

Neuromuscular and Rehabilitation Care -tweens and teens

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Parent **JOIN THE FIGHT.**
Project **END DUCHENNE.**
Muscular
Dystrophy

Disclosures

- Susan Apkon is an investigator in clinical trials sponsored by Sarepta, PTC Therapeutics, Roche, and Biogen.

Tweens and Teens

- Responsiveness to change
 - **World is bigger**
 - **Social issues more prominent**
 - **Separation is normal**
 - Disease progresses

Neuromuscular Care

- Comprehensive care assessments 2x/year
- Continue steroids (consider starting*)
 - Monitor for steroid-related complications (cataracts, weight, growth, puberty, bone health)
 - Adjust dose for side effects
- Review novel treatments and clinical trials

Goals of Rehabilitation Management

- Maintain and maximize function
- Minimize contractures (tight joints) and spinal curve (scoliosis)
- Monitor function through standard assessment tools
 - **Helps team to provide flexible recommendations**

Rehabilitation Tools

- Therapy
- Orthoses (braces)
- Equipment



Therapy in the tweens and teens

- **PT** to guide exercise program, develop home stretching program, monitor equipment and bracing needs
- **OT** to focus on writing, adaptive skills, equipment needs and bracing needs
- **Speech** to focus on language and learning

Training on new skills as function changes

Orthoses

- **Night-time** resting splints (AFO's)
- **Daytime** braces (AFO's) when using wheelchair full-time
- **Hand splints** (WHO's) when signs of wrist and finger tightness

Equipment

- Scooters and lightweight wheelchair for long distances
- Power wheelchair with supportive seating system
- Standing frames
- Bath/toilet equipment
- Lift equipment

Orthopedic management - Spine

- Spine
 - Assess clinically every 6 months
 - X-rays if curve observed or can't see spine on exam
 - Referral to an orthopedic surgeon if curve present
 - Spine fusion for progressive curve

Orthopedic management - Fracture

- Ambulatory tween/teen
 - If goal to walk immediately surgery may be recommended
- Wheelchair dependent teen
 - Stabilize fracture with soft splint

Remember Fat Emboli syndrome