

Summary – Exercise

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Reality versus Research: The reality of day-to-day life for a person living with mitochondrial disease makes the idea of regular exercise seem like an impossibility, regardless of the research! This discussion will try to provide a framework on how exercise can actually help those with mitochondrial disease.

In general, exercise is good for everyone. Its many benefits include increasing the ability to move, maintain balance, and flex joints, improving mood, and decreasing levels of depression and anxiety. Exercise has also been shown to decrease or slow the onset of diabetes and heart disease. Most importantly, the overall effect of exercise is to increase energy production in the body.

In mitochondrial disease, exercise can give you more energy on a biochemical level. Exercise increases the number of healthy mitochondria in the cells by turning on the genes that make mitochondria. One might ask, however, does this also increase the unhealthy or mutated mitochondria in the cells? If the mutation is nuclear, then no, the number of unhealthy mitochondria would not be increased. If it is a mitochondrial mutation, then exercise may increase the unhealthy mitochondria, but because more ATP is also being produced, it is still better to exercise and increase energy production.

Research indicates that exercise makes the body use oxygen more efficiently and increases exercise tolerance and metabolism. One study even demonstrated that resistance exercise (pulling or pushing against some force) actually diluted the unhealthy or mutant load of mitochondria in muscle cells.

Is it safe to exercise when you have mitochondrial disease? Because every case of mitochondrial disease is different, this cannot be answered for everyone. But the research does indicate that exercise, even small amounts, is good. A study in Denmark in 2006 looked at exercise capacity and checked both blood levels and muscles pre- and post-exercise. Researchers found that not only was exercise safe but it increased exercise capacity and aerobic training. Many people with Mito have higher than normal lactate levels and when they exercise this makes their muscles "burn." They do not use oxygen efficiently. We have found that lactate increases with anaerobic activity like heavy weightlifting or high-intensity sports like sprinting or tennis. These activities do not give the muscles time to rest or recover. But some increase in lactate level is not harmful and even if levels rise a little, the muscles can recover. The key is what kind of exercise, the intensity, and the time frame.

If pain or muscle cramps do occur during exercise, cut back or try a different exercise for a while using a different muscle group. Large muscle groups like those in the legs, especially the thighs, use more oxygen and have more Mito myopathy. Therefore, try exercising smaller muscle groups for a while like those in the arms, hands, and fingers.

Exercises can be done while sitting or lying down -- you don't always have to be standing.

Exercise as a treatment for Mito: People with mitochondrial disease often say, "I'm so tired, how can I possibly exercise?" The answer may lie in how we define exercise. Usually we think of exercise as having to be intense and for long periods of time, like a one-hour gym step class, or the whole recess period at school, or trying to ski and keep up with others for 2 to 3 hours. Then, when someone has a bad experience exercising because they perhaps overestimated what they could do, exercise becomes something they avoid. The key to exercise for those with Mito is balance. The slides that accompany this discussion show lots of pictures of frogs. That is because frogs seem to have figured out a balance of rest and activity that we should follow: Frogs hop, then rest on a lily pad, hop, then rest on a lily pad; we should do the same.

Exercise needs to be individualized so that it represents what is right for you, and this may mean redefining what qualifies as exercise. Exercise should be scheduled for the time of the day that is best for you -- for most that would be in the morning. Choose ONE activity per day; do not try to cram all activities into one day ... spread them out. Teachers may need to break up a student's activities into 10-minute "bursts": play, then rest by being the scorekeeper for 10 minutes, etc. Balance snacks around exercise (both before and after). Remember, exercise is cumulative: three 10-minute walking sessions are as good as one 30-minute session.

Someone starting out on an exercise regimen might want to have a complete physical exam first, which would include a 3-lead EKG, especially if there is any risk of cardiac disease. A kinesthesiologist, physical therapist, or trainer may also be helpful. The MitoAction website also has an exercise guide to follow. Balance is the key; start small and build. Have a graded exercise plan and stick to it. Even if you feel "great," do not push yourself. The body makes biochemical changes gradually -- give it time to adjust to the exercises.

Do not jump into a vigorous exercise program, but rather start with a few minutes of stretching and perhaps mild walking. Increase this in minute-by-minute increments -- slowly. It is difficult for children to naturally limit themselves, so parents and teachers have to be vigilant. Work out a plan for children ahead of time. If they are involved in a team sport, have them sit out every other time they would be "on." Have the child be assigned to bench duty, keeping score, or acting as team manager ... be creative.

It is also helpful to keep track of your exercise in a journal or calendar. This provides reinforcement as well as encouragement. For example, plan to walk, cycle, or swim for 5 minutes every other day for 2 weeks, and check it off as you do it. Choose an exercise that works for you, then schedule rest and food around it.

What kind of exercise is best? There is no one kind of exercise that is best -- it is very individual. Aerobic exercise, which includes sprinting and tennis, may not be the best for those with Mito because they do not allow the muscles to regroup and rest.

Anaerobic exercise like walking, swimming, or biking may work for you. Resistance exercise may work for some -- this includes weightlifting and using an exercise bike with resistance -- but these should be done very gradually and only if you are able. All exercise increases your circulation, thereby increasing the flow of red blood cells that carry oxygen. Exercise also makes for stronger bones.

Any exercise plan should be based on past experience. That is why a journal or diary is a good idea. Combining different kinds of exercise if you can tolerate it is also good because this works different muscle groups; try a little aerobic and resistance with anaerobic. For example, a child could try to swim for 30 minutes, then have a snack, rest for 30 minutes, then play. Tolerance may also vary from day to day so you must be aware of this.

Any exercise is good -- it depends on what you can tolerate. Even simply drawing circles with your feet while you are sitting (or lying) down watching television qualifies as exercise! Swimming is great exercise but often the energy expended just getting there and changing can be exhausting. Warm water seems to be better -- but some feel that if they overheat, this is a problem. Five minutes in a warm pool may be enough exercise before you feel drained; hot tubs may be too much and should be used with great caution, if at all. Stretching exercises are good for circulation, joint range of motion, and mobility -- even just 5 to 10 seconds' worth. Yoga, sailing, or horseback riding can also work for individuals. Many have found that using the Wii can be good because you can do this from home and not expend energy getting somewhere to exercise. With the Wii, you can improve balance, muscle function, and reaction time. You can also adjust your activities, like not using your whole arm for tennis if you can't, or sitting in a chair and trying the activity that way.

If you want to go somewhere for an exercise program, there are many listed on various websites. Groups especially for arthritis, Parkinson's disease, fibromyalgia, healthy hearts, or disabled children's riding programs are just some examples. Do some research to find an exercise program that is best for you. In your community there may be a therapeutic pool with a physical therapy program. Some health insurance may cover this, especially if a physical therapist is involved in the plan. A physical therapist will have a different perspective from a trainer at a gym and may be more suitable for those with Mito.

What about fatigue? Again, the way to avoid becoming overly fatigued is to balance exercise with rest. Most folks follow an every-other-day exercise plan rather than an everyday plan. The benefits of exercise are retained more if you rest after the activity and stop BEFORE you are exhausted. For most people, exercising in the morning is best. Often, exercising a couple of hours after vitamin supplements or a snack works well. For others, exercising after a warm bath or shower is best. Obviously, if nausea, vomiting, or pain occur, you should stop, then decrease your exercise the next time you resume. A little pain may be expected, but do not simply "push through" increasing pain -- your body is telling you to stop. With a good exercise plan, you should be able to improve your baseline gradually. For example, over time you could move from

exercising for 1 minute to 5 minutes to perhaps 15 minutes. Goals have to be small and achievable.

Some children/teenagers with Mito have been told, "You should never play sports." This is not true. Exercise is good for them but they need to pace themselves based on their own individual mitochondrial function. If there are other issues, like cardiac disease or risk, then exercise may have to be planned even more carefully.

What to eat before and after exercise: Sports drinks are good to have 1 hour before exercising and during exercise to maintain hydration. Snacks that are high in complex carbohydrates (like whole grains), protein, and a little fat (but not a lot) are good. Examples would be a whole grain bagel with peanut butter, pasta with cheese, or cereal with milk and berries. When kids are playing soccer or participating in a karate match, have a snack on the sidelines for them. Whole grain pitas, bananas, and oranges work in these situations. Again, staying hydrated during exercise is essential and children need to be reminded of this. Do not use energy drinks because these often have caffeine; use water or diluted fruit juices. It is important, especially for children, to have food after exercising -- chocolate milk and a banana or yogurt are good choices. Some Mito patients are concerned about becoming hypoglycemic during exercise; this should not be a problem if a snack is consumed before, during, and after the exercise and if hydration is maintained. Certainly, stop exercising if symptoms appear.

Summary: The do's and don'ts of exercise include:

DO

- plan 3 sessions a week -- not every day
- fuel up before, during, and after exercising
- if you take a break from exercising, get back to it as soon as possible
- warm up and cool down
- factor in rest and nutrition

DON'T

- hold your breath when exercising
- exercise within 3-4 hours of bedtime
- exercise on an empty stomach
- exercise when you are sick
- stand when you can sit
- sit when you can lie down

Exercise can provide another way for you to safely manage your Mito symptoms and to maintain your energy, not drain it!