Exercise in Dystrophinopathy: Frequently Asked Questions (FAQs)

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1. **Could using strollers while a child is still able to walk independently help preserve muscle function longer and/or reduce muscle damage?**

    a. Some families may choose to limit muscle use in the hope of preserving strength, but it is important to remember that a lack of movement can negatively affect both muscle and bone health. As we discussed, the goal is to find the right balance of activity, not too little and not too much. Allowing a young child to use their muscles during normal daily activities can help stimulate bone growth, preserve active range of motion, and support muscle strength during important growth periods. At the same time, there are important precautions to keep in mind: make sure your child is not overexerting themselves, build in rest periods, encourage hydration and healthy snacks to support muscle health, and ensure their heart is healthy enough for exercise. Complete rest can also lead to disuse atrophy, where muscles weaken and shrink from lack of activation. We strongly recommend working with your clinician to determine the right “dose” of activity for your child. They can help monitor both localized muscle fatigue and overall energy levels to find the safest and most beneficial balance.

2. **How can we best support a 20-year-old individual with Duchenne and advanced scoliosis? Are there any exercises, positioning strategies, or supportive interventions you would recommend when surgery is not an option?**

    a. In this situation, stretching is still a great way to work on the muscles of the trunk that are involved. Make sure to include the arms and legs. Trying different positions like side lying, positioning with pillows, soft bolsters, and wedges to stretch the concave side of the curve. Massage is also a great way to relieve discomfort, increase circulation to the area, and overall make a person feel better. If possible, getting in a pool with supportive flotation devices would allow for movement with gravity eliminated and more freedom of movement overall to address arms, legs, and the trunk. For scoliosis, supporting your trunk during static, upright positions is important, but you also need stabilization exercises to actively engage your core. A great way to picture this is the 'Soda Pop Can' concept (developed by Dr. Mary Massery). An unopened soda can is strong because of the pressure inside, not because the aluminum shell is thick. Once opened, it crushes easily. Your core muscles and your breathing create a similar 'internal pressure' that acts as an invisible brace for your spine. Training these muscles ensures your trunk stays strong, stable, and functional against gravity, so you aren't just relying on passive external support.

3. Can you discuss how to implement low tech monitoring exercise in a school environment when exercise may be delegated to paraprofessionals?

a. Yes, using a stopwatch to monitor time, heart rate bands/watches to monitor heart rate, using the Talk Test to monitor if your child is exercising in the moderate intensity range (moderate exercise range the person should be able to talk but not sing). Perhaps, providing an activity calendar to the paraprofessional to track your child's exercise frequency and type of exercise for that session.

4. What guidance would you give for children who are genetically diagnosed but still asymptomatic, highly active, and participating in competitive sports?

a. In this situation, moderation is key. In general, we recommend avoiding exercise to the point of exhaustion, maintaining good hydration, and supporting muscle and heart health with proper nutrition. It is also important to watch for "red flags," such as sprains, strains, significant muscle soreness or cramping, bruising, or dark-colored urine after practices or games. Contact sports, in particular, can place a great deal of stress on muscles, so those activities should be monitored carefully. Even if a child is currently asymptomatic, it is difficult to know how much dystrophin their muscles are producing and how effectively their muscles are recovering after activity.

   For children who may not recognize when they are overexerting themselves, families can help build in regular rest breaks, hydration, and snack breaks throughout activity. We also strongly recommend working with a Physical Therapist (PT). A PT can teach your child how to understand their "Rate of Perceived Exertion" (RPE), meaning what light, moderate, and hard levels of effort feel like for their body. This can also be paired with heart rate monitoring to create more personalized activity zones rather than relying only on standard age-based recommendations.

   Once your child becomes familiar with their own exertion levels, this can make monitoring much easier at school and during sports activities. Some families also find wearable devices, such as an Apple Watch, Garmin, or Fitbit, helpful for tracking activity levels, steps, and overall exertion. Using these tools alongside guidance from your care team can help personalize activity recommendations and identify the right balance of exercise and recovery for your child.

5. How do you measure the impact of exercise on Duchenne?

a. In research settings, we use objective physiological measures to understand how exercise affects boys with Duchenne. These include cardiopulmonary exercise testing to assess peak oxygen utilization and heart rate response during submaximal cycling, along with muscle strength testing, pulmonary function testing, and MRI imaging to measure changes in muscle size and fat infiltration. While many of these tools are not practical for everyday use, some concepts translate well into home and real-world monitoring.

Heart rate, for example, can be tracked with a wearable monitor after a consistent amount of submaximal activity, and improvements in fitness are often reflected by a lower heart rate at the same level of effort, indicating greater efficiency. Similarly, perceived exertion can be used as a simple but powerful tool—using scales such as the Borg scale or a 0–10 rating system—where improvements over time are seen as lower perceived effort for the same activity level. In addition, careful observation of how a child moves during daily activities can provide important insight into fatigue and muscle performance.

There are two complementary ways to help families monitor safe exercise limits. First is teaching the internal sense of effort, helping children learn what low to moderate intensity feels like in their own body (for example, roughly 2–6 on a 0–10 RPE scale or 10–16 on the Borg scale). Pairing this with heart rate monitoring during learning can help establish individualized safe heart rate zones.

Second is observing movement quality as an external cue. When muscles begin to fatigue, you may notice compensations such as changes in form, altered gait, or shifting weight in unusual ways. These are important signs that the working muscles are tiring and that it is time to rest or reduce intensity. Together, these internal and external approaches help create a practical, individualized way to monitor exercise tolerance outside of a research setting.

6. Can you discuss exercise for children who are post gene therapy?

a. Based on current consensus regarding exercise in individuals with dystrophinopathies, activity following gene therapy should follow the same general principles. It is recommended to start “low and slow,” with a gradual, carefully paced progression of activity over time rather than rapid increases in intensity or volume. Consistency is important, with a focus on steady, sustainable participation rather than bursts of high effort.

   Rehabilitation should emphasize gradual development of endurance and strength, while also incorporating balance, coordination, oculomotor skills, attention, and cognitive-motor integration to support motor planning and sequencing. After the initial post-therapy rehabilitation phase, ongoing monitoring is essential. Exercise and activity plans should be regularly reviewed and adjusted to align with the child's daily routines, ensuring they are both practical and sustainable, and to optimize long-term follow-through and benefit.

Gene Therapy PT Considerations: Initial

- Pause new strengthening loads immediately around the infusion.
- Continue standard ROM, positioning, and cardiorespiratory monitoring.
- Limit intense exercise for ~12 weeks to avoid spiking CK levels and confounding lab interpretations (transient CK rise is already expected).
- Monitor functional improvements, noting that early gains may be linked to increased glucocorticoid (GC) doses.
- Coordinate constantly with the gene therapy team as they monitor for liver, cardiac, and immune-mediated myositis risks.

Post-Therapy PT Progression:

- Resume & Progress the Duchenne FITTVP exercise framework.
- Track Functional Gains, particularly noting improvements in Timed Function Tests (TFTs) in younger boys.
- Reassess Baselines at the 6-month and 12-month marks.
- Maintain Strict Contraindications! Do NOT assume the muscle is completely normal; eccentric and high-load exercises are still prohibited.
- Re-set Goals with the family. New gains change what is possible (e.g., returning to biking or stairs).

7. Are there recommended stretch durations? My son is five years old, and we're receiving differing guidance from his care team—some recommend 15-second holds, others 25 seconds, and some suggest up to 60 seconds. What duration is generally recommended in this age group?

a. It is true that recommendations have varied from one source to the next however the following is what is recommended based on what we know about muscle. Stretch the areas that are tight, or sore, or often cramp. Not every muscle needs to be stretched if the person is still ambulatory. Stretch to the point of feeling tightness or slight discomfort, not pain. Time: Hold that position for 10-30 seconds, repeat for a total stretch time of 60 seconds for each muscle. Frequency: At least 3-4 days/week.

8. What are some exercise considerations for Becker muscular dystrophy?

a. This is an excellent question, and the most important point is that exercise recommendations should always be individualized based on a person's current function, goals, daily routine, and overall health status. There is no one-size-fits-all approach, particularly given the wide variability in function seen across individuals with Becker muscular dystrophy.

In general, we recommend avoiding exercise to the point of exhaustion and instead focusing on safe, sustainable activity. Maintaining good hydration and supporting overall muscle and heart health with appropriate nutrition are also important foundational elements. It is equally important to monitor for “red flags,” such as sprains, strains, significant muscle soreness or cramping, bruising, or dark-colored urine following activity. Contact sports can place additional stress on muscles and should therefore be approached with extra caution and close monitoring. Even in individuals who are asymptomatic, it is not always possible to know how much dystrophin is being produced or how well muscles are recovering after exertion.

Because Becker muscular dystrophy spans a broad spectrum of abilities, a range of activities may be appropriate, including cycling, swimming, light resistance or gym-based exercise, and balance or coordination work. Exercise should generally be performed at low resistance, with careful monitoring and gradual progression over time. Key considerations include the type of exercise (aerobic, strengthening, flexibility, or coordination), the individual’s starting point, their goals, and the amount of time available for activity.

Overall, the guiding principle is to keep activity safe, consistent, and submaximal rather than intense or exhaustive, while adapting over time based on tolerance and response.

9. Is exercise beneficial for the older population too? We’ve previously been advised to limit exercise to only stretching and swimming throughout his life. Is the type of exercise you are describing also beneficial for adults with Duchenne?

a. Exercise can be beneficial for individuals in the older age group, and while stretching and swimming are commonly recommended, they are not the only options that may be appropriate. There may be additional forms of exercise your son could safely incorporate, depending on his interests, motivation, and overall goals.

   A key starting point is understanding whether he is interested and motivated to try other types of activity. We know that exercise tends to be most effective and sustainable when it is self-directed, aligned with personal goals, and integrated into daily routines. If these factors are present, then other options can be explored, such as assisted arm cycling, or modified strengthening activities using gravity-eliminated positions or isometric exercises—for example, using a wheelchair tray or another supportive surface.

An occupational therapist can also be a valuable resource in designing and adapting upper extremity exercises tailored to his needs and interests. Simple, low-resistance tools such as pulleys or resistance bands can often be incorporated in a way that minimizes strain while still promoting movement and function.

10. Are there any known hallmarks of Duchenne disease progression that would make even mild exercise detrimental?

a. Currently, there is no established research-based threshold that defines when exercise should be avoided in individuals with Duchenne. In fact, the limited studies that have used objective markers—such as creatine kinase levels or MRI-based measures of muscle health—suggest that moderate-intensity exercise does not lead to increased muscle damage in dystrophic muscle.

   Because of this, exercise should be individualized for each person, aiming for a moderate, personally appropriate intensity rather than a one-size-fits-all prescription. It is essential that any new exercise plan be discussed with the individual's healthcare team, as physician clearance is particularly important given the potential cardiac involvement in both Duchenne and Becker.

   When introducing or adjusting exercise, close attention should also be paid to recovery. Monitoring how the body responds after activity helps determine appropriate rest periods and overall tolerance. Some degree of delayed onset muscle soreness is normal for everyone and typically occurs within 24–36 hours after activity; however, it should not be severe enough to significantly impair daily function or require prolonged bed rest.

   Families and patients should also be familiar with established “STOP exercise” criteria, such as those outlined in PPMD resources, and use these as guidance to help ensure safety while remaining active.

11. Should exercises be followed by a few hours of rest where the child isn't very active?

a. This really depends on how strenuous the exercise is and how your child responds to it, so close observation is key. Fatigue is an important guide, and it's helpful to watch for early signs that your child may be doing too much. Hydration during activity is also essential, so frequent water breaks should be built in, along with appropriate nutrition and post-exercise snacks, since exercise requires adequate fuel.

A helpful rule of thumb is to think about balance: if your child needs a prolonged recovery period afterward—such as a two-hour break or more just to rest—it may be a sign that the activity was too intense. Ideally, exercise should be followed by a return to usual energy levels and participation in normal daily activities, not a day spent on the couch recovering. At the same time, structured rest periods during the day and alternating with lower-key activities can be very appropriate and effective.

It is also important to monitor recovery over time, not just immediately after exercise. Tracking how your child “bounces back” can help you better understand their optimal activity level and how much rest is needed after different types of exertion. Some delayed onset muscle soreness (DOMS) within 24–48 hours is normal for everyone, but it should be mild and should not interfere with daily function or require bed rest. If soreness or fatigue is significant enough to limit normal activities, that is a sign the exercise dose was likely too high.

Finally, families should be familiar with established “STOP exercise” criteria, such as those provided in PPMD resources, to help guide when activity should be reduced or paused to ensure safety.

12. At what age should you consider starting exercise?

a. Children naturally gravitate toward activities they enjoy, and much of early “exercise” can be built into play and daily routines. Simple activities like walking to a neighbor’s driveway each morning, playing ball in the backyard, or other active play are all meaningful forms of movement and can be encouraged from an early age. Setting a family example—such as stretching together or incorporating movement into daily routines—can also help normalize physical activity.

   In addition to free play, structured activities such as stretching and formal physical therapy exercises are often recommended. We are also seeing benefits from cycle-based exercise, so early exposure to activities like bike riding (as appropriate) can be helpful. Adaptive sports can be another excellent option, offering both physical benefits and important social engagement.

   Stretching in particular is a valuable habit to establish early. Parents can model and support this by stretching themselves and gently assisting their child with areas of tightness, which can help make it a natural part of the routine over time.

   A formal physical therapy evaluation early on is also very useful to establish a baseline. Periodic follow-up assessments can then be helpful, especially if concerns arise such as changes in balance or coordination, increased clumsiness, muscle tightness, difficulty with motor control (e.g., bumping into objects or difficulty stopping), or delays in motor, speech, fine motor, attentional, or problem-solving skills. Physical therapists can also play an important role in connecting families with additional resources and adaptive equipment as needs evolve over time.

13. Is strength training for muscular dystrophy possible?

a. Yes, there are different types of strength training that are possibilities for someone with muscular dystrophy.Research has shown moderate-intensity and isometric types of exercise to be beneficial. We do recommend avoidance of high-intensity and eccentric-based strength exercises. An assessment by a healthcare professional familiar with both exercise and muscular dystrophy is important to determine one's baseline strength, the ideal mode/manner of strength training for the individual, personal goals, and how exercise could fit into your routine.

14. Are there suggested exercises to strengthen muscles closer to the hips and delay loss of ambulation?

a. Exercises that may strengthen the muscles around the hips generally involve motions that move the thigh forward, back, and to the side as well as straightening or bending the knee. While cycling can be beneficial as an aerobic exercise, cycling involves some of the muscles around the hip and may strengthen them too. Performing isometric exercises (as outlined below) or doing leg exercises in a pool for the movements of the thigh and knee may also be done for strengthening purposes. Tall kneeling, standing. One-legged stance activities are also great activities for pelvic stabilization allowing for improved or easier movement of legs. It also mimics activities of walking. If you like dancing, it is also a great way to strengthen the hips because it requires shifting from one leg to another while shifting your weight. Salsa and merengue are good examples. . In addition, the trunk muscles should also be addressed since they also play a critical role in keeping the body upright.

15. If someone exercises their whole life, could this stop deterioration altogether, or is damage unavoidable?

a. While exercise is important for all muscles and can have some positive effects on dystrophic muscle that may delay the negative impact of the disease over time, exercise alone is not curative and will not completely stop the disease process for those with Duchenne and Becker. With so many exciting pharmaceutical interventions being currently implemented and others on the horizon, we are hopeful that exercise may be an adjuvant to these interventions to maximize their beneficial effect.

16. Is there a recommended number of reps/sets for isometric exercises, and ideal joint positions for each muscle group?

a. Yes, the recommended parameters for isometric exercise are: four sets of six repetitions, holding each contraction for five seconds, and allowing a rest of 10 seconds between repetitions and a minute of rest between sets. The recommended frequency of isometric exercise is 2-3x week with at least one day between exercise sessions, and the recommended intensity is moderate (exerting about 50% of one's maximal effort during the isometric contraction). Each muscle group has an ideal alignment for strengthening but there are multiple positions to do these in making it an adaptable exercise. You can strengthen a muscle anywhere along its length, though doing so in its "mid-range" should be a good starting point. Example: Quadriceps could be done in sitting, standing, or lying down.

17. Have researchers noticed any differences in response to exercise based on mutation type?

a. Unfortunately, we don't have enough information yet to understand whether certain mutations will affect the exercise response in individuals with Duchenne – noting that in healthy individuals there are individuals who respond more to exercise than others. In our study involving leg isometric exercise training, we had seven boys with Duchenne complete the 12-week intervention, demonstrating improvements in both strength and functional mobility with no signs of muscle damage at the end of the study. Our more recent study had six boys with Duchenne complete six months of cycling exercise, and observed improvements in each individual with no negative effects. Future studies are needed with larger sample sizes to ascertain whether mutation type impacts exercise responsiveness.

18. How can we advocate to our care team to begin an exercise plan?

a. It can be helpful to share relevant articles and webinars with your care team and advocate for inclusion of exercise as a standard part of your or your son's overall care plan. Emphasizing its importance can help ensure it is recognized as a key component of comprehensive management.

Education plays a central role—helping others understand that exercise in dystrophinopathies is not only about muscle health, but also supports multiple body systems, including cardiac, respiratory, digestive, neurological, and broader cognitive, social, and emotional well-being.

For care teams that may not have a physical therapist integrated into their clinic, it may be necessary to take a more proactive approach by working through the care coordinator or similar point of contact to help facilitate appropriate referrals and ensure exercise guidance is included in the overall care plan.