



*Educational Webinar Series for Adults with
Spina Bifida*

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

Preface

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.

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

Amie

- 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.

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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