

**At a glance guidelines:**

**Physiotherapy guidance for people with Mitochondrial Disease**



**Rare Mitochondrial Disorders Service**

For full guideline visit:

<http://mitochondrialdisease.nhs.uk/professional-area/care-guidelines/>

There are many different forms of mitochondrial disease, varying greatly in their genetic basis, clinical presentation, progression and prognosis. We recommend referral to a specialist mitochondrial centre for assessment (<http://mitochondrialdisease.nhs.uk/>).

Many symptoms related to mitochondrial disease may be helped by regular review by a physiotherapist. We therefore recommend that people are reviewed by a physiotherapist at their specialist centre appointment or referred to their local physiotherapy service where indicated.

**Common reasons for referral to physiotherapy:**

- Difficulty walking or getting around
- Problems with balance, posture and falls
- Pain
- Fatigue
- Exercise Intolerance and respiratory insufficiency
- Disorders of movement

**Cautionary note concerning exercise:**

Prior to prescription of exercise we recommend:

- An assessment of an individual's risk factors e.g. cardiac function, previous lactic acidosis, rhabdomyolysis.
- Liaison with a Neurologist or Physiotherapist with experience of working with people with Mitochondrial Disease.
- A recent cardiac screen if heart involvement is suspected. This is usually done yearly and includes an ECG, Echo +/- a cardiac MRI.
- Consultation with a cardiologist/ or specialist in mitochondrial disease should be sought prior to exercising a person with known cardiac involvement.

### **Tips for exercising:**

- Always be well hydrated and carry water with you when exercising.
- Make sure you are well nourished (if diabetic check blood sugars before and after exercise).
- Always start off with low intensity and duration and build up slowly.
- When embarking on an exercise program always program in rest days between exercising days.
- Muscle soreness is to be expected. This should not be a concern unless lasts more than 48hrs. If soreness lasts for longer than this time you have probably over done the exercise, therefore you should reduce either duration or intensity.

### **Never exercise when:**

- Suffering from an infection;
- You have a temperature
- You are severely fatigued

### **Remember:**

When exercising you should feel

- Slightly out of breath,
- Heart rate slightly higher,
- slightly warm

### **BUT**

- should be able to hold a conversation