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?
“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 Oligosaccharides, Disaccharides, Monosaccharides, and Polyols
- 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?

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