT (1–12 MONTHS) 	Spinal reflexes predominate; beginning cortical influence - Same reflex pathways (S2–S4) - Pudendal nerve maturation begins - External anal sphincter (EAS) shows increasing voluntary activation by 6–12 months	Rapid brain growth - Myelination of cortico-spinal and cortico-pontine pathways - Early connections from cortex to pontine center (bridge) - Emerging awareness of internal sensations	Irregular but maturing - Stool frequency becomes more predictable - Can differentiate between gas and stool (around 6–9 months) - May resist dirty diaper	Emerging awareness - Recognizes need indirectly (discomfort, dirty) - No voluntary control yet
TODDLER (1–2 YEARS) 	Increasing voluntary control - Cortical input to pontine defecation center strengthens - Better voluntary contraction of EAS (via pudendal nerve) - Ability to inhibit defecation begins	Growing control networks - Prefrontal cortex (PFC) begins to mature - Improved white matter (corpus callosum) - Greater integration of sensory input and motor output	Stool withholding possible - Can delay stool when engaged in activities - May hide/stiffen or cross legs - Still inconsistent control	Partial control - Interest in potty - Can follow simple routines - Accidents common

KEY NEURAL PATHWAYS INVOLVED

- ➔ **Afferent (sensation):** Pelvic nerves (S2–S4)
- ➔ **Parasympathetic (promotes defecation):** Pelvic splanchnic nerves (S2–S4)
- ➔ **Sympathetic (inhibits defecation):** Hypogastric nerve (T11–L2)
- ➔ **Somatic (EAS & pelvic floor):** Pudendal nerve (S2–S4)

Note: Developmental timelines are approximate; wide variation

reminders



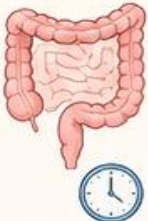
SUMMARY

Bowel control develops from reflex activity of the spinal cord in the newborn to conscious, voluntary control via the maturing brain—especially the prefrontal cortex, its connections to the brainstem, and coordinated muscular control.

exists among children.

NEUROLOGICAL DEVELOPMENT OF BOWEL CONTROL

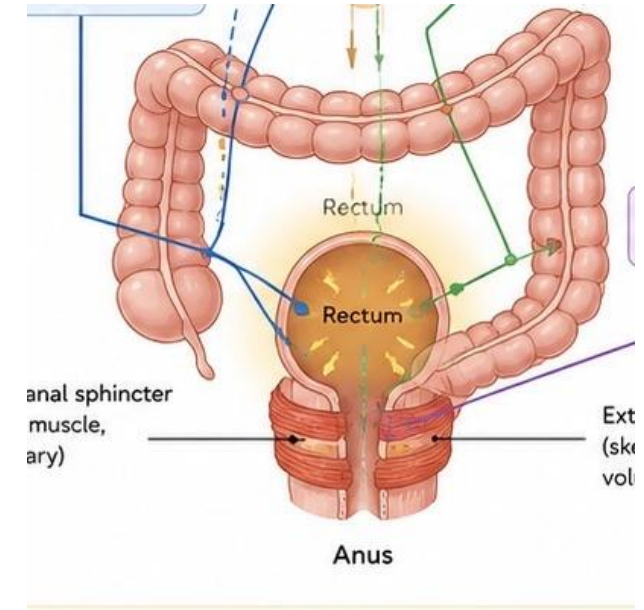
FROM NEONATE TO 5 YEARS OF AGE

AGE	NEURAL CONTROL (PATHWAY MATURATION)	BRAIN DEVELOPMENT (STRUCTURES & FUNCTION)	BOWEL PHYSIOLOGY & BEHAVIOR	CLINICAL MILESTONES
PRESCHOOLER (2–3 YEARS) 	Cortical control improving - Stronger descending inhibitory pathways from PFC - Better coordination of rectal sensation, relaxation of IAS, contraction of EAS - Improved timing and sequencing 	Prefrontal maturation accelerates - PFC growth and synaptic pruning - Basal ganglia support habit formation - Better impulse control and planning 	More predictable patterns - Regular bowel patterns develop - Can sit on potty with prompting - Withholding behavior reduces with success 	Toilet training phase  - Can learn to use toilet with guidance - Daytime continence achieved in most by 2.5–3 yrs - Nighttime control not yet mature
EARLY PRESCHOOL (3–5 YEARS) 	Mature voluntary control - Well-developed cortico-spinal and cortico-pontine pathways - Efficient coordination of pelvic floor, EAS and abdominal muscles - Fine control improves 	Networks near mature - PFC continues maturation through early school years - Stronger executive functions (planning, attention) - Sensory discrimination well developed 	Reliable control - Voluntary bowel movements at appropriate times - Recognizes bodily cues and acts on them - Rare withholding 	Continence expected  - Daytime continence in >95% by age 4 - Nighttime continence in ~60–80% by age 5 - Independence with minimal reminders
MATURATION CONTINUES BEYOND 5 YEARS 	KEY NEURAL PATHWAYS INVOLVED  Afferent (sensation): Pelvic nerves (S2–S4)  Parasympathetic (promotes defecation): Pelvic splanchnic nerves (S2–S4)  Sympathetic (inhibits defecation): Hypogastric nerve (T11–L2)  Somatic (EAS & pelvic floor): Pudendal nerve (S2–S4) SUMMARY Bowel control develops from reflex activity of the spinal cord in the newborn to conscious, voluntary control via the maturing brain—especially the prefrontal cortex, its connections to the brainstem, and coordinated muscular control.			

Note: Developmental timelines are approximate; wide variation exists among children.

Infants & Toddlers

- Starting early
 - Methods for newborns/babies/toddlers
 - Oral Opportunities
 - Rectal Opportunities
 - Navina Mini
 - Potty sitting
 - Normalizing Rectal Interventions



- Remember the goals...
 - Prevent constipation
 - Stabilize stooling frequency
 - Prevent skin breakdown
 - Promote family communication

Navina Mini

- Wellspect site:



- Amazon purchase:



Infants & Toddlers

Promoting Normalization of Rectal Interventions in Infants and Toddlers with Spina Bifida

- Themes from the interviews
 - Parents & Providers: Child development concerns.
 - Parents: Consistency, time, lack of knowledge on the topic.
 - Providers: Diet, step-wise approach, developmentally appropriate interventions.
- Clear definitions of bowel management, bowel program, rectal interventions, and bowel continence were important to define.
- Timeframe to promote teaching should be urged in early infancy and toddlerhood.
- Project completed by Chelsea (Williams) Fleming, RN, MSN, CNL – Children's Wisconsin

Infants & Toddlers

Promoting Normalization of Rectal Interventions in Infants and Toddlers with Spina Bifida

- Common parent perspectives identified through the interviews:
 - Using interventions are not failure. Interventions are not the enemy.
 - We talked about poop from the beginning.
 - Rectal interventions are medically necessary.
 - It's been lifechanging. Consistency is key!
 - A lot of parent/caregiver guilt.
 - My child doesn't really know any different.
 - One drawback, it's a huge commitment.

Promoting Rectal Interventions in Infants and Toddlers with Spina Bifida

Spina Bifida (SB) is a condition where the spinal cord does not develop properly and can cause the nerves and muscles that are associated with walking, peeing, and pooping to work incorrectly. Children with SB can have limited to no sensation in the diaper area and struggle with having predictable bowel function and bowel movements. This can cause a range of issues such as constipation, bowel incontinence, bladder dysfunction, skin breakdown, reduced quality of life, and later challenges with educational and employment opportunities. Bowel management will change based on age and clinical picture; however, most children with SB need some type of bowel program to prevent constipation and promote continence.

Some important words and definitions to know that you will hear!

- Bowel Management - Anything done to help manage the bowels long-term (oral medications, diet, or rectal interventions).
- Bowel Program - Individualized plan or routine to help with bowel movements.
- Rectal Interventions – Insertion of medications, digital techniques, or enemas to aid in the removal of poop, or a medical procedure to help the child have regular bowel movements.
- Bowel Continence - Ability to stay dry and clean between bowel program, limited leaking or accidents of poop.

Getting Beyond the Discomfort

- Many people are uncomfortable with discussing topics about poop. It is important for this topic to be openly discussed. Normalizing rectal interventions in infancy and toddlerhood and having a bowel management plan kindergarten age is an important goal for children with SB.
- As children grow, they gain a sense of self and autonomy and may often resist rectal interventions to help them poop around age 3-4 years.
- Helping infants (birth to 12 months) and toddlers (12 months to 3 years) with SB with pooping can aid in reducing constipation and incontinence when children enter pre-school or kindergarten.
- Everyone needs to poop. Children with SB poop differently and potty training might be different in children with SB.
- Talk about and learn how to perform rectal interventions early and regularly. Interventions are not the enemy.
 - It may take different options to find the right intervention.

What are examples of rectal interventions?

- Digital stimulation or digital sweep
- Suppositories - Pedi-lax, vegetable grade glycerin (liquid form)
- Bulb syringe enemas

Why start rectal interventions in infancy/toddlerhood?

- Maintain physical health – maintain bladder and bowel function and reduce the risk of skin breakdown that can happen with incontinence.
- Assume constipation will occur at different points in your child's life, even if spontaneous pooping is occurring.
 - Constant pooping into a diaper does not mean your child is not constipated.
- Improved quality of life - set the child up for social success.
- Parents tell us a good bowel program is life changing.

What are the goals to rectal interventions?

- Reduce constipation and regulate bowel movements.
- Reduce bowel incontinence and unpredictable BM's that may impact educational and social experiences as the child expands their life beyond home and grows into school age activities.
- Staying consistent with bowel program is key. Life can be busy and can be hard to stick to a bowel program routine, so it is important to start early.
- Normalizing using rectal interventions and pooping in the toilet.
- When a child refuses a bowel intervention, it is important to talk with the child about the why of the refusal.
 - Make the bowel program fun.
 - Build it into the routine of the day.

Other important information

- Babies that are breast fed may have less difficulty with constipation until starting real foods at about 6 months of age. Babies who are formula-fed or whose diet is supplemented with formula may experience constipation earlier and need help with pooping at about 3 months of age. It is important not to be afraid to help your child with pooping if needed.
- When starting foods, start with the 'P' foods (peaches pears, peas, prunes).
- Tummy massages may help move gas and poop through the colon.
- Communicate with your child's health team and learn more about their level of lesion for success in potty training.

This information was compiled from literature and interviews from parents of children with SB and clinic providers.

Options

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

Balloon Enema

- Another common tool for administering enemas, especially for children.
- Uses a latex-free 24fr foley catheter
- Step-by-step instructions for use
- Helpful tips
- Troubleshooting problems

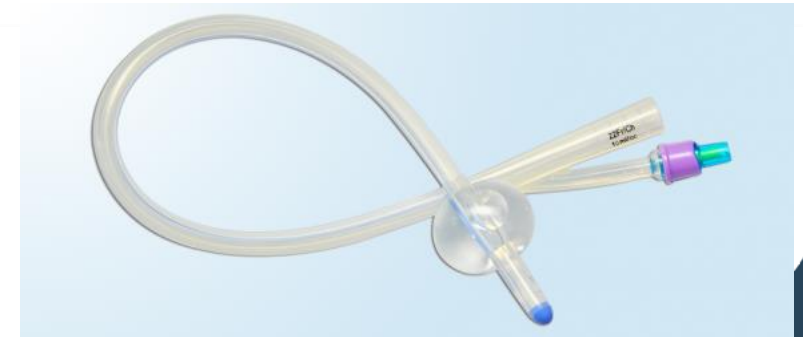
Balloon Enema

A balloon enema requires a latex-free 24fr 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



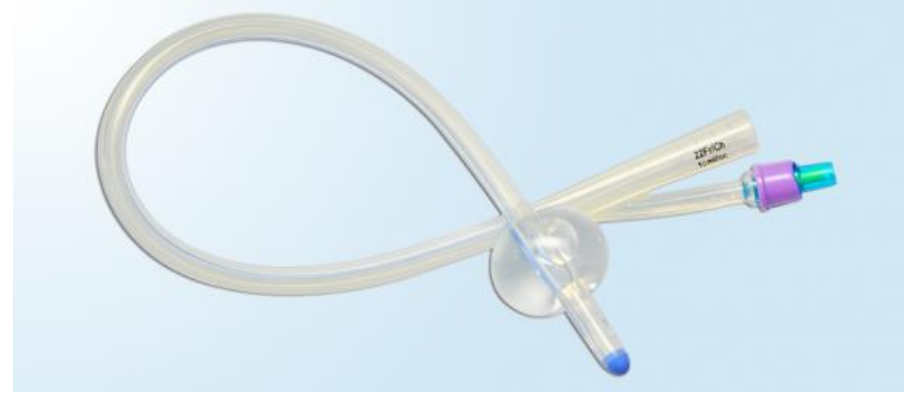
June 2022 | Appendix VII – Enema Basics

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.



Troubleshooting

- Balloon Catheter
 - Meeting resistance/impaction
 - Leakage during administration
 - Leakage immediately after administration
 - Expulsion of balloon catheter
 - Hard stool accidents
 - Loose stool accidents
 - Accidents coinciding with menstruation
 - Abdominal pain/vomiting
 - Slow flow
 - Poor response
 - Rectal bleeding or severe abdominal/back pain



Cone Enema

- A very popular tool for administering enemas, especially for children.
- Step-by-step instructions for use
- Helpful tips
- Troubleshooting problems



Cone Enema
Visi-Flow® Irrigator with Stoma Cone (Courtesy of ConvaTec Inc.)

Available from multiple medical distributors and companies.

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.

Troubleshooting

- Cone enema
 - Meeting resistance/impaction
 - Leakage during administration
 - Leakage immediately after administration
 - Hard stool accidents
 - Loose stool accidents
 - Accidents coinciding with menstruation
 - Abdominal pain/vomiting
 - Slow flow
 - Poor response
 - Rectal bleeding or severe abdominal/back pain



Transanal Irrigation (TAI) (e.g.: Peristeen©, Navina



- Newer enema tools--Peristeen and Navina
- Possibility of independence, and other benefits
- Step-by-step instructions for use
- Helpful tips
- Troubleshooting problems

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 the cone or balloon enemas use. The system consist of a semi-rigid catheter, 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.



Troubleshooting

- Transanal Irrigation
 - Meeting resistance/impaction
 - Leakage during administration
 - Leakage immediately after administration
 - Expulsion of balloon
 - Hard stool accidents
 - Loose stool accidents
 - Accidents coinciding with menstruation
 - Abdominal pain/vomiting
 - Slow flow
 - Poor response
 - Peristeen/Navina contacts for pump issues
 - Rectal bleeding or severe abdominal/back pain



MACE/ACE/Chait/Cecostomy

- Surgical solutions for bowel management
- Can increase rates of independence
- MACE/ACE uses the appendix for a channel
- Chait/Cecostomy uses an artificial tube and a button
- Compares each
- Considerations for solution additives and amounts

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).⁸ ([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

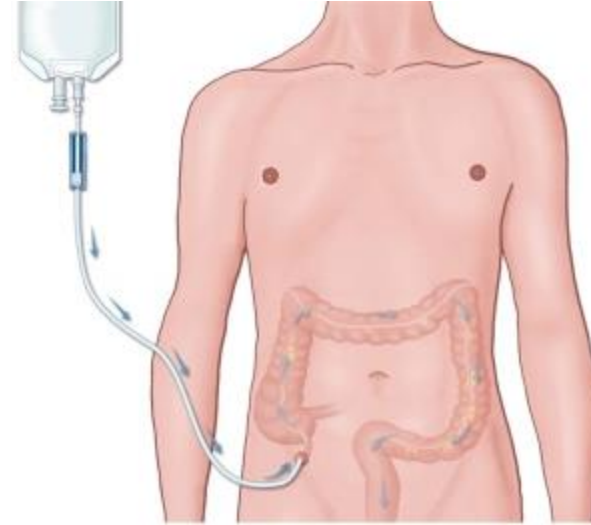
Troubleshooting

- Cecostomy
 - Leakage immediately after administration
 - Hard stool accidents
 - Loose stool accidents
 - Accidents coinciding with menstruation
 - Abdominal pain/vomiting
 - Slow flow
 - Poor response
 - Leakage around cecostomy tube
 - Cecostomy tube displacement
 - Rectal bleeding or severe abdominal/back pain



Troubleshooting

- ACE/MACE
 - Difficulty passing the catheter
 - Inability to pass the catheter
 - Leakage immediately after administration
 - Hard stool accidents
 - Loose stool accidents
 - Accidents coinciding with menstruation
 - Abdominal pain/vomiting
 - Slow flow/stoppage of flow
 - Poor response
 - Rectal bleeding or severe abdominal/back pain



Management

Suggested Monitoring and Follow-Up

- Written Instructions
- Bowel Diary
- Communication
- Change if no improvement Q2weeks
- Enema programs can take 2-3 months to work well

Logistics

- Enemeez is now on GoodRx!

30 day supply ~\$50 versus \$75

The GoodRx logo is displayed in a large, bold, black font, centered within a solid yellow square. The text "GoodRx" is the primary focus of this graphic element.

GoodRx

TAI coverage changes

As of April 1, 2025

- CMS definition of TAI
 - TAI device and rectal catheter that has a sealing function [balloon or cone-based] are covered under the Prosthetic Devices benefit (Social Security Act §1861(s)(9))
 - Manual pump: Correct HCPCS codes to bill are A4459 (device) and A4453 (catheters)
 - Electronic pump: Correct HCPCS codes to bill are A4479 and A4453

Cone enema and CMS

- Gravity-administered enema systems do not meet the CMS DME benefit because these devices do not meet the requirement of durability
- These devices do not meet the CMS Prosthetic Benefit because they do not replace a non-functioning internal body organ

Old Habits...

- Ages 2 and up
- Neurogenic bowel diagnosis
- Failure of 2 other bowel programs
- Significant impact

Tips for starting a continence program

- Do a clean out
- It's normal for it to be messy and stressful at first, it will get better
- Talk to experienced parents for tips and understanding
- Parents should validate feelings but not apologize—just another way to poop!
- Parents' excited attitude helps

Tips for starting a continence program

- Potty in the bathroom
- Limit screens to potty time
- Give power—when, where, how, but not IF
- If child is resistant—ask questions, problem solve
- Get child as involved as possible, increase involvement over time

Tips for starting a continence program

- Make it part of the nightly routine—no skips at first
- Multitask—homework, sibling baths, laundry
- Have at least one backup person who can do the bowel program to avoid burnout
- Toileting is private, but not a secret
- Be patient and persistent—the results can be life-changing

Favorite Potty Seats



Prince Lionheart Tinkle
Trainer Squish



Graco Clean Contour Potty
Ring



Special Tomato Toilet
Seat Reducer



Bedside commode over toilet
(bucket removed) with potty
seat to add stability



Rifton Toileting
System

Favorite Potty Accessories



Tablemate II TV Tray



Squatty Potty Footstool



Any USP Grade Pure Glycerin (byGallon pump makes
the gallon)
less messy



Any pure castile
soap

Bowel Clean Outs

- **Full cleanouts** for starting a new bowel program or when very constipated
- **Partial cleanouts** for mild constipation, accidents, before changing a bowel program
- **Inpatient cleanout** for severe constipation

**Consider a clean out before ANY major surgery*

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.

Bowel Clean Outs

- **Full cleanouts** for starting a new bowel program or when very constipated
- **Partial cleanouts** for mild constipation, accidents, before changing a bowel program
- **Inpatient cleanout** for severe constipation
- Regular enema evening before, morning of and evening of cleanout

**Consider a clean out before ANY major surgery*

Magnesium Citrate Cleanout	
Standard dosing:	
<6 years: 2-4 mL/kg given as a single daily dose or in divided doses	
6-12 years: 100-150 mL	
Children ≥12 years and Adults: 150-300 mL	
Weight:	Dosing:
Weight 20-22 kg	5 mg Dulcolax® OR 10 ml senna, magnesium citrate 2-4 mL/kg (40-88mls)
Weight 23-30 kg	10 mg Dulcolax® OR 15 ml senna, magnesium citrate 2-4 mL/kg (46-120mls)
Weight 31-50 kg	15 mg Dulcolax® OR 30 ml senna, magnesium citrate 2-4 mL/kg with maximum of 300 mls (62-200mls)
Child to drink 8-16oz of clear fluids per hour after drinking weight-based dose of Magnesium Citrate	

Prepare for transition to adult care

- Teach how and where to order supplies
- Visual steps
- Put supplies within reach
- PT/OT as needed
- Communicate using technology if possible
- Explore the barriers / see the bathroom
- Patients may not find adult providers to do neurogenic bowel management, so try to set them up for success before they leave pediatric practice
 - Will adult insurance pay for supplies for the bowel program?
 - Who will manage program and procedures?

Results from survey on adults with NBD

- 154 individuals (mostly white females, 67% with degree beyond HS, 47% working full time)
- 73% attended a multi-d clinic as a child, but only 35% as an adult
- Those attending multi-d clinics had more consistent care, and specialists
- No difference in continence or bother
- Continence is a bother!
- Finding a provider is hard!
- Resources: Healthcare providers, SBA and online

Period Considerations

- Start of menstrual cycle can increase incontinence
- Encourage tracking
- Increase bowel program frequency
- How to clean up



Pregnancy Considerations

- Pregnancy can increase constipation.
- Flushes may become less successful.
- Skin breakdown can occur at cecostomy button site
- Urologist/surgeon may need to be present during cesarean birth.



Colostomy Considerations

- Usually considered last resort
- May be best option considering independence, dexterity, pressure wounds, or personal preference
- Complications include skin breakdown and colostomy hernia

