

Exercise for Mito – Connect call

Nancy Van Doorn, Accredited Exercise Physiologist (EP) from the Children's Hospital at Westmead Institute of Sports Medicine answered questions about exercise for people with mito.

Q: Is there a time when doing even mild exercise is detrimental to health and therefore should be avoided? In other words, can too much exercise cause disease progression?

NVD: Mito presents very differently with each person, but usually the person is referred to the EP from their specialist and therefore ready to exercise. However, if their presentation is changing rapidly or new symptoms are occurring, such as severe fatigue/myopathy or feeling significantly worse after exercise this may mean they need to stop. It is important for there to be a balance between doing enough exercise to get a positive result and not getting hurt. If someone with mito is pushed too hard, it is possible to cause two potentially life threatening conditions called lactic acidosis and rhabdomyolysis. Lactic acidosis occurs when lactate and other molecules, called protons, accumulate in bodily tissues and fluids faster than the body can remove them. The symptoms are muscle pain, difficulty breathing and nausea. Rhabdomyolysis is a condition in which damaged muscle breaks down rapidly. Symptoms may include muscle pains, weakness, vomiting, and confusion. Some of the muscle breakdown products are harmful to the kidneys and may lead to kidney failure. These conditions are rare, but eccentric activity increases risk. Eccentric exercise is where a muscle is lengthening while under load, for instance the portion of a bicep curl where the weight is lowered, or walking downhill – this causes a different strain on the muscle.

It is important for people with mito not to push through pain and fatigue signals but to listen to their body. It is also important to learn the signals their bodies give them and not overdo it. Also, it is best not to jump straight into just any type of exercise (for instance group gym classes) but to start slow and build up gradually.

That said, it is even more important to avoid complete inactivity and deconditioning. It is usually a good idea to avoid doing nothing as this increases the likelihood of physical deconditioning, however there may be periods of time where you should avoid activity. Your treating physician (e.g. Neurologist, Metabolic specialist) will be best able to advise you.

Q: How should I start exercising?

NVD: As mito affects everyone differently, exercise will mean something different to everyone as well. A good place to start is thinking about what you are currently able to do, including your activities of daily living not just thinking of a structured exercise session. Exercise and activity can always be broken down into core parts to help achieve an overall outcome. E.g. Immobile patients might work towards really functional specific outcomes such as wheelchair transfers or brushing/washing hair (as overhead arm activity can be quite intense), or perhaps you might want to work

towards increasing your exercise tolerance to walk a certain distance without symptoms. The aim is always to progress, but taking small steps to do so. Too much too soon can be harmful.

Muscle strength and exercise tolerance can usually be improved and contribute to making daily tasks easier. An EP can help progress functional level in a safe way while ensuring it won't be detrimental to health.

Two key terms for improvement are *intensity* and *frequency*, which should be tracked. Intensity is how difficult the exercise or workout is, and frequency is how often the exercise or workout is performed. The frequency and intensity of exercise should be increased very gradually and should be kept below the threshold of inducing symptoms - but if they are not increased it is not possible to progress. It is important to start very slowly - for instance walking for five minutes two to three times a week, and then adding one minute onto each walk the next week. This will cause fatigue, but the body needs to be challenged as this is how it adapts. There are many different combinations of increasing intensity and frequency. An EP specialises in finding the right combination for your goals and situation.

For some less functional patients, vibration plates may be a way to increase muscle power, check with your doctors before engaging with this. The research can be found here:

<https://archivesphysiotherapy.biomedcentral.com/articles/10.1186/s40945-017-0038-4>

Q: Do numbers of mitochondria increase with exercise, and how fast do mitochondria numbers decline once exercise is stopped?

NVD: Mitochondria are mostly found in organs with high metabolism like muscles the eyes. If exercised, muscles will grow new fibres and mitochondria. Aerobic exercise (or cardio, like walking, swimming etc) is the best for increasing mitochondrial numbers. Resistance training is also important (such as weightlifting) as with new muscle comes more mitochondria. It usually takes about 4 weeks to start seeing decline. With mitochondrial disease, the mitochondria may behave differently, it is difficult to know at an individual level the rate and response to increasing activity levels and subsequently reducing activity levels.

Q: Is EP available under Medicare?

NVD: Yes, there are a few options:

- NDIS funding
- Chronic Disease Management plans – up to 5 mostly subsidised visits per year
- Aged care Australia funding.

Q: Are all EP's able to treat someone with mito?

NVD: Yes, but, it may be rare to find an EP with extensive practical experience. There are also a wide range of EP's that specialise in different conditions and chronic diseases, some of these sharing similar traits to mitochondrial disease especially symptoms of fatigue and exercise intolerance. There are EP's that treat other neuromuscular conditions such as Fibromyalgia which might be well-suited. In general, EPs are university trained with a thorough understanding of the physiology of behind exercise for people with chronic illness so they will be able to help. A good idea would be to get in touch with mito foundation to get the most up to date information.

Q: What about patients that need forced feeding and are experiencing excessive fatigue?

NVD: A mismatch between energy input and energy output can result in fatigue. The timings and amount of feeds is very important, and may need to change if exercise levels increase.

Other contributors to fatigue symptoms might be related to your condition and the structure of your day. Sometime it can help to implement what's called "Pacing", where by the day is broken down into periods of activity and rest. Some general tips related to pacing include; matching a period of physical exertion with physical rest, similarly matching a period of cognitive exertion with cognitive rest, or identifying longer periods of intense activity and breaking these up with short rest periods. It is important to avoid a boom-bust scenario – e.g. pushing yourself very hard which then results in a significant exacerbation of fatigue (a crash or bust) in the following 24-48hrs. If this happens often, it can be quite serious and really exacerbate fatigue. It might also be beneficial to break down all the activities and tasks of a normal day and identify any particularly stressful or intense sections (cognitive or physical as they both contribute to fatigue)

If you are looking for clinicians who specialise in managing fatigue, they are a niche field but are available, and have use evidence based strategies. Two large clinics are the Fatigue Centre and Fatigue Clinic run through UNSW. One final point on PEG feeding – there may be certain guidelines around exercise that need to be adhered to, some movements may need to be avoided, as well as activities that increase intra-abdominal pressure. It is important to exhale on exertion, do not hold your breath and strain at the same time, and be mindful of activities this can occur with (Eg. Lifting heavy things)