Rehabilitation Strategies to Address Physical Disabilities in MAS/FD

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What is a physiatrist?

American Academy of Physical Medicine and Rehabilitation: www.aapmr.org
CAVEAT!

Everyone is an individual with unique needs. **Always consult your local medical and rehabilitation professionals (CYLP) before developing and implementing any program!**
Function and Fibrosis
Stuff you probably already know
Challenges to the skeleton in MAS/PFD

- Bone and joint malalignment
- Bony deformities (e.g. “shepherd’s crook”)
- Spine curves
- Leg length discrepancy
- Fractures
Which results in...

- Pain
- Weakness
- Loss of joint mobility ("range of motion")
- Deconditioning
Which affects function:

- Walking/mobility
- Self care skills, e.g. dressing, bathing, toileting, eating
- Other activities of daily living (ADL’s), including those relating to homemaking, work or school, human sexuality
How can Physical Medicine and Rehabilitation Help?
Basic Rehabilitation Principles

- Prevent or minimize *impairments*
- Compensate for *disabilities*
- Set reasonable, realistic, safe and relevant long and short term goals
- Use physical modalities to achieve these goals

- In PFD, this means keeping you:
  - Straight
  - Supple
  - Strong
  - Safe
STRATEGIES TO ADDRESS IMPAIRMENTS
Water is:
- Buoyant
- Shock absorbing
- Pain relieving
- A force which resists bodily movement

- Not just swimming; upright activities in the water can also help*
- A warm (body temperature) pool is preferred
- Aquatic activities can safely help with mobility, strength, endurance and pain
- When a full sized pool is not available, a hot tub can often help (and a standard tub can work for some smaller children)

*a vest or flotation suit can help hold a person upright in the pool
Leg length discrepancy

- It doesn’t matter if one leg measures longer
- What matters is whether there are asymmetries in standing and walking
- Other factors such as joints with loose ligaments also need to be considered

Shoe modifications
- Always remember to CYLP! It would be beneficial to have a physiatrist prescribe and supervise the fabrication of these modifications
- The goal is usually to level the pelvis
- Up to 3/8” of shoe lift can fit inside a well structured shoe
- If feet are flat, shoe orthotics may help realign the feet, ankles and even knees
- If more than 3/8” of lift is required, it will need to be added to the outsole of the shoe. The increased thickness may also require a “rocker bottom” for the shoe
- Go to https://www.abcop.org/Pages/Individual-Search.aspx to locate a certified pedorthist. They are the healthcare professionals who are trained to make foot orthotics and shoe modifications
Bone and joint malalignment

- May be due to
  - fibrous dysplasia
  - joint laxity
- You can help control laxity (CYLP!) with
  - Muscle strengthening
  - Various orthoses (braces)
- These techniques *may* be able indirectly to stem or slow malalignment due to the dysplasias
Bony Deformities

- Thought to be due to
  - Fibrous dysplasia directly changing bone geometry
  - Changes in ability of the bone to take stress of weight bearing due to the FD’s

- Techniques which reduce stress on bone may be able to help (CYLP!)
  - “Assistive devices” (canes, walkers)
  - Braces
  - Correcting leg length discrepancy
  - Strengthening exercises
Joint mobility

- First identify the reason for loss of mobility
  - Is it due to the bony structures?
  - Is it due to tightness in soft tissues (ligaments, tendons)?

- Bony restrictions are not amenable to direct rehab interventions
- Soft tissue restrictions can be reduced with gentle range of motion exercises
Fractures

- Remember always CYLP!
- Prevention:
  - Make sure the body is balanced
  - Help support the bones with strong muscles
- Reduce fracture impact
  - Get up and going as soon as you can
  - Don’t let other areas become tight and contracted
  - Don’t let other areas get weak
Muscle Weakness

- Can be due to any of the impairments previously discussed
- You need to first identify the cause and complicating factors
- Strength exercises should be done gradually and carefully in a milieu of fibrous dysplasia
- Water may be the safest way to strengthen weakened muscles

- Strengthening requires sustained muscle contraction against some kind of force
- CYLP: You must know your body’s limits and work with your professionals to develop the program that works for you.
Deconditioning

- Decreased endurance
- Due to a vicious cycle of inactivity
- As a result of any of the previously mentioned impairments
- Treat with gradually increasing intensity and amount of aerobic activities
- Aerobic exercise is exercise that gets your heart rate up for an extended period of time
- Endurance exercise is also the way to promote heart and lung health

- Water may be the best way to go
  - Swimming
  - Water Aerobics
- Other potential activities
  - Walking
  - Wheeling
  - Cycling
  - Scooting
  - Rolling
- It's possible that wind instruments may help with lung function
- CYLP!
Pain

- If possible, identify the cause and focus treatment towards that area
- Temperature modalities
  - Cold: reduce swelling and numb area
  - Heat: “countercurrent” and relaxes muscles and soft tissues
- Transcutaneous Electrical Nerve Stimulation (TENS)
- Massage techniques
- Relaxation techniques
- Acupuncture
- Local injections
Strategies to address disabilities
Walking

- Orthoses (braces) may improve endurance for walking
- Assistive devices (canes, walkers) are designed to “unload” limbs which cannot tolerate the full weight of contact with the ground.
- “Strength and joint range of motion impact on walking efficiency in persons with PFD. These findings suggest that treatment focused on strategies to improve or, at least, maintain hip strength and range of motion, correct leg length discrepancies and hip malalignment may help preserve ambulation ability in persons with PFD and that treatment should begin at a young age.”

Assistive devices
Energy conservation & Work simplification

- Easy does it!
- Sit rather than stand
- Keep frequently used items within easy reach
- Plan the steps of an activity before starting

- Make physics your friend
  - Slide instead of lift when you can
  - Good body mechanics
- Put the work at the right height
- Use adaptive equipment
Wheeled mobility: Manual vs. power

- **Manual**
  - Lighter
  - Easier to transport
  - Source of aerobic exercise

- **Power assist wheels (PAW)**
  - Motorized wheels that fit on manual chair
  - Assist the person’s push

- **Power**
  - Doesn’t rely on person’s strength
  - Can include accessories that
    - Recline the back
    - Lower the person to the ground
    - Raise them up
    - Stand them up
    - Interface with environmental control systems
Activities of Daily Living...

THERE’S AN APP FOR THAT!
Bath safety
Toileting
Dressing
Grooming
Eating and Food Preparation
Home Accessibility

- Adaptive equipment
  - Door openers
  - Reachers
  - Rolling carts and trolleys
  - Stair lifts

- Architectural modifications
  - Ramps
  - Widened doorways
  - Lowered cabinets
  - Lowered counter heights
Work adaptations

- Telephone headsets
- Adaptive writing implements, scissors, letter openers
- Ergonomic workstations and chairs
- Voice recognition software
- Your rights under the Americans with Disabilities Act (ADA): reasonable accommodations
Adaptations for fun and fitness

- Adaptive equipment for needlecrafts
- Adaptive equipment for card games
- Adaptive gardening tools and supports
- Adaptive sports equipment, instruction and leagues (Disabled Sports, USA: www.disabledsportsusa.org is a good general reference source)