Bowel Continence Programs
Across the Lifespan

Spina Bifida Association of North Texas Education Day 2023

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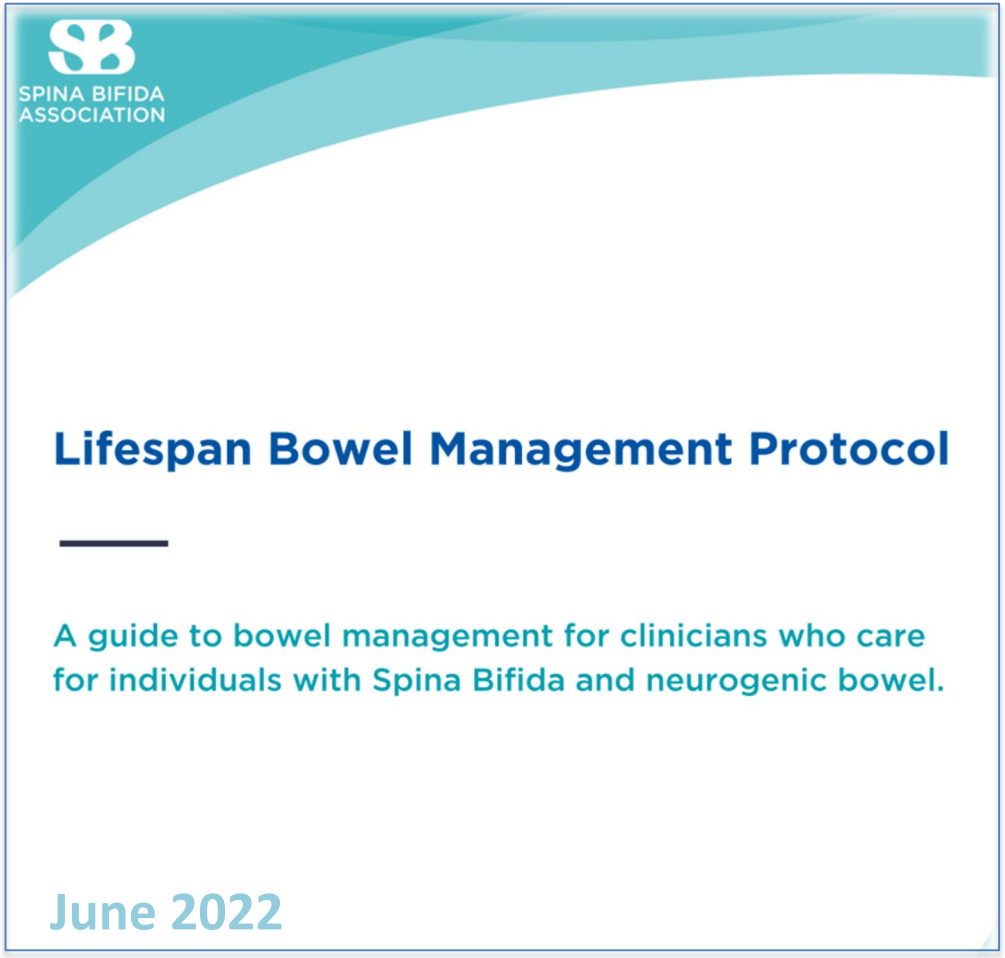
1. **Prevention of constipation**
2. **Avoidance of incontinence**
3. **Support self-directed independence in the process**



www.spinabifidaassociation.org/lifespan-bowel-management-protocol/

To Begin ---- Some Perspective

"Neurogenic bowel treatments and continence outcomes in children and adults with myelomeningocele."
National Spina Bifida Patient Registry.
J Pediatr Rehabil Med. 2022.

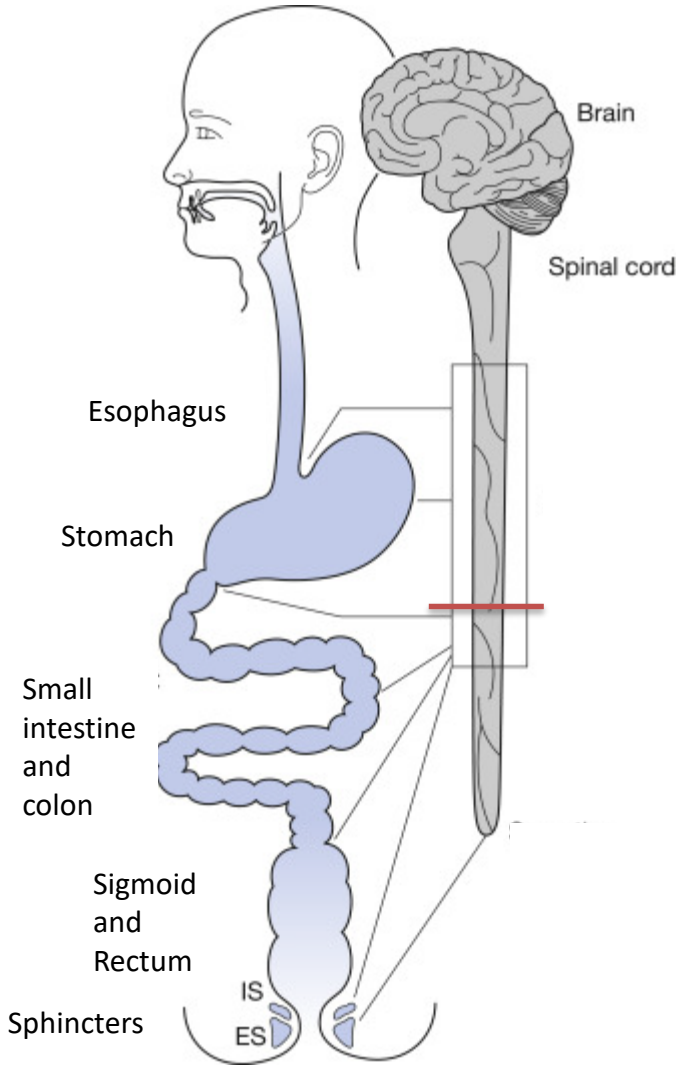
*Overall continence rates for those with NB in this CDC data registry group who used a Criterion Treatment Modality (or more than one) were modest, ranging from **36%** to **69%"***

The Spina Bifida Program at Scottish Rite historically has data showing 65-69% continence rates

- **What are we aiming for with a bowel program?**

1. Regular, planned passage of stool on a daily or every-other-day basis. No unplanned bowel movement or incontinence for those over age ~ 4years. {<1 out of every 40 days}
2. Adequate volume of stool output
3. Evacuations at consistent time of day (approximate)
4. Complete emptying of rectal vault each evacuation
5. Stool consistency: soft, formed, bulky
6. Completion time ~ ≤ 30 min; (max 40)

Develop Age	Developmental Goals	Recurring Clinic Interventions/ Plans
Infant	Keep stools soft (oatmeal consistency)	Fluid Goals. Information of introduction of foods re: fiber Discussion of Bristol Scale and its use over time. Dysphagia issues?
Toddler - Preschool	Support move to Soft-formed stool (Bristol 3-4)	Re-visit fluid goals. Re-visit role of fiber and offer variety of fruits/vegetables. Avoid “food battles”. (Ellyn Satter). Different cups for independence. Concept of potty-training in NB. Accommodations in bathroom as needed.
School-age	Learn about Sp Bif Learn about continence Participant in the BMP Achieve continence	Spina Bifida 101. Address fluid intake and strategies for intake throughout the school day. Child learns about foods with fiber. Bathroom accommodations across environments. Social value of continence. Timing of medications and evacuations with daily activities.
Adolescent	Optimize independence / interdependence	Dietary aspects of health & fitness; Locus of Control. Revisit spina bifida & neurogenic bowel (SB 202). Encourage and support problem-solving . Menses & NB. Specific issues (sports, transfers, etc.).
Adult	Maintain BMP and address when notable changes	Assure transition to health care professional(s) familiar with neurogenic bowel and dietary management.



- ***Neurogenic Bowel:*** *situation wherein the bowel functions differently due to nerve disturbances*

A VERY BRIEF – but important – review

The Enteric Nervous System

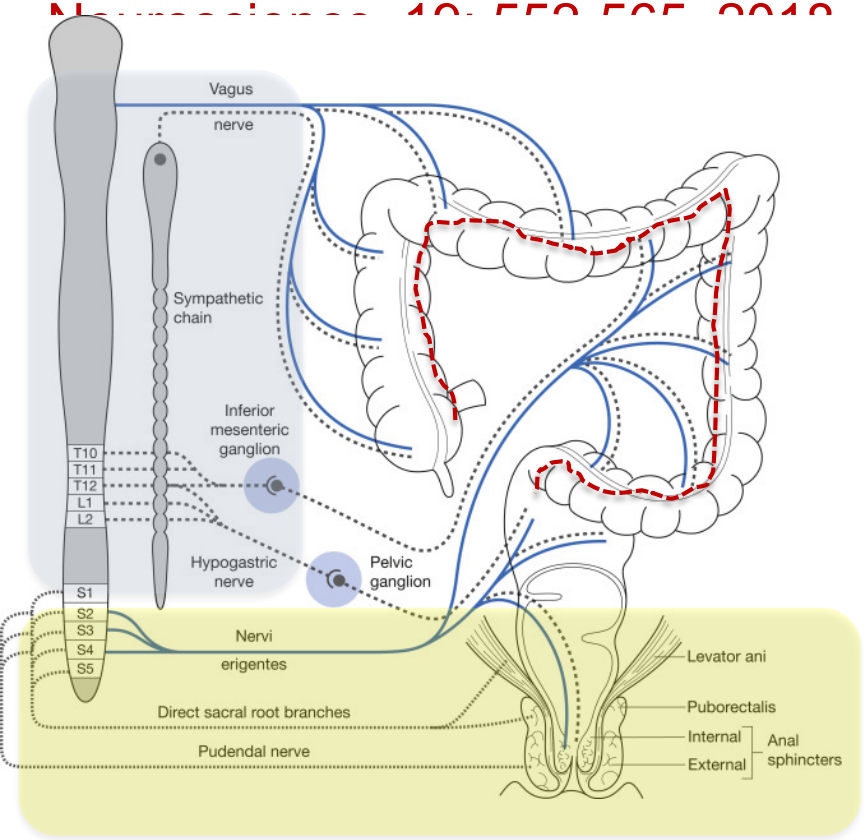
Reflexic Upper Motor NB

Areflexic Lower Motor NB

&

Impact for Bowel Management Program

Enteric nervous system development: what could possibly go wrong? Rao M, GershonMD. Nature Reviews

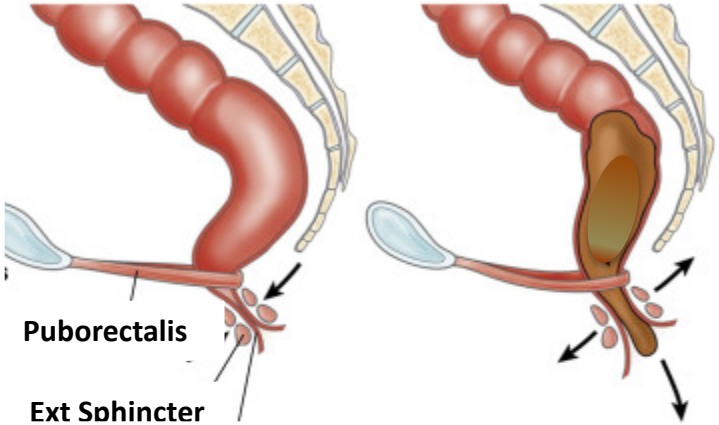


The ENS is a distinct network with its own set of neurons that *coordinate* sensory/motor/secretory actions within the gut itself.

With 10 -100 million neurons, the ENS is largely responsible for segment-to-segment coordination in the intestinal tract. ***MOTILITY***

Between stools

Neuro-typical stooling



Ability to feel stool
Rectum distends
Contract rectal muscles & abdomen
Relax sphincters
Relax P-R muscle

General Concepts for BMP

- Abdominal muscle exercises
- More formed stool
- Avoid overuse of osmotic laxatives / stimulant laxatives
- Assist with manual evacuation

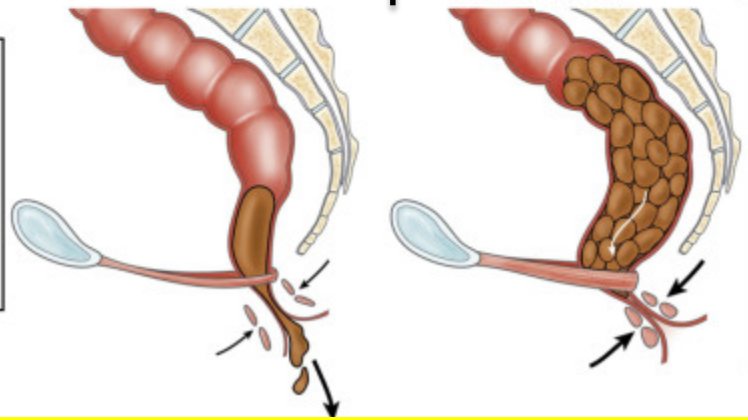
Areflexic neurogenic bowel

- Low resting and/or low squeeze sphincter pressures (weak IAS and EAS)
- Weakness of puborectalis
- Neuropathy
- Altered rectal or anal sensation
- Diarrheal conditions
- Diminished rectal capacity

General Concepts for BMP

- Rectal stimulant medications
- Aim for softer stools
- Motility medications
- Less extensive manual evacuation typically needed

Reflexic neurogenic bowel



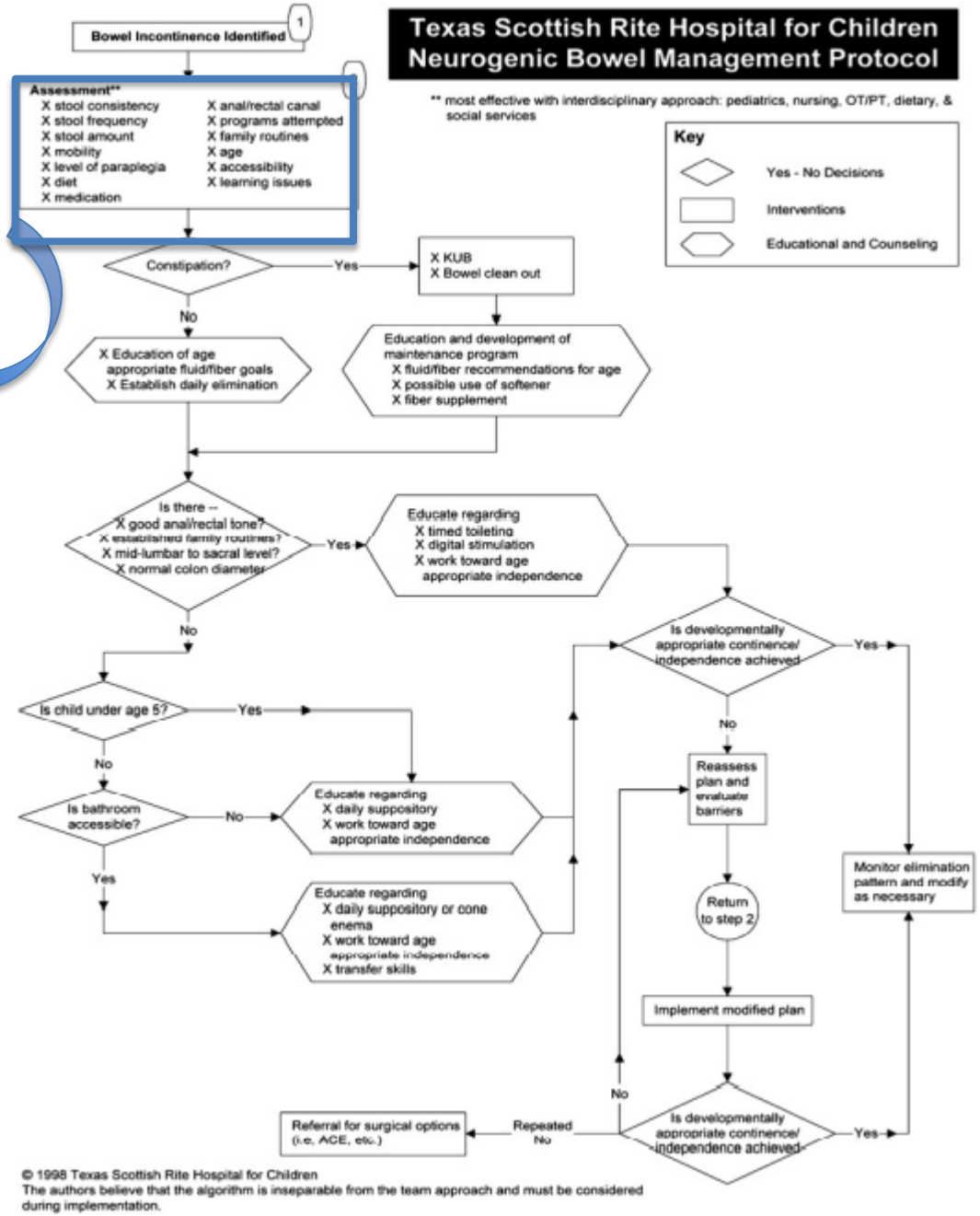
- Prolonged colonic transit time
- Discoordination of abdominal, rectoanal, and pelvic floor muscles
- Rectal hyposensitivity
- Paradoxical increase in sphincter pressure
- < 20% relaxation of resting anal sphincter pressure
- Inadequate abdomino-rectal propulsive forces

NOT ALL NEUROGENIC BOWELS ARE THE SAME

THEREFORE ---- NOT ALL BOWEL PROGRAMS ARE THE SAME

TEXAS SCOTTISH RITE HOSPITAL FOR CHILDREN

- Stool consistency *
- Stool frequency *
- Stool amount +/-
- Anal/rectal tone +/-
- Mobility *
- Level of neuro function*
  - Aware of need to empty
- Diet +/-
- Medications *
- Family routines
- Developmental Tasks
- Accessibility/Equipment
- Learning, EF issues & ADL
- Physical limitations +/-
- Prior regimens +/-



Leibold. Ped Clinic N. Amer 57: 1013-1025. 2010 (From Scottish Rite Program)

TEXAS SCOTTISH RITE HOSPITAL FOR CHILDREN

UT Southwestern Medical Center

SCOTTISH RITE FOR CHILDREN

PEDIATRIC DEVELOPMENTAL DISABILITIES BOWEL DIARY

Name:_____ DOB:____/____/_____ ID#:_____ Date Started:____/____/_____

Instructions: Record each day's bowel activity at the appropriate time. Include stool **type** (*see chart*), **place** (*T = toilet, D = undergarment*) and **amount** (*Smear, S = small, M = moderate, or L = large*). Record daily oral and rectal intervention. Include **name**, **dose** and **time given**.

	EXAMPLE	DAY 1	DAY 2	DAY 3	DAY 4	DAY 5	DAY 6	DAY 7	DAY 8	DAY 9	DAY 10
6 A.M.											
7 A.M.	1, D, M										
8 A.M.											
9 A.M.											
10 A.M.											
11 A.M.											
12 P.M.	8.6 mg of Senna										
1 P.M.											
2 P.M.											
3 P.M.											
4 P.M.											
5 P.M.	D, Smear										
6 P.M.	1 Magic Bullet 2, T, L										
7 P.M.											
8 P.M.											
9 P.M.											
10 P.M. - 6 A.M.											

Bristol Stool Chart

Type 1

Separate hard lumps, like nuts (hard to pass)

Type 2

Sausage-shaped, lumpy

Type 3

Like a sausage but with cracks on its surface

Type 4

Like a sausage or snake, smooth and soft

Type 5

Soft blobs with clear-cut edges (passed easily)

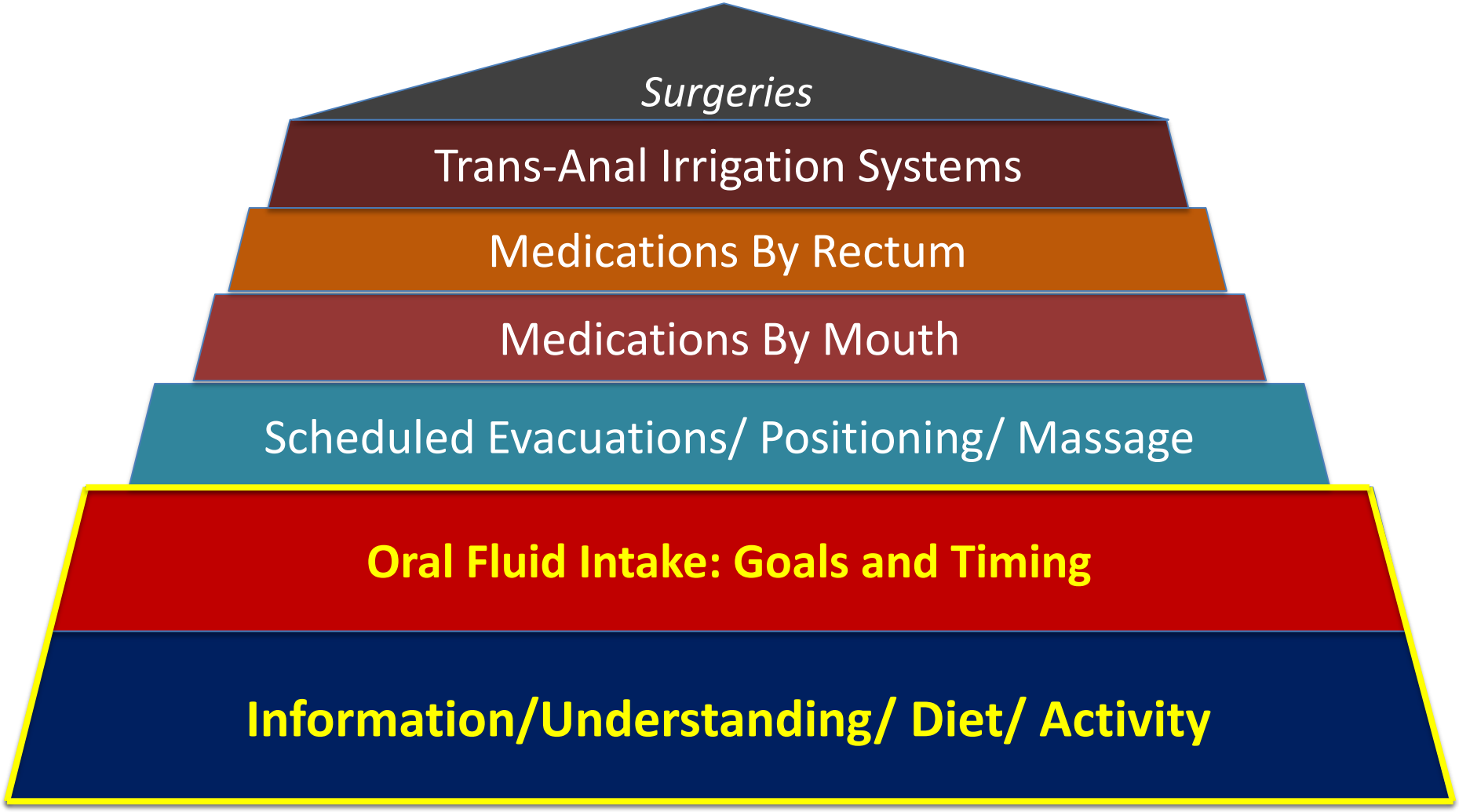
Type 6

Fluffy pieces with ragged edges, a mushy stool

Type 7

Watery, no solid pieces, entirely liquid

Components for Neurogenic Bowel Management over the Lifespan



Information/Understanding/ Diet/ Activity

- Understanding *the nature of the neurogenic bowel* and the need for ***continual re-assessment and management*** *is critical*
- As the child grows and incorporates their *own understanding and ownership of the condition*, the less there are of issues of denial, mystical thinking, avoidance of the topic, etc.
- Re-visiting the concept of "Spina Bifida" and bowel/bladder issues *through successive developmental stages* is also critical to adherence and success in continence.

Information/Understanding/ Diet/ Activity

Daily fiber intake Ages 3 – 20 years: (Age + 5-10) grams/day
Adults: 25-35 grams/day Arch Dis Children101:876-880. 2016

- ***Soluble Fiber*** – By attracting water, it absorbs excess fluid from the feces – making the stool more formed and decreasing liquid stool output.
  - **Oats, peas, barley, apples, citrus fruit; Benefiber, Gummies, etc.**
- ***Insoluble Fiber*** – does not dissolve in water; stays intact and adds bulk to the to the stool
  - *Whole wheat, bran, potatoes, nuts, green beans;; etc.*
- Inadequate Fluid Intake + Extra fiber makes constipation worse
- Monitor **Activity & Diet** (Under-weight/Over-weight) impacts BMP.

Oral Fluid Intake: Goals and Timing

Fluid:Fiber Balance: is *critical for bowel consistency*

- Adequate fluid optimizes the effects of osmotic laxatives
- Important for renal health as well

General Guides for amount of water daily throughout the lifespan (based on weight)

- ***5-10 kg*** 500-1000ml ***10-20 kg*** 1 – 1.5 liters
- ***20-30kg*** 1.5 – 1.75 liters ***30-40 kg*** 1.76 – 2 liters
- ***40-50kg*** 2 – 2.25 liters ***>50 kg*** 2.25 – 2.5 liters

The *timing* of fluid intake needs take into consideration: bladder volume, CIC frequency, active sports, etc.

Scheduled Evacuations/Massage/Positioning

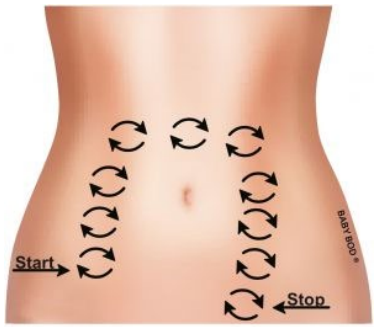
Scheduled bowel evacuation - about the same time each day

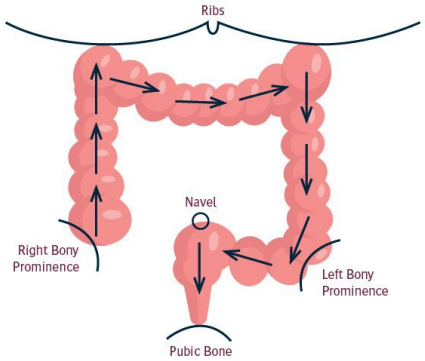
Positioning can help:

knees higher than hips; feet on a surface, not "dangling" (relaxes pelvic floor muscles); knees/hips bent in "squat"; adaptive equipment as needed

Abdominal Massage - for older children through adults

reported as beneficial in about a quarter of individuals with neurogenic bowel ↓colonic transit time and incontinence episodes; CIC prior to starting





Stimulation of gut secretions & motility? (parasympathetic effect)

Mechanical effect?

Scheduled Evacuations/Positioning/Massage

MANY Accommodation Options

See your O.T.

Medications By Mouth

Probiotics

- To date, no evidence to support the use of probiotics for constipation due to neurogenic bowel.
- Little to no adverse effects of their use

Am J Clin Nutr. 110: 177-195. 2019

Clinical Practice Guidelines: Spinal Cord Medicine 2021;27(2):75-151 American Spinal Injury Association

Osmotic Laxatives

- **Poorly absorbed by intestine –> causing a retention of intestinal water**

  Lactulose
  - Not absorbed in the small intestine
  - In large intestine, fermentation by bacteria increases water retention in the intestine to soften stool
  - Often used in younger children
  - 1ml / kg up to 30ml
  - Response effect time 24-48 hours

Medications By Mouth

Osmotic Laxatives (poorly absorbed; →retention of water)

- **Polyethylene glycol**
  - Not metabolized nor absorbed by the gut
  - Stools can be notably soft → watery
  - This can be problematic in those with neurogenic bowel who have little sphincteric tone; *onset of action: 8 -24-96 hours*
  - Typical daily dose is ~ 0.5 gram/ kg/ day up to 17grams
  - Issues of *loose stools, frequent stools, bloating, nausea*
  - Used by some centers from Toddlers to Adults

Medications By Mouth

Osmotic Laxatives (poorly absorbed; →retention of water)

- **Magnesium Hydroxide (Milk of Magnesia)**
  - Generally, works over first 8 hours after taking
  - In addition to the osmotic effects like the others, M-O-M stimulates the release of cholecystokinin → increases Motility
  - **Avoid in infants / people with renal dysfunction !!**
  - Common doses: 0.5 -1 - 2ml / kg / dose; 1-2X daily
- **Magnesium Citrate – for over age 2 years**
  - **Cautious in people with renal dysfunction !! (CrCl < 50)**
  - Common doses: (Avoid in infants)
    - 2-6 years old: 0.5ml/kg up to 3-4X daily (60-90 ml max per day)
    - 6-12 years old: 90-120 ml in a single dose or divided doses with a full glass of water;Teen/Adult: up to 200 once daily
    - **Use only for "Clean Out" – not for regular use**

Medications By Mouth

Lubricants

- **Mineral Oil –** petroleum derivative; thus, not absorbed well
  - Effect seen 24-48 hours
  - 1 – 3ml / kg /day; "Magic Mousse" for children
  - Avoid in people with dysphagia / aspiration concerns
- **Docusate (Colace)**
  - Acts as surfactant to increase water and *unabsorbed fat* into the stools
  - No evidence-based studies re: effectiveness in children
  - Considered a "stool softener" -- no effect on motility.
  - 50-150 mg/day for ages 2-12yrs
  - 50 – 350 mg/kg/day for ages 12 - adult

Medications By Mouth

Stimulant Laxatives stimulate motility and contractions

- **Senna** (anthraquinones) (liquid/tabs/other)
  - Metabolized by bacteria into the active form, sennoside
  - Stimulates colon contractions and secretion of water
  - Effect time generally 5-6 hours
  - Doses ranges 4mg - 8.5mg – 12mg. Adult max: 50/day
- **Bisacodyl** (diphenylmethanes) (tablets)
  - Irritation to smooth muscles of intestine – stimulates peristalsis
  - Effect time ~ 6-8 hours taken orally
  - Dose ranges 5-15mg daily orally

Medications By Mouth

Secretory Agents – approved for ages 18 and older

Lubiprostone – a *prostaglandin E1 derivative*

- Activates the chloride channel in gut lining
- Studies show *increase in the number of stools /day*
- Side effects: nausea, vomiting, diarrhea, abdominal pain
- Dose: 8 – 24 micrograms usually twice daily for constipation

Prucalopride / Tagaserod *– Serotonin receptor agonists*

- Evidence on effectiveness – in children, none; variable in adults
- *↑s frequency and softness of stools*

Other Motility Agents – Curry, Lander, Stringer. 2001

- **Low-dose erythromycin**
- Prokinetic effects in upper GI tract with some element of spread further down; most data in premature babies

Medications By Mouth

Oral Medications – A summary

1. Response to oral medications among children/youth with neurogenic bowel is *quite variable*
2. Start at low doses and expect a need to change in 4-5 days if no responses noted.
3. Changes, when made, should be done for 4-5 days before altering up/down
4. Also, variable among individuals re: the effect
5. Their use is best decided jointly by patient/parent; medical nutritionist; the medical physician closely managing continence and lack of constipation

Medications By Rectum

Rectal Therapies

* Instillation of liquids/medications into the rectum to evacuate stool
* Used regularly, this is a common component of the bowel regimen for most with neurogenic bowel: child/adult

Two main approaches

1. Large volume of water/saline into the colon to produce a mechanical flush
2. Use of a strong stimulant to act locally to enhance contraction & movement

Medications By Rectum

Glycerin suppositories

- *Lubricant*
- Used mostly in infants, early toddlers

Bisacodyl suppositories

- *Stimulant action* on gut lining
- Used with older children/ youth/ adults
- Time to effect widely variable over hours
- Water-based bisacodyl suppositories effective time 10 – 30 minutes
- Come in liquid and solid suppository forms

Medications By Rectum

Saline Enemas

- 10ml/kg up to 20/kg maximum
- Used, but little evidence re: effectiveness

Sodium Phosphate Enemas - hyperosmolar liquid

- 33ml – 150ml based on age/size of person
- Mainly for "Clean out" protocols; No more than two/24 hours
- **Electrolyte imbalances major side effect**
- **Can ↓serum phosphorous &/or calcium**
- **CAREFUL: in those with renal impairment / age < 2 years**
- *Long-term use can be problematic*:
  - Colitis due to chronic irritation
  - Diarrhea due to a narrow, hyperactive colon

Medications By Rectum

Mineral Oil Enemas – a lubricant enema

- Dosing ranges from 2 -5 oz based on age / size of the person
- Often used in "clean out" protocol when *hard, inspissated stool* is present in lower colon/rectum

Suppository of sodium bicarbonate & potassium bitartrate

- Polyethylene glycol base for fast release
- Generates ~ 175mL of the gas carbon dioxide CO(2)
- Distends the rectum, stimulating peristalsis
- Effect in 10-20 minutes
- Shown safe in individuals with renal or electrolyte disorders

Trans-Anal Irrigation Systems

Bulb Syringe Enemas

- **For Infants & Small Toddlers**
- 60-90 ml water, body temperature

Balloon Enemas

- 24Fr Foley catheter
- Side-lie; insert and expand balloon inside the lower rectum to “seal”
- Transfer to toilet; deflate balloon
- *Not functional for many due to transfer issues*

Trans-Anal Irrigation Systems

Cone Enemas: gravity filling

- Tip of soft silicone cone is inserted until “sealing” the anal opening
- Cone is connected to enema tubing and fluid bag;
- Cone is washable and re-useable
- Very cost ($) efficient
- Many pre-teens/adolescents can perform by themselves over 30-40 min

Trans-Anal Irrigation Systems

Balloon Enemas: fluid is pumped into the rectum

- Tip of catheter tube and balloon are inserted
- Balloon is pumped up to achieve a "seal" in the rectum
- Catheter is opened; water is pumped. Balloon is deflated; and catheter removed for evacuation
- Cost can be a barrier with insurance companies/families; 4-6 months start
- Some adolescents can use by themselves

Trans-Anal Irrigation Systems

For either the cone gravity or the balloon pump method:

- Complete emptying of the irrigating fluid and stool can take from 30 min – 45 min on the commode
- Careful monitoring of skin for pressure wounds needed
- Daily or every-other day; based on degree of clean out
- Literature review encompassing > 1,000 (average age: 8 yrs)
  - 78-84% with improved continence
  - 95% with improved QOL scores Mosiello, et al. J Pedi Gastro Nutri. 2017
  - Some youth/adults never achieve full independence in the procedure due to anatomy / motor function barriers
- May be used with glycerin, stimulants, etc. if needed
- Proven to be as effective as surgery in most outcome studies
- **Diet/Fluid/Activity – all remain important**

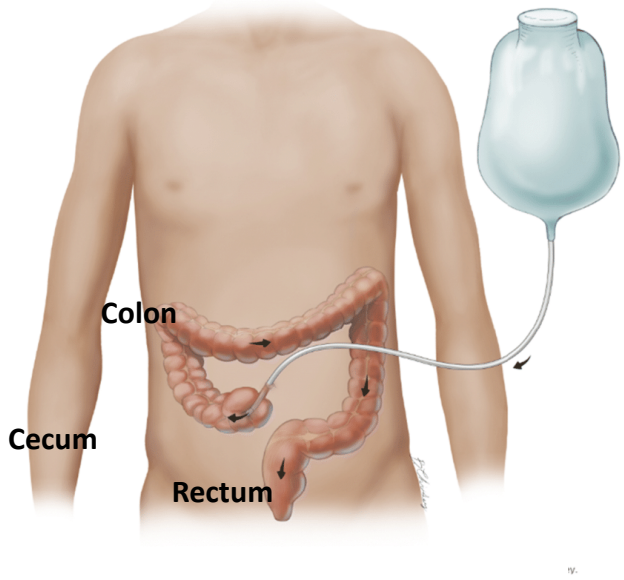
Goals for Surgical Intervention for Neurogenic Bowel

- To evacuate the colon at a time/place of the individual's choosing.
- *Avoid incontinence accidents*
- Create an artificial "upstream" opening to administer the washouts described earlier used in the TAI systems
- May be particularly helpful in those with history of severe high colon impactions
- As with TAI, many teens and adults can administer this themselves; (many still require assistance as with the other TAI methods).

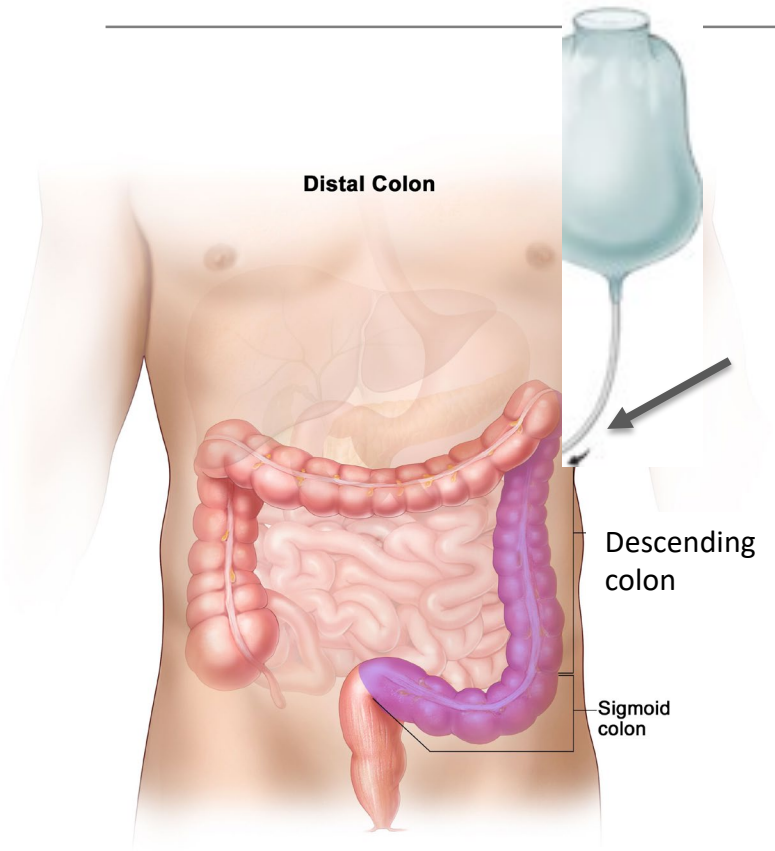
Surgeries

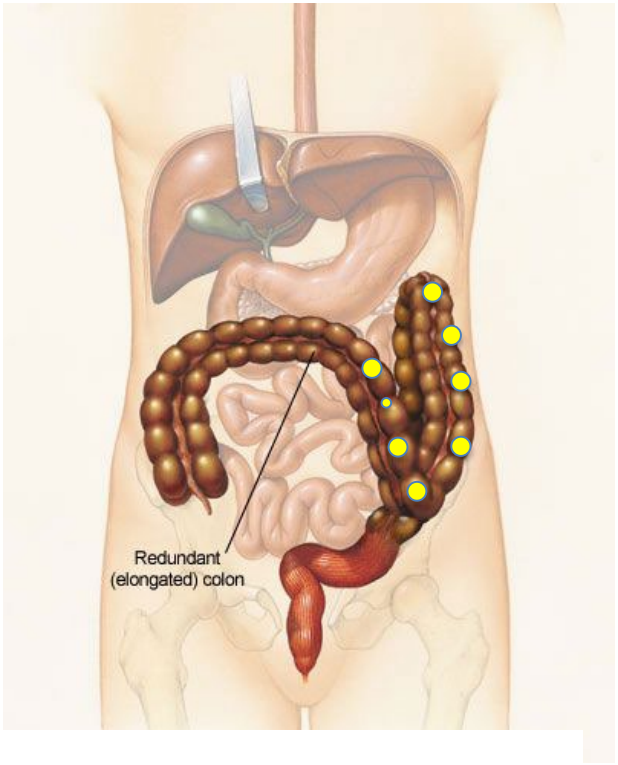
(Malone) Antegrade Continence Enema (M)ACE

- Most commonly used procedure

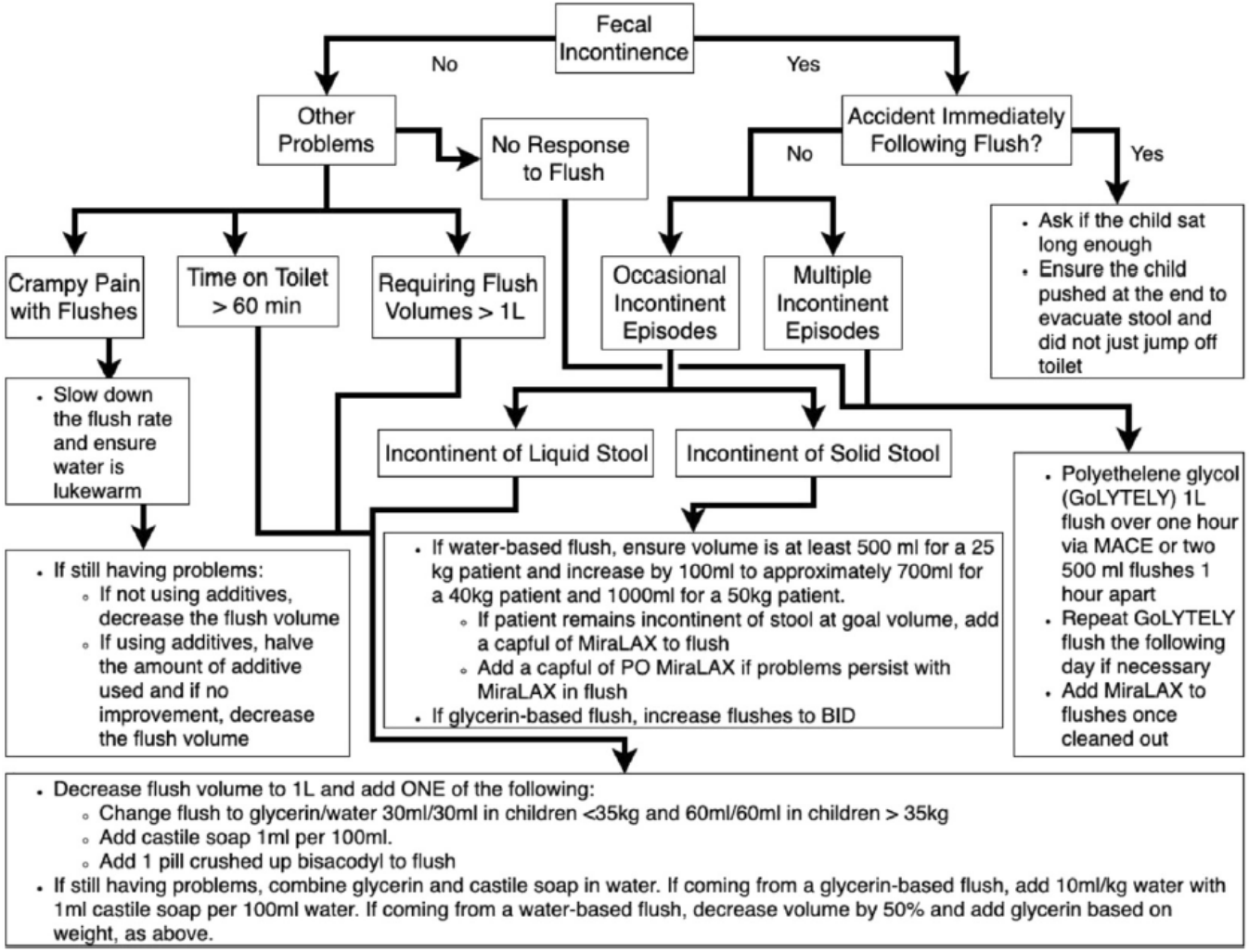


- Create (usually with the appendix or small bowel segment) an opening and channel for catheter from abdominal wall into the cecum
- The fluid and gravity pressure helps to soften and move the fecal material through the colon, through the sigmoid colon, and out the rectum.





- If pre-surgical assessments reveal particularly slow lower colon transit time or distal colonic fecal impaction or redundant colon anatomy, "**distal ACE**" should be considered.
- Stoma for irrigation is placed in descending colon



Example of a problem-solving approach when issues occur with appendico-cecostomy (ACE)

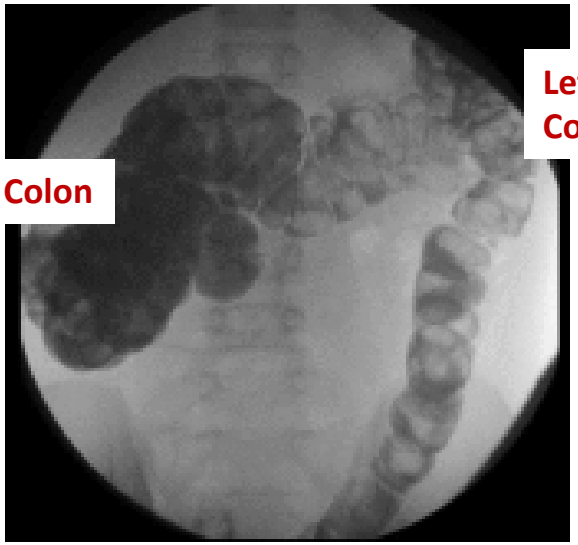
Indiana University

Roth JD, Misseri R, et al. Journal of Pediatric Urology (2021) 17, 446.e1e446.e6.

Surgeries

Considerations when ***problems with ACE*** occur:

- If having accidents, when does the incontinence occur?
- If having accidents, is the stool liquid or solid?
- If having accidents, are they occasional or multiple/day?
- Is there excessive cramping pain with the flushes?
- Is there a “fainting” feeling during the flush?
- Is the time on the toilet each day exceeding an hour?
- Has the volume of the flush risen to > 1 liter?



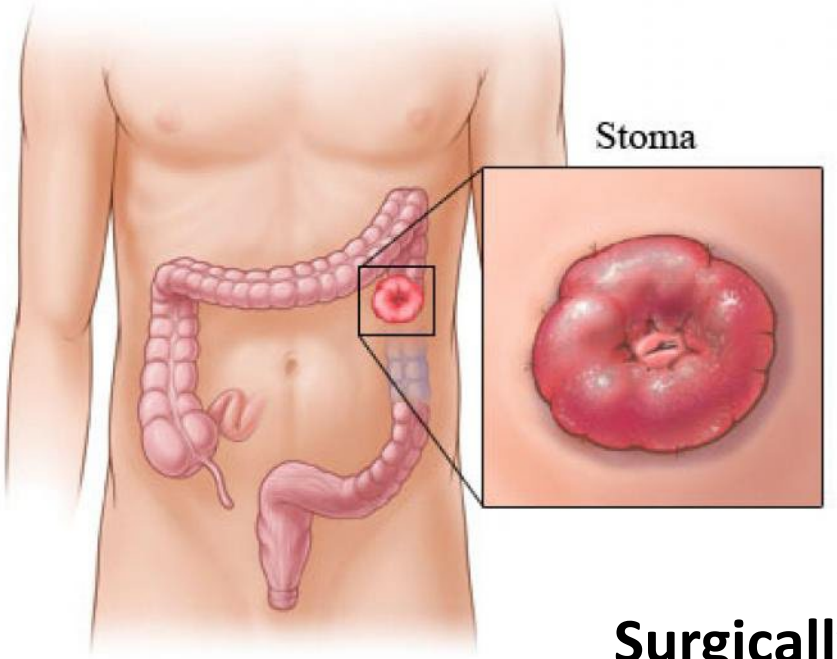
The antegrade continence enema (ACE) surgical procedure: patient selection, outcomes, long-term patient management.
Ekmark E, Adams R. Eur Jour Ped Surg. Suppl 1:49-51. 2000.

Enema-Induced spastic left colon syndrome: An unintended consequence of chronic enema use

Penna A, et al. Journal of Pediatric Surgery. 56 (2). 2021

- 22 Patients; **21 with ACE**
- Ave Age 19.6 yrs
- Ave time with ACE 13.7 yrs
- Common presenting concerns:
  - ↑ time and fluid volumes
  - ↑ pain with procedure
- Dramatic dilatation of right colon
- Spastic changes in transverse & descending colon.
- Needs more study

Surgeries



Surgically Created Ostomy

Infrequently used, but occasionally most pragmatic solution

1.	Stool consistency	*	
2.	Stool frequency	*	
3.	Stool amount	+/-	
4.	Anal/rectal tone	+/-	
5.	Functional Mobility		*
6.	Level of neuro function	*	
7.	Diet	+/-	
8.	Medications	*	
9.	Family routines		+/-
10.	Developmental Tasks	*	
11.	Accessibility/Equipment		*
12.	Learning, EF issues & NB		*
13.	Physical limitations	+/-	
14.	Prior regimens		+/-

Leibold; Ekmark, Adams. 2010

Summary

Topics to Consider in the recurring assessments of the Individualized Neurogenic Bowel Program

Thank You !

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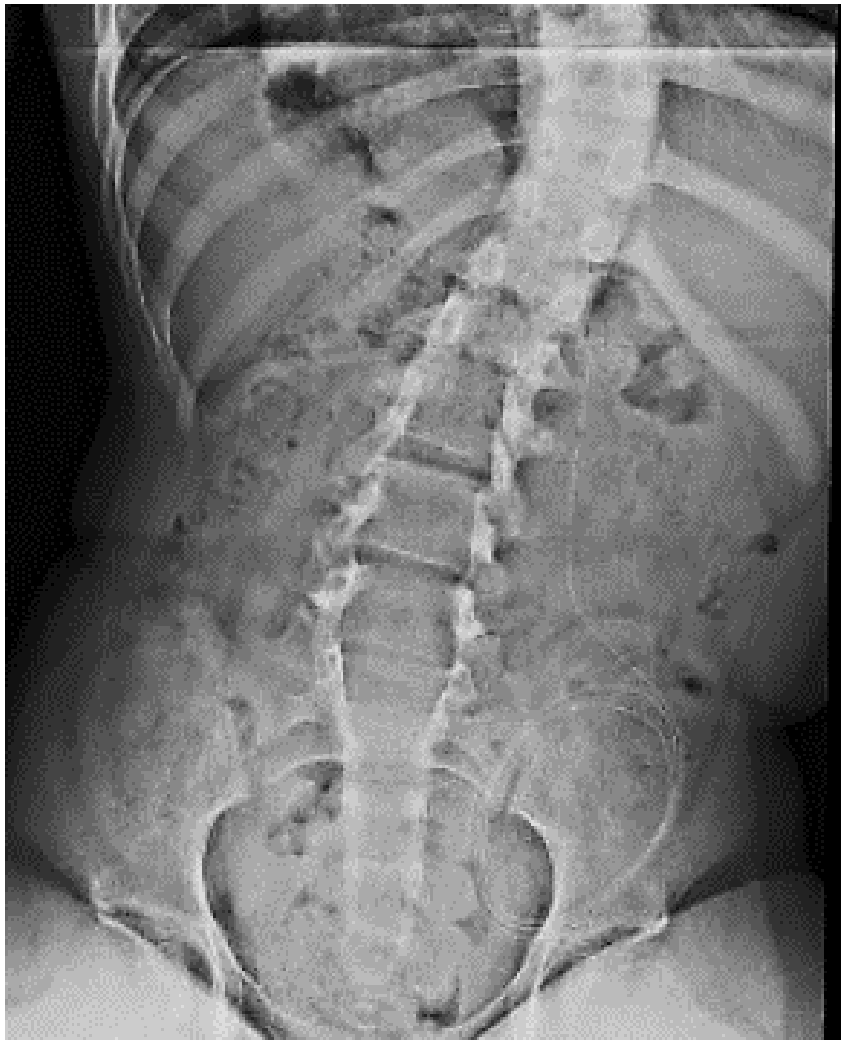
Example Cases for Management Discussion

Young adult man
Independent in managing bowel and bladder

TAI “about every 3rd day”
Rare bowel accidents
Presently using no medications by mouth for bowel management

Taking oxybutynin for bladder.

Relatively active, FTWC user



Young adult female
Sits and pushes when her "tummy feels full"

q 3 hr CIC, but often leaks between; often wet in middle of night
Miralax daily
Bowel "smears" through the day. Bowel evacuations some Bristol 2, mostly 5.

Will use an enema when she goes >4 days without "True" BM

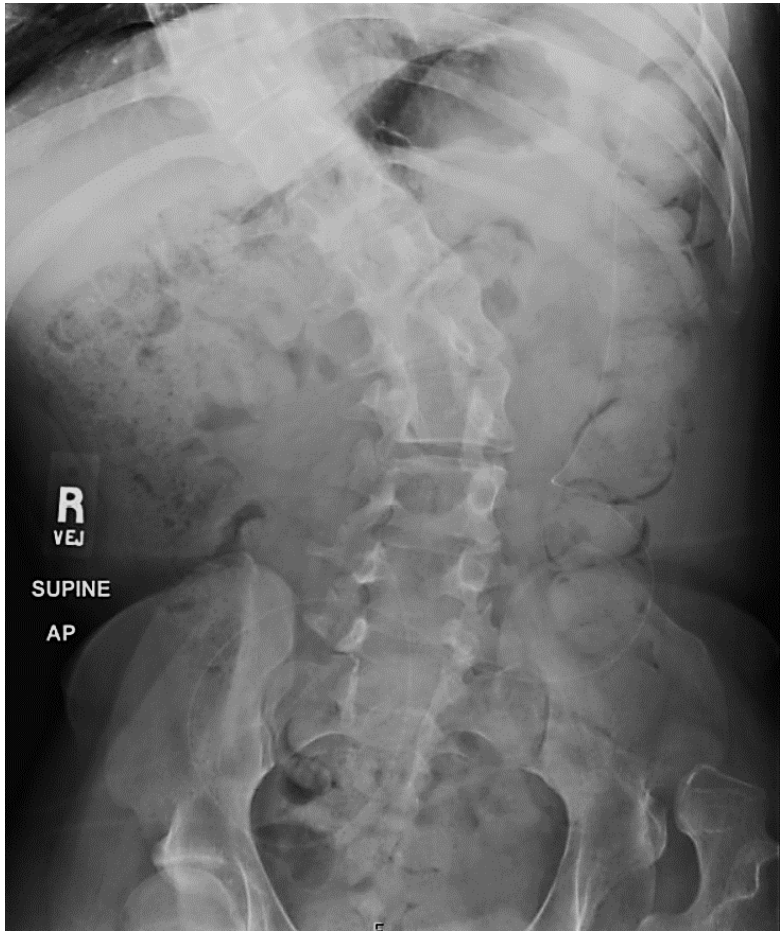
Young adult man
Dependent for bowel
Hi pressure bladder; on oxybutynin BID; q 3 hr CIC

“Infrequent, painful” bowel movements; pull-ups.

Taking Seroquel (mental health); fluoxetine (for depression).

Miralax “prn” (as needed)

FTWC user



Adolescent young man
Dependent for bowel

Hi pressure bladder; on oxybutynin BID

“Spontaneous” bowel movements; pull-ups.

Miralax “prn” when no bowel movement in 3 days

FTWC user

Selected References

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