



**MITOLINKS**  
**The Adult Metabolic Diseases Clinic**  
**Mitochondrial Disease**  
**Support Group Newsletter**

Thank you to all who attended our latest support group on Wednesday, September 25, 2013. As a group, we watched the new DVD on exercise in neuromuscular and neurometabolic diseases by Dr. Mark Tarnopolsky in Hamilton Ontario, which will be summarized here. We are hoping to get a lending library going so that people can borrow the DVD to watch at home.

Dr. T recommends focusing on strengthening first through resistance exercises (e.g. using a band or light weights) before introducing endurance exercise.

**Three myths related to exercise in neuromuscular/metabolic disease:**

- Need to conserve your energy by not exercising
- Don't move if you're weak and in pain
- Exercise damages the muscles

***The reality is that exercise actually INCREASES energy.***

**Reasons WHY to exercise:**

- Weakness from lack of exercise adds to disability which then adds to handicap (e.g. not being able to go to the toilet by yourself). Increased strength from exercise decreases the impact of disability and maintains ability.
- Exercise burns calories and keeps excess weight off. Obesity increases and compounds handicap and disability.
- People with muscle disease are living longer and developing diabetes and heart disease. Exercise mitigates these risks.
- Not moving/exercising leads to joint stiffness and contractures. Exercise slows down contractures formation.

## **Endurance exercise**

Endurance exercises increase function such as climbing stairs and walking. Examples of endurance exercise are biking (inside or outside), hiking, walking. These are cardiovascular exercises that increase your heart rate and get the blood pumping to your arms and legs. They are done at a lower intensity over a longer period of time (i.e. longer duration). Start slow, listen to your body and gradually ramp it up. Dr. T recommends aiming for 20-30 minutes of endurance exercise where it's hard to carry on a conversation.

It is important to know how to take your pulse so that you can check it while doing endurance exercises.

To learn how to take your pulse, go to <http://my.clevelandclinic.org/heart/prevention/exercise/pulsethr.aspx>

Your age – 220 = **your maximum heart rate**

Start exercising to reach 50% of your maximum heart rate. Work towards the goal of reaching 75% of your maximum heart rate.

Dr. T recommends exercising every other day to allow your body to recover in between and alternating different types of activity. For example, you could walk one day, then ride a stationary bike two days later.

## **Resistance exercise training**

Resistance training uses weights to strengthen the muscles. The variables in resistance training are:

- the number of repetitions you do
- the amount of weight or resistance you use
- the number of sets you do

For example, you may begin with 3 sets of 5 repetition each, using a 2 lb weight.

If you belong to a gym, it's best to do a circuit to work all the muscle groups. If you are doing the exercises at home, choose body parts (e.g. upper body, lower body, core muscles) and do 3 sets of 3 repetitions.

Resistance training increases strength and muscle mass.

Dr. T recommends the use of hand weights



vs 'dumb bells'.



Resistance bands are also recommended. They come in different colours which represent different degrees of resistance. Start with yellow or red.



### **Combining resistance and endurance training**

Dr. T recommends combining resistance and endurance training:

e.g. Monday—endurance training (e.g. walking for 30 minutes)

Tuesday—resistance (e.g. using a resistance band to do some exercises for 30 minutes)

Wednesday—endurance (e.g. riding a stationary bike for 30 minutes)

### **When have you pushed yourself too far?**

It's normal to have sore muscles after exercising. It's not normal to have muscle swelling or cola-coloured urine (called myoglobinuria). If these things happen, go to the nearest emergency room.

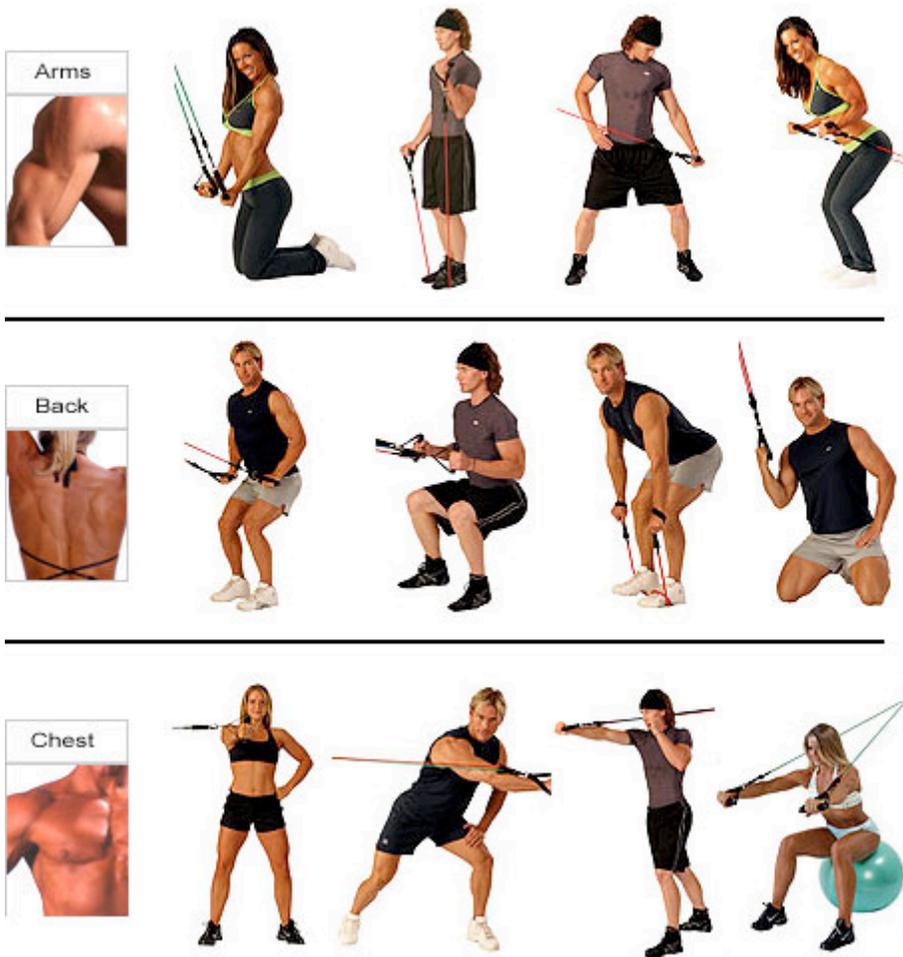
### **Exercise in mitochondrial disease**

Mitochondrial disease affects aerobic activity. People with mitochondrial disease have lower maximum oxygen consumption in exercise tests. They have decreased endurance (called exercise intolerance). The key is to work towards your individual strengths. Resistance exercises are often easier for people with mitochondrial disease to do. Exercise is particularly effective in mitochondrial disease as it activates the myo-satellite cells and turns them into new, healthy muscle cells.

If you have trouble with your balance, try using a recumbent bicycle or the elliptical rider at a community centre or local gym, or trying Wii Fit at home.

***Never exercise in a fasting state or when you are ill.***

Some suggestions for exercises you can do at home. Many can be adapted to be done sitting in a chair if you have trouble with balance or are weak:



There are lots of exercises on the internet if you google “resistance band exercises”.

**Lower body**

-just getting in and out of a chair is a great exercise for your legs and buttocks. Keep your arms crossed (i.e., don't help yourself up). The height of the chair is important. You don't want it too high or too low. Your body should be at a 90 degree angle to your thighs while seated. Work up to getting in and out of the chair 12 times.

-heel lifts: up on your toes and down works your calf muscles. To help with your balance as well, you can go up and down on one foot. To increase resistance you can do heel lifts while holding weights.

### **Core muscles**

It's really important to exercise your core (abdominal and pelvic floor) muscles properly so as not to hurt your lower back. Here is a link to a slide show from the Mayo Clinic on core muscle exercises for beginners:

<http://www.mayoclinic.com/health/core-strength/SM00047>

### **Ideas for future sessions from today's participants:**

-dealing with chronic pain using mindfulness and meditation

-how to explain your diagnosis to others (e.g. trainers)

-we talked about how handy it would be to have a wallet card for the 'lay person' to help explain the disorder to non-medical people. Margaret is working on this.

We are working on a clinic website (yay!) and are going to look into trying to get the DVD on the site. We are also expecting a group of kinesiology students in the new year that will lead groups in Wii Fit. Stay tuned!

**At our next meeting, our new genetic counselor, Kirsten Bartells, will be speaking to the group. Stay tuned for the topic and date!**

