

Mitochondrial Myopathy

How exercise can help




Overview

- Why exercise?
- Is it safe to exercise?
- Defining exercise
- How can I exercise when I have no energy?
- Coming up with a plan: when to exercise, what to eat, how to manage fatigue
- The do's and don'ts of exercising with mito



Why exercise?

- Improves energy production in the body
 - Improves ability to walk
 - Improves mood
 - Decreases risk of heart disease and diabetes
 - Promotes independence
- 
- The background of the slide is a solid blue color. In the lower right quadrant, there are several faint, concentric white circles that resemble ripples on water, creating a decorative effect.

What the research shows

- Better use of oxygen by the body
- More efficient metabolism
- Increased numbers of healthy mitochondria
- Increased enzyme complex levels (Koene & Smeitink, 2009)
- resistance exercise can lower the mutation load, thereby increasing the functional mitochondrial load (Taivassalo & Haller, 2005)
- improvement in quality of life (Taivassalo et al., 2006).

How is mitochondrial function affected by exercise?

- Mutated and wild-type (healthy) mitochondria live in the same cell
- Ratio (called the mutation load) determines how bad the disease is in each tissue (e.g. muscle)
- Exercise in the form of resistance training (light weight lifting or strengthening exercises) can dilute the mutation burden
- Increased healthy mitochondria in cells
- Better muscle function

Is it safe to exercise?

- Researchers in Denmark studied the effect of 12 weeks cycle training on:
 - Exercise capacity
 - Quality of life
 - mtDNA mutation load in muscle, CK levels, mitochondrial enzyme activities

The results

- Yes
- Aerobic training improved mitochondrial function
- Mutation load, CK levels remained stable
- (Jeppesen et al., 2006).

What about lactate?

- Lactate is what makes our muscles burn after we exercise
- Some people with mitochondrial disease have higher than normal levels of lactate in their blood
- Focus on exercise capacity and symptoms rather than lactate levels

What is your definition of exercise?

Think for a minute about how you define exercise for yourself or your child.



"How can I exercise when I'm so tired I can barely get through the day?"

- People with mitochondrial myopathy have often had bad experiences with exercise because they have over-estimated what they 'think' they should do to get exercise
- They have over-exercised and felt worse as a result.



The key is Balance



Practical applications

- Schedule appointments with doctors, therapists etc in the morning
- Only one appointment per day when possible with rest afterwards
- teachers need to know that mito kids need to break up activity: e.g. have a 10 minute recess and then 10 minutes of a quiet game, or 10 minutes of gym time with 10 minutes on the sidelines being the scorekeeper or other quiet 'job'
- spread exercise out throughout the day: 3 10 minute sessions are just as good as one 30 minute session

Before you start...

- 12 lead ECG (Parikh et al, 2009)
- Whenever possible, exercise regimens should be supervised by a therapist, trainer or kinesiologist
- “Exercise and mitochondrial disease” guide is available at www.mitoaction.org

Graded Exercise

- An exercise plan that starts out **SLOWLY** and increases in very small steps
- Stick with it even if you're having a good day and feeling like doing more!
- Lets your body make the changes it needs to cope with activity and exercise



How to come up with a graded exercise plan

- **Start very slowly.** Don't jump into a vigorous exercise program. Start with just a few minutes of very gentle exercise, such as stretching. When you are comfortable with stretching exercises, add very short periods of a mild aerobic activity such as walking or swimming.
- **Increase very gradually.** After you know that your body can tolerate this level of exercise over the course of several sessions, increase the length of your exercise session by only 1 minute. Rest frequently, and build up your exercise intensity a little bit at a time.
- **Don't push yourself too hard.** You can easily become overtired, which will defeat the purpose of exercise.
- **Keep track of your exercise** on a calendar or use a progress chart

The steps

1. Choose the exercise(s) that work best for you
2. Factor in the timing of exercise around rest periods, snacks and meals
3. Review when to increase, decrease and stop exercise
4. Be familiar with the do's and don'ts of exercise in mito....

What exercise is best?

The best exercise for you/your child:

- can be done easily
- is low impact
- can be done regularly
- doesn't cause a crash
- doesn't use up so much energy that there isn't any left over for regular activities



Figuring out what's best for you

- Learn from past relapses. For example, if walking for 20 minutes worsened your symptoms, try walking for five minutes and see how that goes. It may be helpful to keep a diary to keep track of what works and what doesn't.
- Remember that your exercise tolerance will differ from one day to the next
- those with gait instability or excessive fatigue may better tolerate exercise on a recumbent exercise bike or in a pool

Remember....

ANY exercise is better than NO exercise!



Ideas of exercise options

- Walking (many communities have walking programs)
- Swimming/pool therapy (especially in a warm pool)
- Gentle stretching
- Tai chi
- Wii fit
- Sailing
- Horseback riding
- yoga

S-t-r-e-t-c-h-i-n-g

- Stretching seems to be well tolerated by people with mitochondrial disease. You may prefer to stretch while lying down in bed.
- Stretching promotes circulation and maintains your body's range of motion
- do shorter stretches, holding 5 to 10 seconds so you don't stress your muscles and expend a great deal of energy

How the Wii helps

- Research studies show benefits in patients with cerebral palsy, Parkinson's, strokes and spinal cord injuries
- Improved gait and balance
- Promote motion, increasing heart rate and burning calories
- Improved motor function
- Distraction from pain
- Adaptable for people with various abilities
- Can save energy as you don't have to leave the house to do yoga, aerobics, walking, running
- Fun!

Where to look for programs

- Community centres
- Adapted exercise programs
- Recreation/sports complexes
- Walking clubs
- Arthritis programs
- FM programs
- Healthy heart programs
- Disabled Sailing and horseback riding programs

Managing fatigue

- Rest at least 48 hours between exercise for strengthening muscles (e.g. using weights) and at least 48 hours between aerobic exercise (e.g. stationery bike or walking program)
- rest after the activity when possible so that all of the benefits of exercise are retained without an increase in fatigue
- Stop the physical activity well before you feel tired. Pacing yourself is very important.

When to exercise

- Exercise in a.m.
- exercise a couple of hours after the supplements so that your body gets the peak effect
- After a warm shower or bath. This relaxes muscles, increases circulation and can make exercise feel easier
- Within 1-4 hours of eating

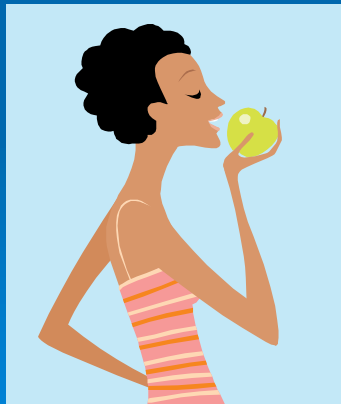
When to stop

- if you experience nausea or vomiting. Decrease the intensity and/or duration of the exercise the next time
- If the exercise causes you pain. However, it is natural to feel some temporary muscle aches or discomfort at the start of any form of new exercise



What to eat to fuel your body *before* exercise

- Eat 1-4 hours before exercise for extra energy, fluid and to prevent hunger



Suggestions

Choose foods rich in carbohydrate with some protein and little fat:

- Whole grain Bagel with peanut butter
- Small plate of whole grain pasta with cheese
- Small bowl of whole grain cereal with milk and berries
- Cheese and whole grain crackers



Snacks on the sidelines

- For kids and adults involved in sports such as soccer, karate, hockey, ideas for healthy and energy-boosting snacks on the sidelines are:
 - Mini whole grain pitas with hummus or cheese
 - Granola or cereal bars
 - Juice boxes
 - Bananas
 - Raisins
 - Trail mix
 - Orange sections



Staying hydrated during exercise

- Kids have a poor sense of thirst and need to be reminded to drink during exercise
- **Sports drinks:** mostly water with some sugar, minerals and flavour
- **No energy drinks!** Energy drinks are not sports drinks. They have caffeine and chemicals and are also fizzy, making it hard to drink enough to stay hydrated during exercise
- Diluted **fruit juice**
- **WATER**



What to eat *after* exercise to re-fuel

- Carbohydrate, protein and fluid will help your muscles recover after exercise
- have a snack (or your meal) *as soon as possible* after exercise
 - chocolate milk with a banana
 - Homemade shake (milk, yoghurt, fruit, juice)
 - Cereal
 - Yoghurt



The Do's



- Aim for three exercise sessions per week
- Fuel your body before, during and after exercise
- listen to your body – if you don't feel up to exercising on a particular day, don't
- If you need to take a break from your exercise plan, get back to it as soon as possible

The Don'ts



- Don't hold your breath while exercising
- Don't exercise within 3 to 4 hours of going to bed for the night. Exercising just before you go to bed may make it harder to fall asleep.
- Don't exercise on an empty stomach
- Don't exercise if you are sick

From warm up to cool down....

- Exercise is a safe and effective way to manage the symptoms of mito
- Making an individualized graded exercise plan that factors in rests and nutrition is the key to **maintaining, not draining**, your energy levels

Resources

- Exercise guide: www.mitoaction.org
- Exercise records

<http://www.webmd.com/hw-popup/progress-chart-for-graded-exercise>

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