Your Bowel Management Program – It’s All In The Routine!

September 2019
SB-YOU is for, about and by YOU

- Conversational presentations by subject-matter experts
  - Adults with Spina Bifida who are “life experts” on the subject
  - Health care professionals
- Practical information, tips and suggestions
- Content is driven by YOU
  - Based on surveys of adults with Spina Bifida who shared their concerns about day-to-day life with Spina Bifida
We tend to avoid talking about bowel management.

But, recent surveys of adults with Spina Bifida show that bowel management is a top concern because it affects practically every aspect of life, and is vital to one’s quality of life.
Today’s session will cover:

● Medical and social reasons for keeping a bowel management routine.

● The importance of hygiene in social interactions.

● Elements of a successful bowel management routine, commonly-used routines, and suggestions to establish and maintain a routine.

● Suggestions for communicating about your bowel management routine.

● How sources of support can help with your routine.
Today’s presenters

• 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
How does defecation work?

Fiona

- Transport of stool through the colon
- Filling the rectum from the sigmoid colon
- Rectal stretch/distention initiates:
  - an involuntary reflex which relaxes open the internal anal sphincter
  - the sensation to defecate
  - a contraction in the external anal sphincter (voluntary control)
What is neurogenic bowel dysfunction?
Fiona

- Colonic transit (can be slow, fast, or normal)
- Sigmoid colon function (can be weakened)
- Response of internal anal sphincter (opens with less pressure, remains open)
- Sensation (diminished or absent)
- Control (weaker or absent)
Why is it important to keep a bowel management routine?

Fiona

- Medical reasons
  - Attain social continence
  - Impact on bladder (urinary retention, leaking)
  - Prevent UTIs
  - Preserve colon function
  - Prevent skin irritation and breakdown
  - Impact on mental health
Why is it important, socially, to keep a bowel management routine?

Adam

- You want to avoid smelling bad.
- You don’t want to have frequent accidents while out with friends and family.
Why is it important, socially, to keep a bowel management routine?

Amie

● Allows you to stay focused on other important life goals.

● Fear of accidents could cause you to isolate yourself, become sedentary.

● Help you be on time to appointments and avoid embarrassment about being late.

● Important to sexual intimacy, confidence, and comfort during sexual intimacy.
How is hygiene vital to personal interactions?
Amie and Adam

- There is a constant worry and anxiety about possible smell – even if there is none.
- Significant others and close friends may also be concerned that the person they care for will feel embarrassed.
- Without emergency supplies, you will have to leave some social situations.
- Always be prepared. Bring extra diapers/pads and personal supplies.
How have you adapted your routine to fit your needs and schedule?

Adam

- Check yourself frequently.
- Keep a regular workout schedule.
  - Working your core and getting enough cardiovascular exercise really helps!
- Keep track of what you eat and don’t eat.
Social events can throw off your schedule.

Create a routine based on best medical practices, but adapt it to work for YOU, your schedule, your life and social activities.

Encourage young people still living at home to take control of their routine so they learn on their own to keep a routine.

How have you adapted your routine to fit your needs and schedule?

Amie
What are common challenges to keeping a routine?

Amie

- Accidents happen at the worst times.
- You don’t always have access to a restroom (and private restroom!) where you can clean up from accidents.
- Your GI system's reaction (sometimes it works, others it doesn’t).
- Work responsibilities, schedule.
- Mental health.
What are common challenges to keeping a routine?

Adam

- Social engagements.
- Living arrangements.
- Your own motivation, mental health status.
- Re-establishing your routine once it’s broken.
- Support system.

- Sometimes you may have back-to-back engagements: i.e. school or work.
- Having a routine won’t eliminate accidents, but it helps to reduce the frequency of accidents.
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.
How do you approach bowel management?

Adam and Amie

- Have a balanced view of bowel management. Your routine will not be perfect and there will be times when it falls apart.
- Part of having a good routine is knowing how to quickly and cleanly address accidents – both the physical clean up and how you communicate about it.
- Do whatever you need to do with consistency to maintain your health, safety, and productivity.
What are bowel management routine methods?

Fiona

- Diet, timed sitting, lifestyle modifications
- Medications (lubricate, soften, stimulate, motility drugs)
- Rectal interventions (suppositories, enemas)
- Transanal irrigations
- Antegrade continence enemas (ACE)
- Diverting ostomy
How and when do you talk about it?

Adam

- Develop your go-to phrase.
- It’s important to be open with the person you are intimate, even in detail (as needed).
- Learn to advocate for yourself.
- It’s a big part of your life; learn to confide in some people.
- Determine who needs to know, what they need to know, and how much they need to know.
Who are your sources of support?

Amie

- Nurse, primary care provider, other trusted health providers.
- Trusted friends.
- Allies who also have Spina Bifida.
- Don’t fall into “why do I even try?” mentality!
- Don’t let accidents get you down, keep you down, or keep you from living your life.
- Just do your best to keep a routine.
Ask the specialist
Fiona

- Patient-provider relationship is important.
- If your provider doesn’t bring up your bowel management routine, speak up!
- It's not always possible to see a gastroenterologist (GI), or to see a GI that is familiar with Spina Bifida.
- Other providers can address your routine.
Don’t give up!

- Don’t be afraid to speak up!
- One size does not fit all.
- Effective bowel management relies on collaboration between you, your providers, and your sources of support.
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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