



Memorial Sloan Kettering
Cancer Center™

Living with Chordoma

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Disclosures

No financial relationships exist



An Overview

Physical Medicine and Rehabilitation (PM&R), also known as physiatry, is a medical specialty that **emphasizes the prevention, diagnosis, treatment and rehabilitation of people disabled by disease, disorder or injury.** It is one of the newer subspecialty areas of medicine that manages a diversity of conditions involving the nervous and musculoskeletal systems, and focuses on function, independence and quality of life.

Physiatry provides integrated, multidisciplinary care aimed at recovery of the whole person by addressing the individual's physical, emotional, medical, vocational and social needs. **Physiatry is unique among medical specialties in that its area of expertise is the functioning of the whole patient,** as compared with a focus on an organ system or systems. A doctor who specializes in physical medicine and rehabilitation is called a physiatrist. Physiatrists can be medical doctors (MD) or doctors of osteopathic medicine (DO) and practice in a variety of clinical settings, including inpatient and outpatient facilities.



Have More Questions?
Contact us and we can help answer them or connect you with a physiatrist!

What can physiatry do for patients living with chordoma?

Relieve Symptoms

Pain
Bowel/bladder dysfunction
Spasticity
Sexuality & Intimacy

Prevent Further Complications

Bone health
Spinal instability
Fractures
Pressure injuries
DVT

Enhance Functional Independence

Neurological impairments
Functional impairments
Equipment/bracing needs

Treatment Decision Making/Medical Management

Discussion of Clinical Findings
Electrodiagnostic testing
Cardiovascular management
Pulmonary management
Pressure injuries/wound management

Improve Quality of Life

Relieve symptoms
Prevent Further Complications
Enhance Functional Independence
Education
Psycho-social support



Caring for Patients with Chordoma-Physiatry Assessment

History

- Present Illness
- Past Medical History
- Medications
- Social history
- Prior/current functional status
- Support system

Evaluation

- Musculoskeletal evaluation
 - abnormal spine alignment, pelvic obliquity, joint subluxation/dislocation, spine/ extremity fractures, assess areas of tumor involvement
- Muscle strength-key & non-key muscles in upper/lower extremities
- Sensation to light touch/pin prick/proprioception
- Assess for abnormal range of motion in the spine/extremities
- Cognition
- Blood pressure/fluid status
- Skin integrity
- Evaluate gait biomechanics/kinematics if able



Physiatry Assessment

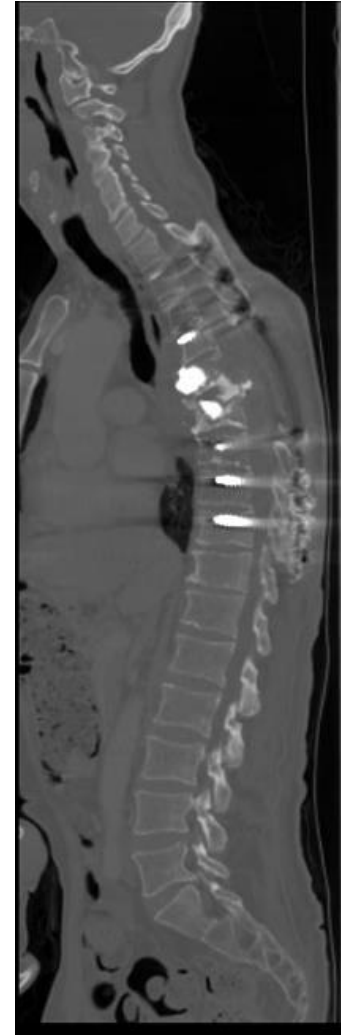


- Imaging
 - Tumor
 - Fractures
 - Abnormal alignment
 - Degenerative changes
- Precautions-medical/bone/spine
- Anticipated treatment/clinical course
- Patient and caregiver goals



Goal of physiatry evaluation is to understand symptoms, their impact on function, and to establish a management plan

- NLI/Patterns of injury
- Pain
- Musculoskeletal contributions
- Precautions-medical/bone/spine
- Anticipated treatment/clinical course
- Patient and caregiver goals



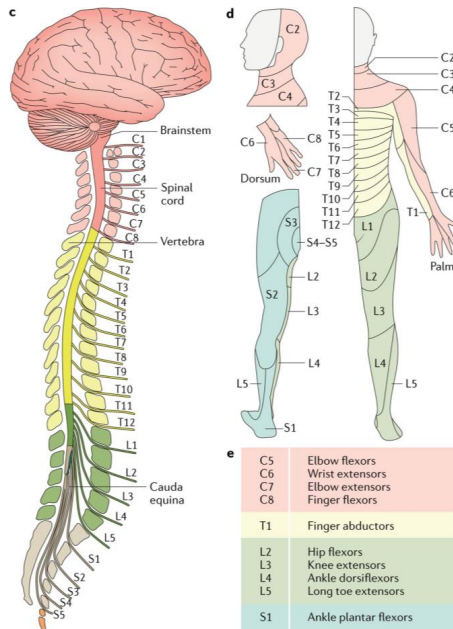
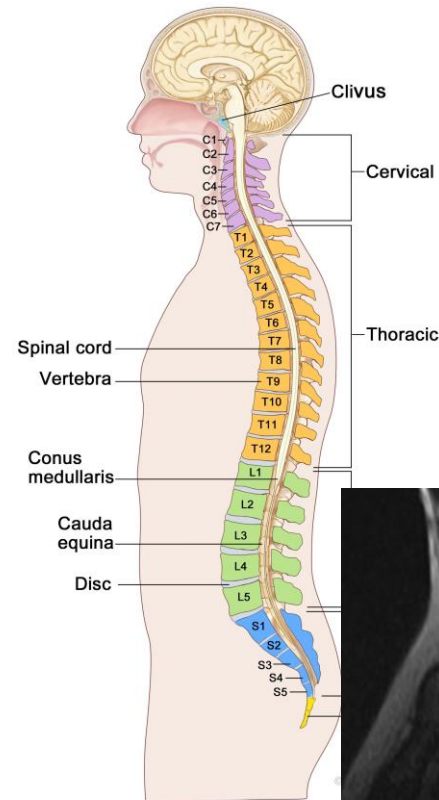


Caring for Patients with Chordoma-Physiatry Recommendations

Pain



Symptoms of Pain



Rehabilitation Recommendations-Pain

- Collaborate with neurosurgery, orthopedics, medical oncology, radiation oncology, interventional radiology, anesthesia pain, supportive care
- Education on spinal precautions
- Postural/extremity bracing
- Medication management
- Physical/occupational therapy
 - Core strengthening, muscle strengthening, weightbearing exercises, resistance exercises, activities of daily living
- Nutritional assessment
- Adaptive equipment
 - Bracing, cane, walker, wheelchair



Spinal braces are named based on regions of the spine they encompass

Thoraco-Lumbar Orthosis (TLO)



Thoraco-Lumbo-Sacral Orthosis (TLSO)



Cervical Orthosis (CO)



Lumbo-Sacral Orthosis (LSO)

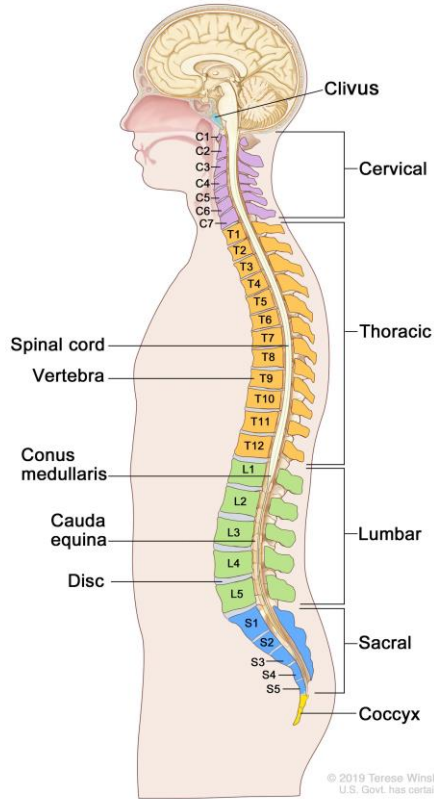


Caring for Patients with Chordoma-Physiatry Recommendations

Mobility impairments



Mobility Impairments

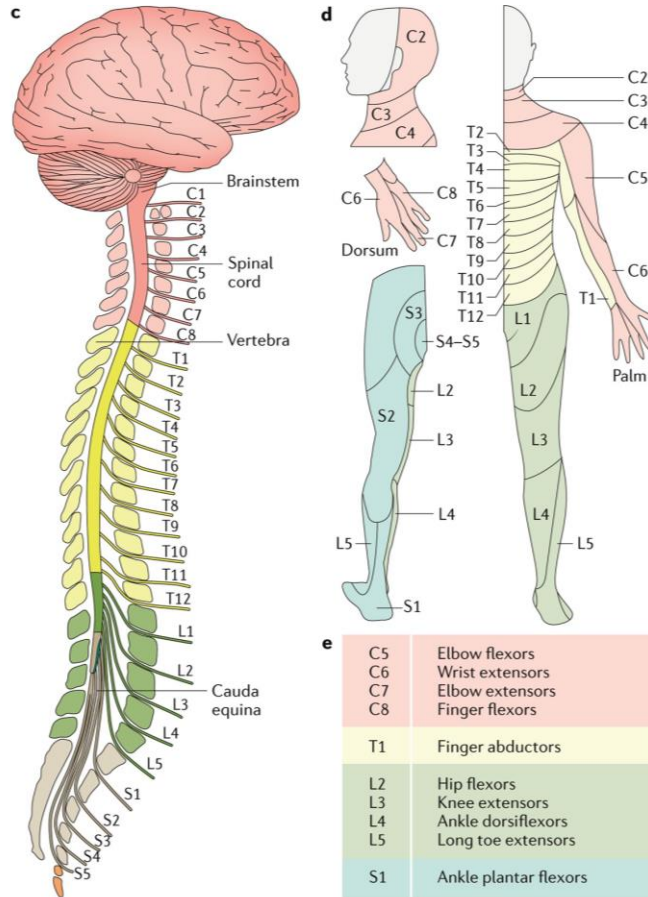


Musculoskeletal abnormalities

- Scoliosis, kyphosis, pelvic obliquity, surgical resections
- Abnormal postures, restricted movement, changes in weightbearing status
- Impacts: pain, bed mobility, transfers, walking, ability to utilize adaptive equipment, seating in wheelchair, ability to operate a wheelchair



Mobility Impairments



Nature Reviews | Disease Primers

- **Weakness**

- Impaired upper and lower extremity movement
- Impacts: bed mobility, transfers, walking, ability to utilize adaptive equipment, ability to operate a wheelchair

- **Sensory**

- Loss of awareness of environment, positioning of joints, balance
- Impacts: pain, bed mobility, transfers, walking, ability to utilize adaptive equipment, seating in wheelchair



Rehabilitation Recommendations- Mobility

- Physical Therapy
 - Strength training, endurance training, standing and balance training, sensory reintegration, transfers, gait training, wheelchair mobility (if needed), pain management, stretching, range of motion, exercise program, equipment assessment
- Occupational Therapy
 - Strength training, balance training, fine motor skills, range of motion, positioning, ADLS, pain management, exercise program, equipment assessment



Rehabilitation Interventions-Adaptive Equipment

- Bracing
- Assistive devices
- Wheelchairs
- Other durable medical equipment



Extremity braces are named based on joints they encompass



**Ankle Foot
Orthosis
(AFO)**



**Hip Knee
Ankle Foot
Orthosis
(HKAFO)**



**Knee Ankle Foot
Orthosis
(KAFO)**

<https://www.gillettechildrens.org/your-visit/patient-education/hip-knee-ankle-foot-orthosis-hkafo-reciprocating-gait-orthosis-rgo>

<https://www.bostonoandp.com/products/lower-limb-orthotics/kafos/>



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Assistive devices are recommended based on individual need and upper extremity function

- Assistive devices may include
 - Cane (single point, quad)
 - Walker (standard, rolling)
 - Crutches (axillary, forearm)



Wheelchairs

- In-depth evaluation is key
 - Wheelchair should be customized to patient
 - Proper wheelchair dimensions
 - Determine appropriate chair type (power vs manual)
 - Assess for certain modifications
 - ie: cushion type, anti-tippers, truncal support, head and neck support, drive controls





<https://www.nsm-seating.com/mobility>



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Additional durable medical equipment to meet mobility needs –lifts, standers, transfer benches



<https://www.assistedliving.org/best-hoyer-lifts/>



<https://dmesupplyusa.com/drive-medical-folding-universal-sliding-transfer-bench>.



<https://www.rehabmart.com/product/easystand-original-evolv-sit-to-stand-standing-frame-itemized-48592.html>



<https://www.walmart.com/ip/BeasyTransfer-System-BeasyGlyder>



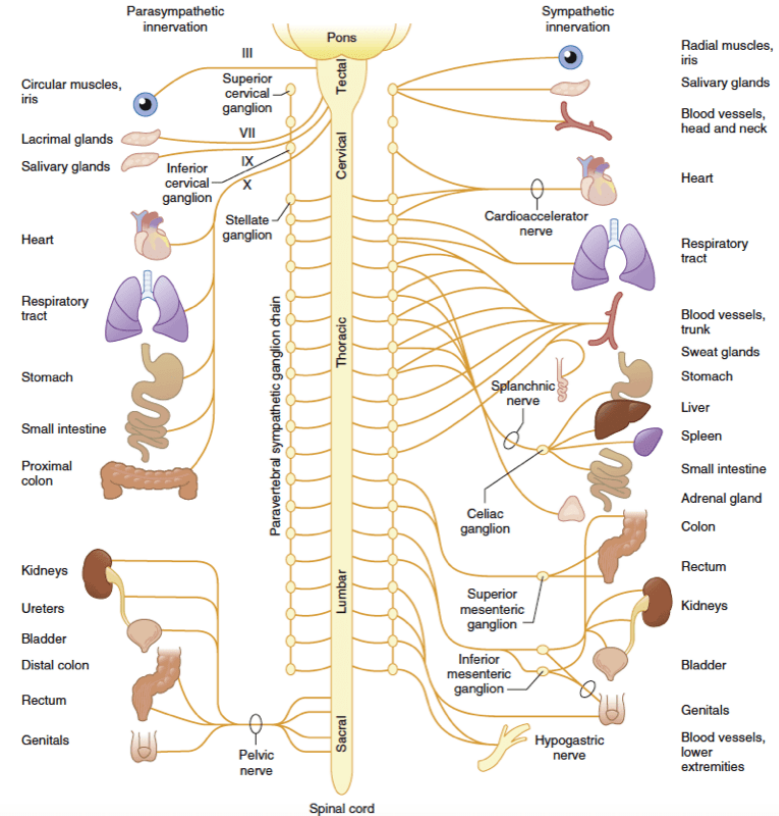
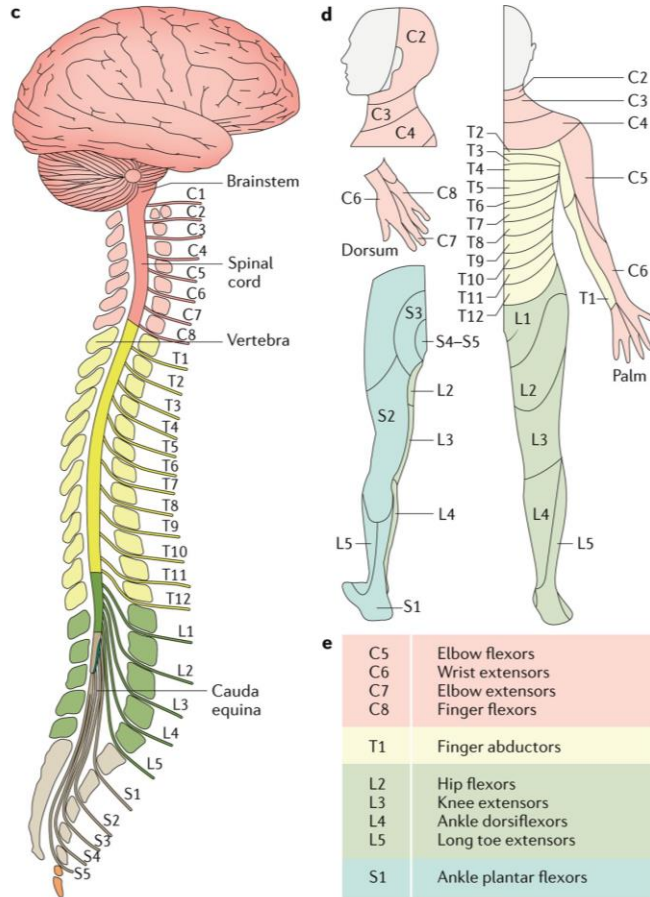


Caring for Patients with Chordoma-Physiatry Recommendations

Bowel and bladder function
Intimacy and sexuality



Bowel, bladder and sexual function



Nature Reviews | Disease Primers



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Physiatry Assessment-Bladder



Anatomic Diagnosis: (Supraconal □, Conal □, Cauda Equina □)

Lower Urinary Tract, Bowel and Sexual Function

System/Organ	Score
Lower Urinary Tract	
Awareness of the need to empty the bladder	
Ability to prevent leakage (continence)	
Bladder emptying method _____ (specify)	
Bowel	
Sensation of need for a bowel movement	
Ability to Prevent Stool Leakage (Continence)	
Voluntary sphincter contraction	
Sexual Function	
Genital arousal (erection or lubrication)	Psychogenic Reflex
Orgasm	
Ejaculation (male only)	
Sensation of Menses (female only)	

2 = Normal function, 1=Reduced or Altered Neurological Function
0=Complete loss of control NT=Unable to assess due to preexisting or concomitant problems

Urodynamic Evaluation

System/Organ	Findings	Check mark
Sensation during filling	Normal	
	Increased	
	Reduced	
	Absent	
	Non-specific	
Detrusor Activity	Normal	
	Overactive	
	Underactive	
	Ascontractile	
Sphincter	Normal urethral closure mechanism	
	Normal urethral function during voiding	
	Incompetent	
	Detrusor sphincter dysynergia	
	Non-relaxing sphincter	

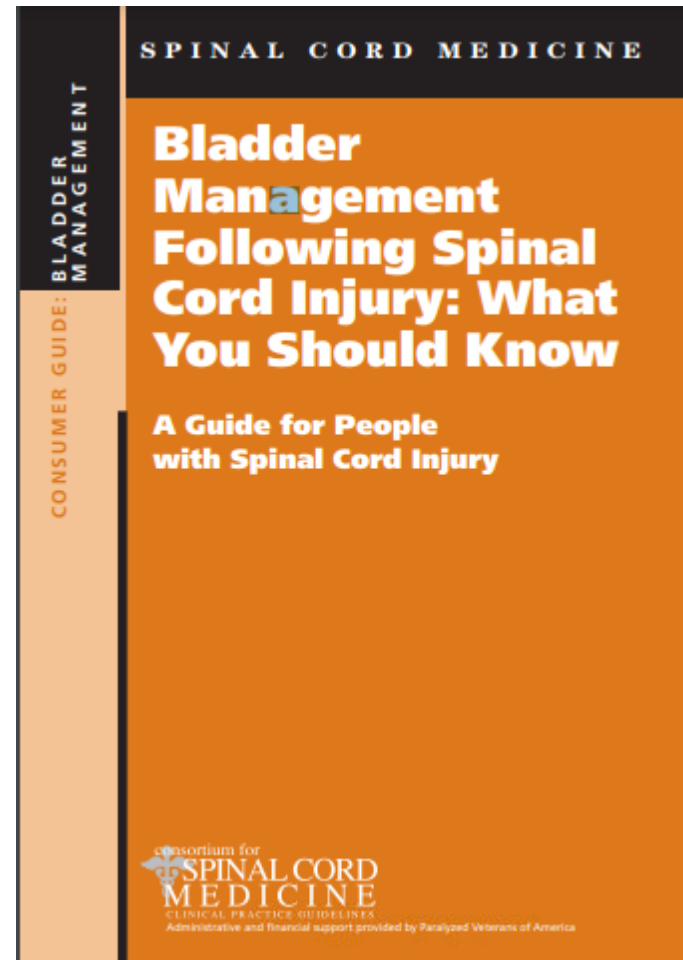
• Evaluation

- History
- Physical examination
- Voiding diary
- Assessment of post void residual volumes
- Urodynamic studies










Rehabilitation Recommendations- Bladder

- Collaboration with urology
- Dietary/lifestyle recommendations
- Medications
- Catheterization
- Pelvic floor therapy
- Breathing/positioning strategies for emptying



Physiatry Assessment-Bowel

- Evaluation
 - History
 - Physical examination
 - Stool dairy
 - Stool studies, cultures
 - Occult blood
 - Abdominal films
 - CT scan

BRISTOL STOOL FORM SCALE			
The Bristol Stool Form Scale was developed at the University of Bristol in the United Kingdom. It is a medical tool designed to classify one's bowel movements into seven distinct categories. There is a direct correlation between the form of the stool and the amount of time food wastes have spent in the gastrointestinal tract. If stools stay in the gut for too long, the body may not be able to eliminate wastes efficiently. If stools are runny and hard to contain, the body is unable to fully absorb water and nutrients from food.			
Type 1		Separate hard lumps, hard to pass, known as "rabbit droppings"	CONSTIPATION These stools are difficult to pass and require a lot of straining. Constipation could be caused by many reasons, including: <ul style="list-style-type: none">• Intestinal diet lacking in fruit and vegetable fibre and high in animal proteins, fat, processed foods.• Stress both physical and emotional often causing Irritable Bowel Syndrome (IBS).• Slowing or adhesions in the bowel.• Parasites.• Street drugs and some medications.• Inclusion of gut flora (bacterial dysbiosis).• Allergies and intolerances.• Long-term laxative abuse etc.
Type 2		Sausage-shaped, lumpy, uncomfortable to pass	HEALTHY STOOLS This type of stool is difficult to pass and requires a lot of straining. Constipation could be caused by many reasons, including: <ul style="list-style-type: none">• Intestinal diet lacking in fruit and vegetable fibre and high in animal proteins, fat, processed foods.• Stress both physical and emotional often causing Irritable Bowel Syndrome (IBS).• Slowing or adhesions in the bowel.• Parasites.• Street drugs and some medications.• Inclusion of gut flora (bacterial dysbiosis).• Allergies and intolerances.• Long-term laxative abuse etc.
Type 3		Like a sausage, with cracks on its surface	HEALTHY STOOLS This type of stool is difficult to pass and requires a lot of straining. Constipation could be caused by many reasons, including: <ul style="list-style-type: none">• Intestinal diet lacking in fruit and vegetable fibre and high in animal proteins, fat, processed foods.• Stress both physical and emotional often causing Irritable Bowel Syndrome (IBS).• Slowing or adhesions in the bowel.• Parasites.• Street drugs and some medications.• Inclusion of gut flora (bacterial dysbiosis).• Allergies and intolerances.• Long-term laxative abuse etc.
Type 4		Like a sausage or snake, smooth and soft	HEALTHY STOOLS This type of stool is difficult to pass and requires a lot of straining. Constipation could be caused by many reasons, including: <ul style="list-style-type: none">• Intestinal diet lacking in fruit and vegetable fibre and high in animal proteins, fat, processed foods.• Stress both physical and emotional often causing Irritable Bowel Syndrome (IBS).• Slowing or adhesions in the bowel.• Parasites.• Street drugs and some medications.• Inclusion of gut flora (bacterial dysbiosis).• Allergies and intolerances.• Long-term laxative abuse etc.
Type 5		Soft blobs with clear-cut edges, passes easily	PRECURSOR TO DIARRHOEA Although occasionally everyone has soft lumpy sticky foul-smelling stools, if this is a regular occurrence then one should re-evaluate their diet: reduce intake of alcohol, processed products, animal fats, as some can cause reduce food intake, which helps regulate and make sure that there is an overall balance of proteins, vegetables and grains in the diet.
Type 6		Fluffy pieces with ragged edges, a mushy stool	DIARRHOEA This type of stool is difficult to control. There is always urgency and immediacy associated with diarrhoea. Watery stools mean that the body was unable to extract water, electrolytes and nutrients from the food, causing malnutrition and dehydration. In severe diarrhoea, a medical practitioner needs to be consulted immediately. Some causes of diarrhoea include: <ul style="list-style-type: none">• Food poisoning.• Stress both physical and emotional often causing Irritable Bowel Syndrome (IBS).• Allergies and intolerances.• Parasitic infections.• Use of antibiotics.• Laxative abuse.• Anxiety, autism and other psychosomatic disorders.
Type 7		Watery stool, virtually no solid pieces, entirely liquid	DIARRHOEA This type of stool is difficult to control. There is always urgency and immediacy associated with diarrhoea. Watery stools mean that the body was unable to extract water, electrolytes and nutrients from the food, causing malnutrition and dehydration. In severe diarrhoea, a medical practitioner needs to be consulted immediately. Some causes of diarrhoea include: <ul style="list-style-type: none">• Food poisoning.• Stress both physical and emotional often causing Irritable Bowel Syndrome (IBS).• Allergies and intolerances.• Parasitic infections.• Use of antibiotics.• Laxative abuse.• Anxiety, autism and other psychosomatic disorders.



Rehabilitation Recommendations-Bowel

- Goal-allow individual to have control over the time and place of their bowel movements with the desired frequency and without incontinence.

Upper Motor Neuron Pattern

**Soft but formed stool*

Dietary modifications
Ensure adequate fluid intake
Oral medication
Digital stimulation, suppository
Pelvic floor therapy

Lower Motor Neuron Pattern

**Firm stool to maintain continence*

Dietary modifications
Ensure adequate fluid intake
Oral medication
Manual removal
Pelvic floor therapy

*Pending findings of physiatry assessment additional recommendations for work up/collaboration with GI made be made



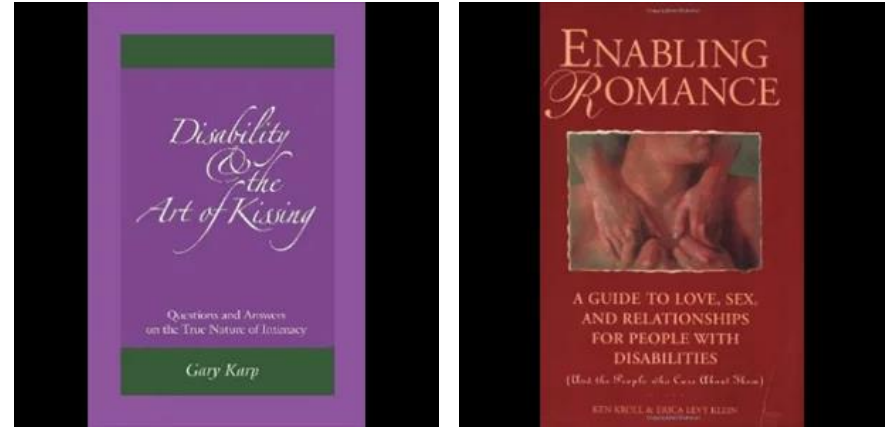
Physiatry Assessment-Intimacy and Sexuality

- Evaluation
 - Discussion of concerns
 - Physical examination
- Poor body image/self esteem
- Impairments in mobility, hand function, and sensation
- Difficulty with positioning
- Pain
- Erectile and ejaculatory dysfunction (M)
- Impairments in vaginal lubrication and vasocongestion (F)





Rehabilitation Recommendations- Intimacy and Sexuality

- Counseling/education
- Adaptive equipment
- Pelvic floor therapy
- Collaborate with urology, women's health specialists, reproductive specialists





it can be **difficult** to communicate about sexual problems

 Just over 61% of respondents said they have been able to successfully communicate with their partner(s) about these issues.


 Even fewer—only 45%—have been able to successfully discuss these problems with a healthcare provider.

there are resources that can help

 Search for a [support group](#)

 Find a [certified menopause provider](#)

 Contact a [sexuality counselor or therapist](#)

 Learn [what to expect and how to manage sex safely](#)

 Get [tips on healthy and safe sexual activity after cancer](#)

Learn more at www.nccc-online.org



Resources

-Paralyzed Veterans of America Consumer Guides: <https://pva.org/research-resources/publications/consumer-guides/>

-American Spinal Injury Association Guidelines for Use of Durable Medical Equipment for Persons with Spinal Cord Injury and Disorder. <https://asia-spinalinjury.org/product/guidelines-for-use-of-durable-medical-equipment-for-persons-with-spinal-cord-injury-and-dysfunction/>

-Spinal cord injury communities

<https://www.spinalcord.com/life-after-a-spinal-cord-injury>

<https://facingdisability.com/>

<https://axisproject.org/programs>

-Finding a physical therapist

<https://aptaapps.apta.org/APTAPTDiretory/FindAPTDiretory.aspx>

