

Family/Community Breakout Session: Movement, Mobility, and Everyday Care

Speakers



Doug Levine, PT

CureDuchenne Certified
Physical Therapist

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CureDuchenne Certified
Physical Therapist

PHYSICAL THERAPY CARE PLAN

Frequency for PT visits

Specific home program

Parent education on progression and “dos and don’ts”

PT treatments to delay progression

Equipment recommendations and evaluations

Modifications for daily activities

Accommodations for school



FREE: CureDuchenne Caregiver Course

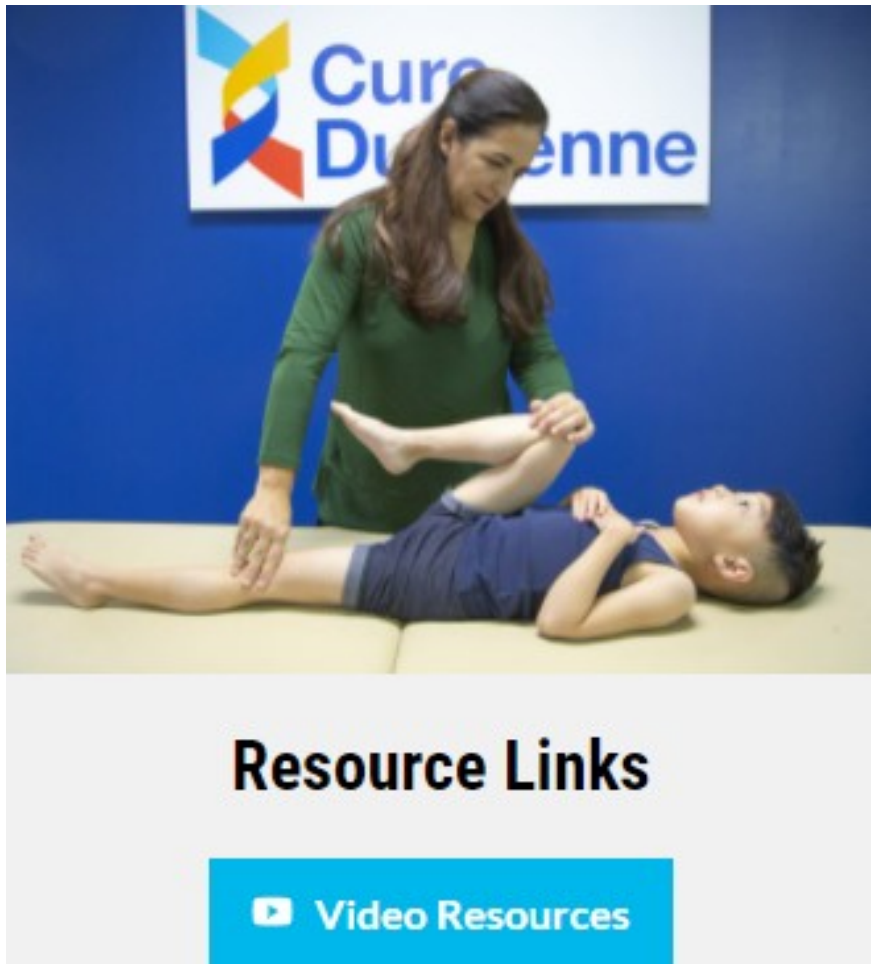


First-of-its-kind online caregiver training

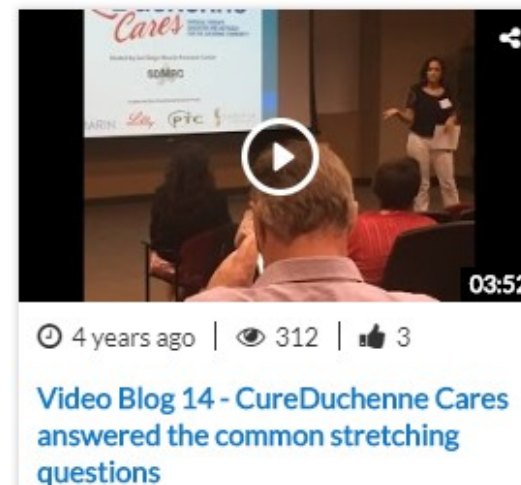
TOPICS INCLUDED:

Understanding Duchenne, Energy Conservation, Standards of Care, The Role of Physical Therapy, Stretching and Appropriate Exercise, and Mobility Equipment.





<https://www.cureduchenne.org/physical-therapy/for-families/>



ONLINE VIDEO STRETCHING RESOURCES

YouTube Channel: CureDuchenneMD



CureDuchenne YouTube Video-
Passive Stretching for Duchenne
(Available in Spanish also)



CureDuchenne YouTube Video-
Self-Stretching for Duchenne

ANKLE FOOT ORTHOSES

Examples:



Cascade DAFO
3.5 Softy



Cascade DAFO
9 Softy

HAND WRIST ORTHOSES

- To prevent or treat tightness
- Assist with maintaining hand strength



EXERCISE GUIDELINES

Potential Benefits Being Studied

When expertly designed and closely monitored, exercise may help support:

- Muscle health, strength and function
- Cardiovascular health
- Range of motion and flexibility
- Bone health
- Emotional and social well-being

Under professional guidance, What Types of Activities Might Be Considered?

Low-load, Aerobic, Frequent rest

Some examples include:

- Assisted range-of-motion exercises
- Shoulder pulley systems
- Aquatic therapy or activity
- Arm and/or leg cycling
- Isometric (static position) exercises
- Power wheelchair sports such as soccer and hockey



EXERCISE BLOG AND WEBINAR



<https://cureduchenne.org/blog/exercise-duchenne-muscular-dystrophy/>

SWIMMING

Low load, concentric exercise

Exciting socialization

Relieve stress on joints

Respiratory benefit

Sensory input



BIKE PEDALING



ASSISTED RANGE OF MOTION



EXERCISE

CRITICAL SAFETY CONSIDERATIONS

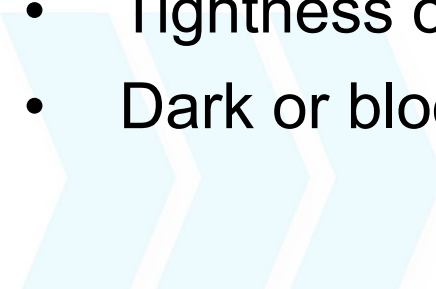
Even as research evolves, **long-standing precautions still apply:**

Avoid eccentric contractions (jumping, squatting, lunging, sit-ups and more)

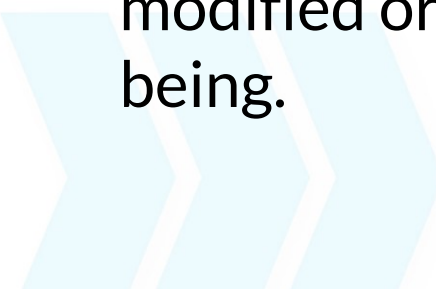
Ensure cardiac clearance before aerobic activity and define acceptable heart rate parameters

More is not always better

Stop immediately and contact your physician if you notice any of these, during or in the days after exercise:

- Muscle pain or spasms
 - Tightness or swelling
 - Dark or blood-colored urine
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GENERAL RULES FOR ACTIVITY

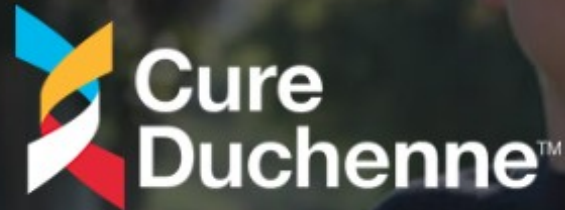
1. Try to avoid activities like stairs, hills, running, and jumping when possible.
 2. Avoid activities that make muscles work over and over until they feel very tired.
 3. Think about all the activity your child does throughout the day at home, school, therapy, and play when deciding if changes or supports are needed.
 4. Standard PE programs that focus on building strength or pushing performance are usually not the best fit for children with Duchenne at any age.
 5. PT and OT should focus on helping maintain strength and flexibility, protecting movement, and making daily activities easier and more efficient.
 6. It is important to help children stay involved with siblings and friends through modified or alternative activities to support social connection and emotional well-being.
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CURE DUCHENNE DME GUIDE

<https://www.cureduchenne.org/durable-medical-equipment-guide/>

DURABLE MEDICAL EQUIPMENT (DME) GUIDE

FOR INDIVIDUALS LIVING WITH DUCHENNE MUSCULAR DYSTROPHY



MOBILITY DEVICES

ORTHOSES

HOME EQUIPMENT

RESPIRATORY DEVICES

HANDOUTS, LITERATURE, ORGANIZATIONS

VIDEO COLLECTION

STANDING ACTIVITIES

Benefits of passive standing:

Passive long duration stretch

Isometrics exercises in extension

Bone health from weight bearing

Pelvic and spinal alignment



Easy Stand

ENTRY-LEVEL POWER MOBILITY DEVICES

Benefits:

Independent mobility

Lightweight and easy to transport

Conserve energy for other activities

Can be used at a young age

Safe and Inclusion: Field trips, community events with peers

Drawbacks:

Minimal trunk and back support

Limited adjustability of seating and size

Short term solutions

Not many power seating functions



MANUAL WHEELCHAIR

Benefits:

- Lightweight
- Folding option
- Tilt in space
- Accommodates seating systems
- Can be easily transported
- Optional power assist wheels

Drawbacks:

- Not independent mobility option without power assist added
- Extra devices add weight
- Limited seated position changes available



POWER WHEELCHAIRS

Indications:

Walking is too fatiguing

Walking is too unsafe

Missing out on socialization

Benefits:

Supportive seated position

Independent mobility

Seated and standing positions

More flexible seating options and support

Drawbacks:

Need to plan for access at home, school and transportation



POWER WHEELCHAIR OPTIONS

Options to be considered:

Upgraded or Custom seating
Power Seat elevator
Power Elevating leg rests
Power tilt and recline
Power tilt and recline
Power Standing



Permobil F5 VS



Motion Concepts
AVIVA FX MPS



CUSTOM WHEELCHAIR SEATING SYSTEMS

Indications:

Off the shelf seating is not sufficient for support or pressure relief

Mild curvature has been detected

Benefits:

Custom to the individual

Necessary support in required areas

Can be used on most manual and powerchairs

Drawbacks:

Need a trained vendor in your area

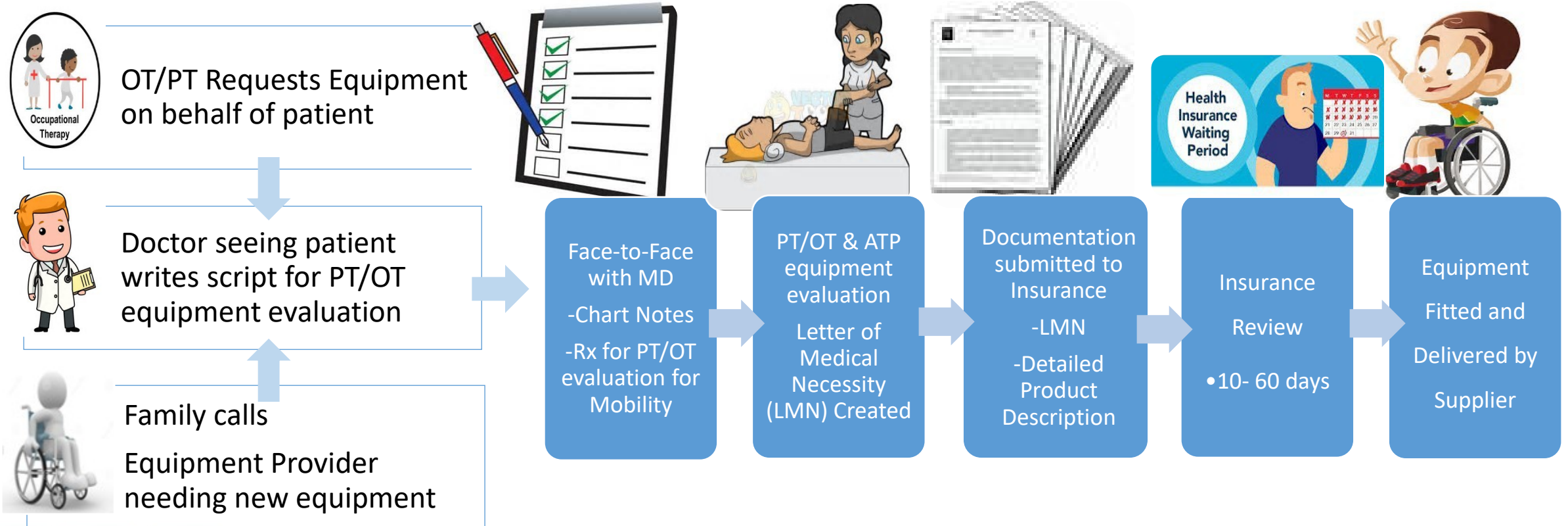
“Break-in” period can take longer

Change in user size can be difficult to accommodate



RIDE – Custom seat and back

PROCESS FOR COMPLEX REHAB TECHNOLOGY PROVISION





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