



*Educational Webinar Series for Adults with
Spina Bifida*

Questions & Answers: Your Bowel Management Program

November 2019

Bowel management is a top concern among adults with Spina Bifida

- Bowel management affects practically every aspect of life
- Bowel management is vital to one's quality of life.

Today's session

- Review: Elements of a successful bowel management routine and methods
- Previous questions
 - Neurogenic bowel
 - Diet and nutrition
 - Enemas / ACE
 - Rectal and trans-anal irrigation systems
- Open question and answer session

Today's panelists

- **Fiona Paul, RN, PhD, CPNP, Boston Children's Hospital, MA**
 - Pediatric Nurse Practitioner, Division of Gastroenterology, Hepatology and Nutrition Nurse Coordinator, Colorectal Program
- **Adam Guerrero, Motivational Public Speaker, CA**
 - Weight-lifting enthusiast
- **Amie Richards, Board of Directors for SBA of Greater New England, MA**
 - Tutor, Reading Specialist, Special Education Teacher, SBA Adult Advisory Council

What are elements of a successful bowel management routine?

Fiona

- Patient preference, needs to fit lifestyle.
- Step up from least to more invasive techniques.
- Developmentally appropriate goals.
- Individual abilities (mobility, cognitive level).
- Need to modify as needed for: illness, activity change, travel, life changes, etc.

What are bowel management routine methods?

Fiona

- Diet, timed sitting, lifestyle modifications
- Medications (lubricate, soften, stimulate, motility drugs)
- Rectal interventions (suppositories, enemas)
- Trans-anal irrigations
- Antegrade continence enemas (ACE)
- Diverting ostomy

YOUR questions

Neurogenic bowel

- How does exercise help neurogenic bowel?
- Do you ever experience pain when your bowels are full and you are ready to cath?
- Is it my imagination that I feel that I have to cath more often when I am constipated?
- I am in my 60s and have a urostomy bag. Does having a urostomy interfere with getting a colostomy?

Diet and Nutrition

- What are specific examples of dietary restrictions?
- How does one determine what foods trigger diarrhea?
- What are your thoughts on the FODMAP (fermentable oligosaccharides, disaccharides, monosaccharides, and polyols) diet?

Diet and Nutrition

- “I take probiotics and Benefiber every day, but often have to rely on prune juice to help keep me cleaned out, often resulting in a blowout. I have tried Miralax and did not feel good when I was on it.

Any suggestions for a simple and effective daily program?”

Foods which may trigger diarrhea

- **Osmotic carbohydrates** - foods high in fructose or high fructose corn syrup (apples, pears, peaches, cherries)
- **High fat foods**
- **High fiber (can go either way)**

High FODMAP Diet

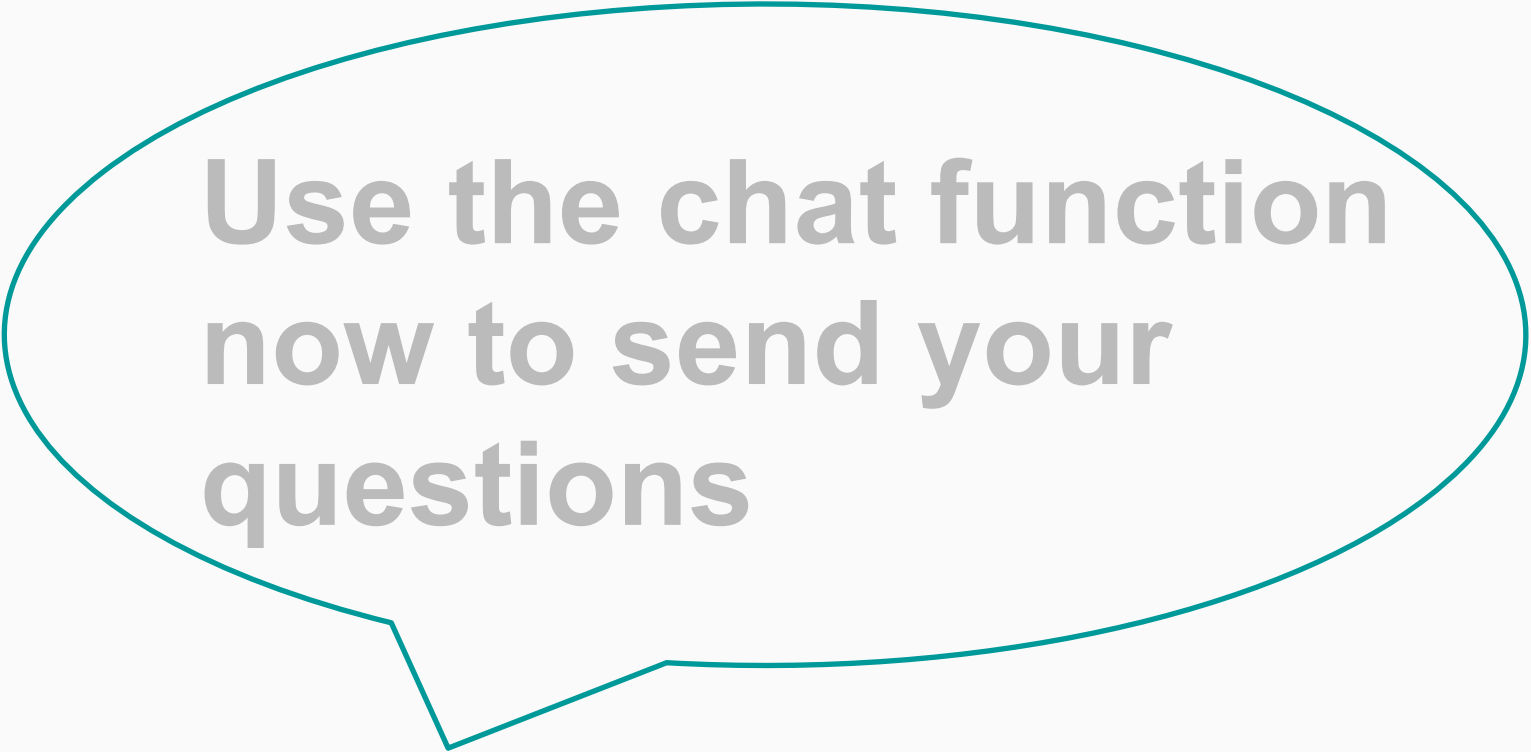
- Fermentable **O**ligosaccharides, **D**isaccharides, **M**onosaccharides, and **P**olyols
- Short chain carbohydrates and sugar alcohols that are poorly absorbed
- Osmotic –pull water into the colon
- Ferment producing gas

Enemas / Antegrade Continence Enema (ACE)

- I'm curious about trying the ACE procedure. Should I speak with my urologist about this?
- Is there a time where you may need to have your ACE redone?
- Would you ever add something to the ACE, like using milk and molasses?
- How long should a child (age 8) need to sit on the toilet after an enema?

Rectal and trans-anal irrigation systems

- Are you still having major issues with insurance authorizations for things like Peristeen?
- Are there other rectal and trans-anal irrigation systems on the market?



**Use the chat function
now to send your
questions**

Additional materials

- Booklet: Bowel Management and Spina Bifida (ask the NRC for details)
- [Bowel Management for Spina Bifida \(an unofficial guide\)](#)
- Facebook groups:
 - [Bowel Management for Spina Bifida](#) group
 - [Bladder/ Bowel care \(peristeen, catheters, etc\)](#) group
- Reading on transanal irrigation systems: [Peristeen](#), [Wellspect](#)
- Guidelines for the Care of People with Spina Bifida: [Bowel Function and Care Guidelines](#), Ages 18+
- [Adam Guerrero's exercise routines](#)

Thank you!

See the full list of resources and an archived recording of this session: <https://www.spinabifidaassociation.org/education/sb-you/>

Questions?

- Judy Thibadeau, jthibadeau@sbaa.org
- Juanita Panlener, jpanlener@sbaa.org