

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-guidlines/>

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