Living with Chordoma

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Disclosures

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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.
### What can physiatry do for patients living with chordoma?

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<th>Relieve Symptoms</th>
<th>Prevent Further Complications</th>
<th>Enhance Functional Independence</th>
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<td>Spinal instability</td>
<td>Functional impairments</td>
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<td>Spasticity</td>
<td>Fractures</td>
<td>Equipment/bracing needs</td>
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<td>Sexuality &amp; Intimacy</td>
<td>Pressure injuries</td>
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<td>DVT</td>
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### 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

• **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)

Knee Ankle Foot Orthosis (KAFO)

Hip Knee Ankle Foot Orthosis (HKAFO)


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

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

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


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
Physiatry Assessment - Bladder

- 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
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.

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<th>Upper Motor Neuron Pattern</th>
<th>Lower Motor Neuron Pattern</th>
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<tr>
<td>*Soft but formed stool</td>
<td>*Firm stool to maintain continence</td>
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<tr>
<td>Dietary modifications</td>
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<tr>
<td>Ensure adequate fluid intake</td>
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</tr>
<tr>
<td>Oral medication</td>
<td>Oral medication</td>
</tr>
<tr>
<td>Digital stimulation, suppository</td>
<td>Manual removal</td>
</tr>
<tr>
<td>Pelvic floor therapy</td>
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*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 vaso-congestion (F)
Rehabilitation Recommendations - Intimacy and Sexuality

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

https://facingdisability.com/resources/sex-and-fertility
https://www.nccc-online.org/hpvcervical-cancer/sexuality-cancer/
Resources

- Paralyzed Veterans of America Consumer Guides: https://pva.org/research-resources/publications/consumer-guides/
- Spinal cord injury communities
  https://facingdisability.com/
  https://axisproject.org/programs
- Finding a physical therapist