RANGE OF MOTION MANAGEMENT IN DUCHENNE MUSCULAR DYSTROPHY – TREATMENT OPTIONS

Parent Project Muscular Dystrophy
JOIN THE FIGHT. END DUCHENNE.

General Guidelines – Getting Started at Home

Included in this document are general guidelines for methods for management of range of motion in children and adults with Duchenne muscular dystrophy. These are guidelines based on currently available research and information known about muscle and the natural history of Duchenne.

**As always, please consult an experienced physical therapist in Duchenne for individualized recommendations.

Not everything in this document will apply to every person with Duchenne. Individualized plans are best carried out by an experienced physical therapist who is familiar with your loved one.

Find a routine that fits for your family and child.
Be reasonable in what will work into your daily schedule.
Prioritize based on your child's needs and your physical therapist's recommendations.

SUMMARY OF GUIDELINES AND DEFINITIONS OF TREATMENT OPTIONS

ANKLE NIGHT SPLINTS

A brace is used to provide a long (maintained) stretch by holding the foot in a better position over the course of several hours. Most often recommended for wearing overnight, if tolerated. They are often made of plastic and are made specifically to fit an individual's foot & ankle by an experienced orthotist. They are not recommended for wear during walking activities.

RESTING HAND SPLINTS

A splint is intended to support the hand, wrist, and fingers in a neutral or flat position when at rest. Resting hand splints are typically molded from a plastic material with Velcro straps and padding specifically to fit an individual's hand & wrist. They should be custom-fitted by an experienced occupational therapist, physical therapist, or orthotist.

POSITIONING

Positioning consists of using bolsters, rolls, or pillows to position or support a body part in a good alignment. When individuals are spending increasing amounts of time in a seated position or lying down, muscles and joints become stiff more quickly. It is important to be sure they are in a good position to help maintain their range of motion and comfort.

STRETCHING

Stretching involves moving an individual's body part (ex: arm or leg) to their comfortable, available end range of motion. Stretches should be performed with a slow, gentle movement and holding the position for a specific length of time. To view our series of stretching videos, please visit **parentprojectmd.org/stretching.**

STANDER

Standers are custom-fitted equipment designed to help an individual stand up for a prolonged amount of time.

SERIAL CASTING

Serial casting describes the process used to place a series of rigid casts over an individual's joint (most often used for heel cords at the ankle). The casts are used to slowly (with frequent cast changes over several weeks) increase range of motion at a specific joint. The joint is stretched "slightly" further with each new cast placement.

GUIDELINE SPECIFICS

ANKLE NIGHT SPLINTS

- Starting at a young age may improve tolerance & wear time.
- Most useful before your child gets tight or stiff muscles.
- If NOT tolerated at night, splints may be used for daytime positioning, when seated or lying.
- Custom-made braces from an experienced orthotist are recommended. Off-the-shelf night splints may not fit as well, may be less tolerated, uncomfortable, and are not made specific to your child.

Good to Know
Your PT or orthotist will know the right recommendations for your child.

Caution
Night splints may not work for everyone. The position of the foot and ankle will determine if your child is a candidate for night splints – always check with an experienced PT in Duchenne that is familiar with your child.

Examples of commonly used orthoses:

Not all night splints will look like these, however the design should be similar with the idea to hold the ankle for a maintained period of time.

Photo images courtesy of Cascade DAFO

RESTING HAND SPLINTS

(not intended to be used during functional activities)

- Considered for older children or adolescents when signs of finger and wrist tightness is noted.
- More likely to be tolerated if resting splints are worn on one arm at a time.

Good to Know
- Consult your experienced OT/PT, and orthotist for individual recommendations. A custom fitting is suggested.
- Resting hand splints are not for everyone.

Caution
Not recommended for adolescents and adults where the hand and fingers are fixed in fisted position.

Fingers and wrists tend to get tight over time as seen in this photo:

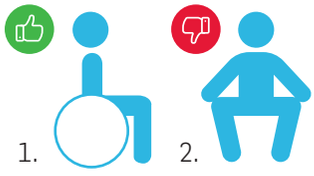
A typical wrist and finger splint used when wrist and fingers are tight:

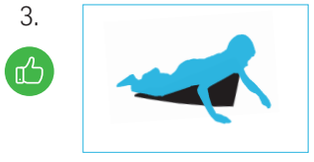
POSITIONING

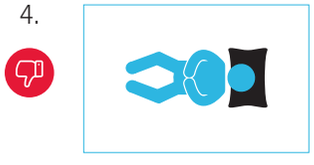
- Proper positioning may assist in maintaining range of motion.
- **Ideal seated positions:**
  1. Both feet flat on the floor or footrest (or box step for younger boys), with hips & knees at a 90° position and back & pelvis aligned with knees in line with hips.
  2. Avoid long periods of time with legs in frog position (splayed out). Knees should be in line with feet & hips.

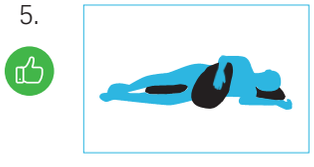
Good to Know
- Changing positions regularly is recommended.
- Positioning may help decrease complaints of pain and discomfort for those who have muscle and joint stiffness in the arms, legs, and back.
- Your PT will know what is best for your child in your own environment.

Caution
- Prolonged periods of time in any position may increase the risk of skin breakdown, discomfort or pain, and further tightness. (Example: lying on back with the knees propped with pillows)
- Limit the amount of time the knees are positioned apart. Your PT will have suggestions for your child.









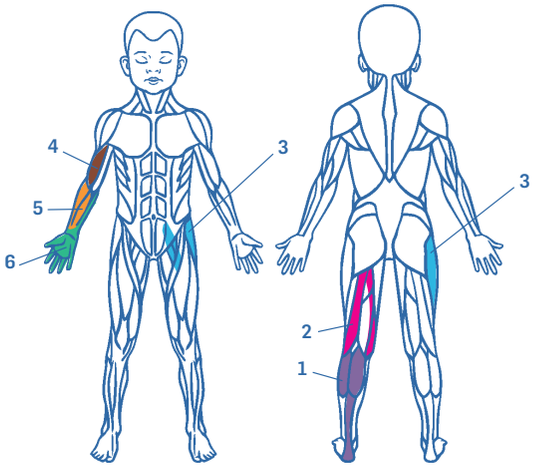
Limit amount of time with legs open wide as seen in examples 2 and 4 above.

- **Ideal positioning when lying down:**
  3. Lying on your stomach can provide a long stretch to hip muscles if comfortable & tolerated – placing a pillow or wedge under the chest may be helpful.
  4. When lying on back: position legs as straight as possible but comfortable (do not force the legs straight), support tight hip and knee muscles with pillows or blanket or towel rolls for comfort. A pillow under the knees may relieve pressure on the back. Be sure to alternate positions.
  5. When lying on side, support the body with pillows or towel rolls. Support between the thighs can reduce strain on the back & hips. Supporting an arm may provide additional comfort.

STRETCHING

– Potential benefits of doing stretching may include:

– Temporary improvement in blood flow to the muscle
– Decrease report of discomfort
– A feeling of wellbeing
– Temporary increase in tolerance to stretch
– Temporary decrease in muscle stiffness
– Continued movement through the joint's full available range of motion



– Muscles most commonly developing tightness:

Legs

1. Calf muscles (often referred to as heel cords):
   – tightness limits ability to move ankles up or stand with the feet flat
2. Hamstrings (located behind the hip and knee):
   – tightness limits ability to straighten knee
3. Hip muscles (often referred to as hip flexors and/or hip abductors):
   – tightness limits ability to lie flat on stomach or move leg towards the middle of body bringing the legs together

Arms

4. Elbow flexors:
   – tightness limits ability to straighten elbow
5. Forearm pronators:
   – tightness limits ability to turn hand/palm up
6. Long finger flexors:
   – tightness limits ability to straighten fingers

– General guidelines for stretching:

– Hold the position of the arm or leg when you feel tightness or resistance of the joint or muscle.
– General recommendations are a 30 second hold. Let your PT guide you on repetitions and frequency.

Good to Know

— There may be benefits to stretching.
— Prioritize your routine based on your PT's recommendations and your child's condition.
— Stretching may not prevent muscle tightness from developing. Individuals will continue to develop tightness over time. The progression of tightness varies from one person to the next with Duchenne.
— Stretching may not fit into your daily routine. THAT'S OK! Talk to your PT to help you prioritize.

Caution

— Bones, muscles, and tendons can be fragile so stretching should be slow, gentle, ensuring proper alignment. NEVER go beyond point of resistance, tightness, or tolerance. AVOID fast or forceful movements.
— Pushing too far during stretching may not provide added benefit.

WATCH: Stretches for Duchenne

PPMD's comprehensive Video Library walks you through different types of stretches for Duchenne. To view our series of stretching videos, please visit **parentprojectmd.org/stretching.**

STANDING DEVICES

– Walking activities are more beneficial than supported standing, if safe.
– Standers could be considered in children who are unable to stand by themselves, have difficulty standing, or have lost the ability to walk.

– Options for standing devices:

1. Sit-to-stand standers – allow a person to go from sitting to a standing position.
2. Supine standers – provide support along the back of the body. The child lies down and then is brought to standing.
   **These standers can be more difficult for the caregiver.*
3. Wheelchairs that transition to standing.

Good to Know

— Active standing may be beneficial for bones and muscles.
— Standing can make people feel good.
— There may be a delay in equipment arrival after ordering, so begin the process prior to loss of range of motion and ability to stand and walk.

Caution

— The effects of standing on bone mineral density is not well understood in this population.
— Standing when there is a loss of range of motion (ROM) – i.e. unable to straighten the knees or hips, unable to get a good foot position, or to keep the back flat (i.e. arched away from surface) – may be painful. DO NOT push through pain.
— Standing with muscles and joints in a poor alignment is not considered beneficial.

SERIAL CASTING

- **Serial casting may improve ankle range of motion (ROM) in select individuals with Duchenne who:**
  1. Have mild ankle tightness at the heel cord
  2. Have the ability to straighten their leg when sitting
- Serial casting must be applied & managed by a PT experienced in serial casting in Duchenne.
- Frequency of cast change may vary by site but should generally include cast changes 1-2 times per week.
- Demonstration of improved ankle range of motion between cast changes should be present to continue serial casting – consult your expert.
- Total time of casting should be about 4 weeks.

Good to Know

- Serial casting should only be done by an experienced PT.
- ROM gained with this option is usually temporary but may assist a child who is still walking.
- Night braces are commonly prescribed after serial casting.
- This option is considered when certain criteria mentioned above is met.
- Consult a therapist or orthotist familiar with serial casting.

Caution

- Assess for signs of skin irritation (redness that doesn't go away within 20 minutes) or blisters noted with cast changes.
- NOT recommended for individuals with severe muscle tightness.
- NOT recommended for individuals who can't walk in the cast.
- NOT recommended for individuals who can't get up from the floor without a chair or help from someone.
- NOT recommended for an individual that cannot straighten their knee while sitting in a chair or on the edge of a table.
- Limit total duration of casting to about 4 weeks since long periods of immobilization may impact strength.

Prior to casting

Preparing to cast

This boy is wearing his shoes over the casts and demonstrates he can stand and walk with the casts on. Not all casts will fit in regular shoes. In that case a walking surface can be added to the bottom of the cast.