REHAB GUIDELINE | NEUROGENIC BOWEL

Children's MINNESOTA

Aim: A protocol for progressing independence with bowel skill management in children who have a neurogenic bowel.

EVALUATIONS

Physician | Nurse | Occupational Therapy (OT) | Physical Therapy (PT) | Speech Therapy (ST) | Dietitian

General assumptions	
New injury	Protocol initiated within 24–48 hours of admission with physician order
History of neurogenic Dx	Protocol initiated when able to demonstrate skills of Rehab Indicators of Readiness (See page 3)
Procedure occurring changing current routine	Protocol initiated to facilitate new POC

Design specific bowel management protocol based on evaluation results

Begin protocol education for patient and family/caregivers

OT/PT/ST treatment as established based on evaluation results

Monitor progress

Successful as established for 3 cycles?
(Cycle = 14 days no incontinence)

- Yes → **Physician follow-up at end of treatment period to DC from bowel protocol**
  - Patient/family satisfied with daily management protocol
  - **Follow-up with physician in 6 months to monitor progress since discharge**
- No → **Team to re-evaluate protocol**
  - **Adjustments made or new plan created**

Level of involvement	Functional independence level
C1–C5	Total assist. Able to give verbal direction to caregivers based on cognitive abilities
C6–C8	Some to total assist
T1–S5	Independent

Source: Consortium for Spinal Cord Medicine, 1999

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INITIATION OF PROTOCOL

Appointment with physician/CNP, resulting in referral for initiation of the protocol to nursing, dietitian, OT and PT (ST, if appropriate)

Dietitian:

- Initial appt. before OT/PT to start

Surgical interventions:

- To be taken into account when initiating therapies
- Can assess for functional skill with therapies prior to surgery taking place to allow for development of skill until cleared after surgical intervention

Nursing:

- Initial appt. before OT/PT to start
- Start working with existing therapists or referral to therapists completing protocol

OT/PT progression:

- Start after nursing and dietitian appts.
- Continue education with nursing
- **Inpatient:**
  - Eval within 24 hrs of admission
- **Outpatient:**
  - Wk 1–4: 1–2x/wk OT/PT
  - Wk 5–8: 1x/wk OT/PT
  - Wk 9 and beyond: 1x/wk or EOW OT/PT working to monthly/ quarterly checks as appropriate

When successful with 3 cycles, and patient/family satisfied with home protocol, then return to primary for follow-up before DC from program

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COMMON CAUSES/PATHOPHYSIOLOGY OF NEUROGENIC BOWEL DYSFUNCTION

- Myelodysplasia/Spina Bifida
- Sacral agenesis
- Anorectal malformation (ARM)
- Cerebral Palsy (up to 90% kids with CP suffer constipation and 47% fecal incontinence)
- Muscular Dystrophies/Mitochondrial Disorders
- Acquired brain injury
- Acquired pelvic injury
- Acquired spinal cord injury
- Down syndrome (multifactorial consider could be partially neurogenic)
- Autism (multifactorial consider could be partially neurogenic)
- Transverse Myelitits
- Guillan-Barre syndrome (bowel dysfunction seen in up to 15% patients)
- Cauda Equina syndrome
- Acute Disseminated Encephalomyelitis and Meningitis-Retention syndrome

Mosiello et.al. 2021

REHAB INDICATORS OF READINESS

If child is new to therapies/rehab then these will be assessed as part of intake into protocol.

BOWEL PHYSICAL READINESS

- Extended periods of continence during day
- Awareness of urge for BM, awareness distress/dislike of being soiled following BM
- Making connections between elimination and toileting/hygiene
- Regular voiding/BM patterns established or emerging

OT

- Dressing/undressing UE/LEs
- Fine motor function for managing equipment and clothing
- Hygiene skills for washing hands
- Sensory prepared for toileting
  - Sitting without diaper, noises of the bathroom, level of distress with being wet/soiled, tolerance of wearing underwear, etc.
- Interoception sensory awareness regarding bowel urge, act of elimination, being soiled

PT

- Ability to transfer on and off toilet/commode
- Sitting balance for 10 min.
- Standing balance for 10 min.
- Dynamic weight shift while in seated position for 20' outside of base of support in all planes

ST

- Understand and respond to directions, questions, or words related to toileting routines
- Communicates need to go/having went/outward signs of needing to go (verbally or nonverbally)
- Cause and effect
- Follows modeling

Kaerts, et al. 2012

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TYPICAL DEVELOPMENTAL STAGES

Skill	Task	**Age** (in years) 90% has mastered skill
Toileting	Indicates when wet/soiled	2.0–2.5
	Manages toilet, clothing management	3.0–3.5
	Takes self to bathroom, distinguishes need to void vs. eliminate	3.0–3.5
	No bowel accidents	3.5–4.0
	Dry day and night	4.5–5.0
	Thoroughly wipes	6.0–6.5
Dressing	Don/doff elastic waist pants	3.0–3.5
	Don/doff pull on shirt	3.5–4.0
	Removes and unfastens all clothing	4.5–5.0
	Dons and fastens all clothing	5.5–6.0

Skill	Task	**Age** (in years) 90% has mastered skill
Grooming	Washes/dries hands thoroughly	4.0–4.5
Transfers	Unsupported sitting: toilet	2.0–2.5
	On/off low potty	3.0–3.5
	On/off toilet: arms	3.0–3.5
	On/off toilet: no arms	6.0–6.5
Locomotion	Moves between rooms with no difficulty	1.0–1.5
	Opens/closes doors	3.0–3.5
	Walks up/down full flight of stairs without difficulty	3.0–3.5

Haley, Coster, Ludlow, Haltiwanger and Andrellos, 1992

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TYPICAL DEVELOPMENTAL STAGES
with Myelodysplasia (80th percentile)

Skill	Task	L2 and above	L3, L2–L4	L4–L5	S1 and below
Grooming	Washes hands – no help	9 yrs	6.5 yrs	6.75 yrs	5.25 yrs
Dressing	Removes pants	10 yrs	8 yrs	6.33 yrs	5.5 yrs
	Dons pants	12.5 yrs	11.33 yrs	7 yrs	5.75 yrs
	Pull on garment	10 yrs	8 yrs	6 yrs	6 yrs
	Shirt with buttons	11.25 yrs	6.5 yrs	7 yrs	6 yrs
	Removes braces	9.25 yrs	9.25 yrs	7 yrs	8.5 yrs
	Full dressing self (except difficult snaps)	10 yrs	10 yrs	9 yrs	7 yrs
Personal awareness	Asks about routine bodily functions	7 yrs	5.66 yrs	4.83 yrs	4.5 yrs

Sousa, Telzrow, Holm, McCartin and Shurtleff, 1983

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MEDICAL MANAGEMENT

Physician:

- Create written Plan of Care (POC) for team to follow
- Diagnostics as needed:
  - KUB, anorectal manometry, endo-anal ultrasound, barium enema MR proctogram, Electromyography, MRI/CT, colonoscopy (rare)
  - Sensation Testing/Level of Innvervation
- Treatment options as appropriate single or combination:
  - Digital stimulation
  - Manual evacuation
  - Bulb syringe
  - Balloon enema
  - Cone enema
  - Transanal irrigation
  - ACE (bowel surgery)
- Medications/supplement regime
- Orders for rehab, dietitian or any additional services
- Equipment/supplies orders as necessary

(Newman, 2012) (Mosiello 2021)

Nursing:

- Bowel and bladder assessment (current and history)
- Start daily diary of bowel for what currently doing and effect of interventions — at least 72 hrs
- Begin toileting program and education
  - Intervals of every 2–3 hours
  - Upon waking, after breakfast, after lunch, after dinner and before bed; can also do at night is necessary
  - Patient and family/caregiver education and assisting with interventions
  - Skin management if incontinent

(Newman, 2012; Hasbro Children's)

Dietitian:

I. Assessment of:

- Diet record to evaluate regular intake of fiber-rich foods
- Evaluation of fluid intake and hydration status
  - Regularity of bowel movements
  - Is there a bowel regimen already in place?

II. Management:

- Personalized regimen with a goal of intervention that is effective in the shortest amount of time, promotes continence and avoids constipation
- High fiber diet: consistent intake of whole grain products, fruit and vegetables to achieve optimal stool consistency
- Fiber containing enteral formula: simulates high fiber diet in achieving optimal stool consistency
- Suppositories and enemas: effective acute intervention, not a long-term treatment
- Laxatives: Oral laxatives appropriate for achieving optimal stool consistency, but can result in diarrhea or fecal incontinence if used in excess

III. Education of parents/caregivers:

- Encourage balanced diet following with adequate daily fruit and vegetable consumption
- Education on fiber rich food sources and daily need for patient, based on Dietary Guidelines for Americans*
- Enteral tube flush regimen

IV. Monitoring:

- Stool consistency, issues with constipation

V. Fiber recommendations per age

- AGE plus 5 grams up until the age of 20 year when can move to 25–35 grams of fiber as an adult dose.

(Williams et al 1995) (Mosiello 2021)

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REHABILITATIVE MANAGEMENT

Bowel and Bladder Specific Rehabilitation (Occupational Therapist and/or Physical Therapist)

Education:

- Pelvic floor anatomy/function
- Bladder function urinary system anatomy, age appropriate
- Neurogenic bowel function; GI system anatomy age appropriate
- Bladder irritants
- Hydration
- Constipation
- Nutrition related to constipation, fiber
- Kidney, bladder, GI system, rectum, and pelvic floor relative function

Logging information:

- Bladder diary
- Bowel diary

Training:

- Voiding/elimination schedule
- Task analysis for specific management program including: bathroom analysis, ability to assemble supplies, cleaning up supplies, hand hygiene, assessment adaptation to tasks as necessary
- ADL skill – level of assist specific to clothing management and hygiene. Ability to access supplies.
- Transfers/sitting balance
- Wiping/skin care
- Toileting posture
- Constipation management with titration of medication as directed by primary medical provider including but not limited to: bulk forming laxatives, fiber therapy, osmotic laxatives, saline laxatives, magnesium supplements, stimulant laxatives, fecal softeners, enemas, rectal laxatives, disimpaction/clean outs
- Core strengthening
- Postural stability
- Visceral mobilization/tissue mobilization/manual therapy/scar mobilization
- Breathe control and coordination as it relates to posture, GI function, voiding/elimination function
- Anal manometry, rectal balloon training
- Working with bowel management care provider (physician, nurse practitioner) to assist with function of management options including: Digital stimulation, Manual evacuation, Bulb syringe, Balloon enema, Cone enema, Transanal irrigation, ACE (bowel surgery) as needed
- Assessment for adaptations and adapted tools as necessary

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GENERAL REHABILITATION SERVICES

Occupational Therapy (OT):

- Assess and provide intervention as needed for: Hand Function — grip/pinch testing; finger ROM/Opposition; Grasp patterns; In-hand manipulation; Stereognosis; Propioception of UEs; Visual Perceptual skills (as needed)
- ADL Skill completion
- Feeding needs as it relates to bowel function/constipation
- Interoception techniques
- Communication with client/caregivers for needs

Physical Therapy (PT):

- Sitting balance for 10 min.
- Standing balance for 10 min.
- Dynamic weight shift while in seated position for 20' outside of base of support in all planes
- Spine mobility for all directions in toileting posture as needed for function
- Foot/ankle strengthening for posture if appropriate
- Communication with client/caregivers for needs

Speech Therapy (ST):

- Current cognitive status
- Executive function
- Understand and respond to directions, questions or words related to toileting routines
- Communicates need to go/having went/outward signs of needing to go (verbally or nonverbally)
- Cause and effect
- Follows modeling
- Communication with client and caregivers for needs

BOWEL MANAGEMENT OPTIONS (not all-inclusive)

- Antigrade Continent Enema (ACE)
- Enema
- Peristeen
- Cone enema and bulb enema
- Scheduled voiding
- Bowel augmentation
- Colostomy or ileostomy
- Medications
- Diet
- Manual evacuation

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TYPES OF ADAPTIVE EQUIPMENT

- Folding frame or fixed frame
- Self-propulsion or attendant propulsion
- Tilt-in-space commode
- Custom-made pressure-reducing foam seat with vinyl cover
- Smaller or extended aperture
- Padded/custom backrest/ seatrest
- Toilet ring
- Arm rests
- Headrest
- Handles
- Leg rests
- Anti-tip bars
- Easy wipe
- Toilet aid/self wipe
- Bottom Buddy™
- Adaptive clothing
- Transfer board
- Mechanical lift
- Reacher
- Mirrors
- Reducer ring

EQUIPMENT BASED ON LEVEL OF INJURY

C1–C4	• Mobile shower commode with custom padded seat • Arm supports, head rest/support • Lateral supports • Tilt-in-space
C5–C6	• Mobile shower commode with custom padded seat • Potential need for seat-to-back resting angle or arm rests
C7–C8	• Mobile shower commode with custom padded seat • Full or partial side cutouts for access • Adaptive equipment (i.e., suppository inserter)
T1–L1	• Mobile shower commode with custom padded seat with full or partial side cutouts for access • Padded toilet seat • Over-toilet aid with padded seat
L1–S5	• Mobile shower commode with custom padded seat with full or partial side cutouts for access • Over-toilet aid with custom padded seat

ACI State Spinal Cord Injury Service, 2014; Galant and Victor, 2016

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BOWEL MEDICATIONS: BOWEL MAINTENANCE MEDICATION

Medication	Generic/Brand Name(s)	Mechanism of Action	Age	Dosing	Method of Administration	Onset After Administration	Side Effects
Polyethylene Glycol 33350	Miralax GlycoLax Movicol Restorolax Lax A Day	Osmotic Laxative	General amounts:	0.4–0.8 g/kg per day Max of 17 g daily Mix with 8 oz of fluid/17g	Oral	24–96 hrs	
			< 18 mo	.5–1 tsp per day	Oral	24–96 hrs	
			18 mo to 3 yrs	2–3 tsp per day	Oral	24–96 hrs	
			3 yrs +	2–4 tsp per day	Oral	24–96 hrs	
			Adults	17 g per day	Oral	24–96 hrs	
Docusate Sodium	Colace Surfak	Osmotic Laxative/ Stimulant Laxative	< 3 yrs	10–40 mg per day (divided into 1–4 doses)	Oral	1–3 days	Liquid is Bitter
			3–5 yrs	20–60 mg per day (divided into 1–4 doses)	Oral	1–3 days	
			6–12 yrs	40–150 mg (divided into 1–4 doses)	Oral	1–3 days	
	Enemeez	Stool Softener Laxative	< 6 yrs old	60 mL	Rectal	1–3 days	
			> 6 yrs	120 mL	Rectal	1–3 days	
Lactulose (70% solution)	Lastulose Kristalose	Osmotic Laxative	Children	1 mL/kg (up to 60 mL per day) in 1–2 doses per day	Oral	1–2 days	Flatulence, abdominal cramps
			Adults	15–30 mL once daily (max of 60 mL per day)	Oral	1–2 days	
Magnesium citrate		Osmotic Laxative	< 6 yrs	60–90 mL PO daily; divided in 1 to 2 doses	Oral	0.5–3 hrs	Hypermagnesemia leading to muscle weakness, hypotension, or respiratory depression
			6–12 yrs	90–210 mL PO daily; divided in 1 to 2 doses	Oral	0.5–3 hrs	
			12+ yrs	200- PO daily; divided in 1 to 2 doses	Oral	0.5–3 hrs	
Magnesium Hydroxide **400 mg/5 mL (80 mg/mL) liquid:**	Milk of Magnesia	Osmotic Laxative	1–11 yrs	1–3 mL/kg daily of 400 mg/5 mL solution Max of 60 mL in single or divided doses	Oral	0.5–6 hrs	Hypermagnesemia leading to muscle weakness, hypotension, or respiratory depression
			12–adult	30–60 mL daily dose of 400 mg/5 mL solution (single or divided dose) 15–30 mL daily dose of 800 mg/mL solution (single or divided dose)	Oral	0.5–6 hrs	

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Psyllium	Metamucil Fiberall	Bulk Laxative	< 6 yrs	1.25–2.5 g/dose 1-3x/day Dose must be mixed in full glass of water or juice	Oral	12–72 hrs	Abdominal cramps, esophageal or bowel obstruction Contraindicated in fecal impaction or GI obstruction. Use caution with esophageal strictures, liver dysfunction, and rectal bleeding
			6–11 yrs	2.5–3.75 g/dose 1–3x/day Dose must be mixed in full glass of water or juice	Oral	12 to 72 hrs	
Mineral Oil		Emollients	1–11 yrs	1–3 mL/kg	Oral		
			12–adult	15–45 mL daily	Oral		
Sorbitol 70%			2–11 yrs	1–2 mL/kg	Oral	24–48 hrs	Flatulence, abdominal cramping
				30–60 mL of a 25–30% solution	Rectal	24–48 hrs	
			12–adult	15–30 mL once or twice per day	Oral	24–48 hrs	
Bisacodyl	Dulcolax	Stimulant Laxative	< 2 yrs	5 mg/day ***OR*** 0.5–1 suppository/day	Rectal	15 to 60 min	Nausea, vomiting, abdominal cramps
			2–10 yrs	5–10 mg per day ***OR*** 0.5–1 suppository/day	Rectal	15 to 60 min	
			11–adult	5–10 mg per day ***OR*** 1 suppository/day	Rectal	15 to 60 min	
			3–10 yrs	5–20 mg/day	Oral	6–10 hrs	Nausea, vomiting, abdominal cramps; do not crush or chew pills
			11–adult	5–15 mg per day	Oral	6–10 hrs	
Glycerine	Fleets Pedialax	Stimulant Laxative	Neonates	0.5 mL/kg rectal solution as enema ½ infant suppository once daily	Rectal	15 to 60 min	Abdominal cramping/ discomfort
			< 6 yrs	2–5 mL rectal solution PR as an enema 1 infant suppository once daily	Rectal	15 to 60 min	
			6 to adult	1 adult suppository/day	Rectal	15–30 min	

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Medication	Generic/Brand Name(s)	Mechanism of Action	Age	Dosing	Method of Administration	Onset After Administration	Side Effects
Sodium phosphate enemas		Stimulant Laxative	2–4 yrs Not recommended for < 2 yrs old	½ pediatric enema	Rectal	1 to 5 min	Risk of trauma to rectal wall, abdominal distension, vomiting, hyper-phosphatemia, hypocalcemia Contraindicated in renal failure, megacolon, and bowel obstruction
			5–11 yrs	1 pediatric enema	Rectal	1–5 min	
			12–adult	1 adult enema	Rectal	1–5 min	
Senna as sennosides	Senokot ExLax	Stimulant Laxative	1 mo to 2 yrs	2.2–4.4 mg	Oral	6 to 24 hrs	Nausea, vomiting, abdominal cramping, idiosyncratic hepatitis Syrup may be given with juice or milk, or mixed with ice cream. Granules may be sprinkled on food or mixed with drinks Avoid prolonged use more than one week.
			2–5 yrs	4.4–6.6 mg	Oral	6 to 24 hrs	
			6–12 yrs	8.8 mg to 13.2 mg ***OR*** 1–2 tabs	Oral	6 to 24 hrs	
			12–adult	5–15 mL 1–3 tabs	Oral	6 to 24 hrs	

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BOWEL CLEANOUT MEDICATIONS

Bowel Cleanout

Additional Notes:	• Pick 1 stool osmotic laxative and one stimulant laxative • If you are on these medications for maintenance doses, these amounts for cleanouts will be different

Bowel Disimpaction/ Bowel Cleanout	Age	Mechanism of Action	Dosing	Method of Administration	Side Effects
Polyethylene Glycol	< 6 yrs	Osmotic Laxative	2–3 caps over two days	Oral	
	> 6 yrs		136 g in 34–36 oz fluid (Equivalent to small bottle of Miralax. If small size, then can do half of a bottle).	Oral	
Enema	Infant	Stimulant Laxative	6 mL (0.2 oz) per kg (max of 135 mL or 4.5 oz).	Rectal	None
	1+ yrs		6 mL/kg (max 135 mL) every 12–24 hrs over one to three administrations	Rectal	
Senna	2–6 yrs	Stimulant Laxative	2.5–7.5 mL ½–1½ tablets	Oral	Nausea, vomiting, abdominal cramping, idiosyncratic hepatitis
	6–12+ yrs		1–2 tablets per day		
Bisacodyl	> 2 yrs	Stimulant Laxative	1–3 tables per day	Oral	

(Nurko MD & Zimmerman MD, 2014); (Biggs MD & Dery MD, 2006); (TRC - Pharmacists Letter, 2017); (UpToDate, 2021)

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Created by Teanna Nelson, MA, OTR/L; Nicole Brown, DPT; Lynn Lamott, RN; Kaylynn Annis, CNP; Pam Hollatz, RN; Laura M. Wolles, RD, LD.

Updated 2022: Teanna Nelson, MA, OTR/L; Carrie Gorzek DPT.