

Useful resources

For you:

Check out our website for many more useful resources:
<https://mitocamb.medschl.cam.ac.uk/>

The Lily Foundation is the biggest mitochondrial disease charity in the UK and has lots of helpful information, including links to an active Facebook support group:
<https://www.thelilyfoundation.org.uk>

For your GP:

The following book is a comprehensive textbook for practitioners of all levels:
"Clinical Mitochondrial Medicine"
by Patrick Chinnery & Michael Keogh
<https://doi.org/10.1017/9781139192460>

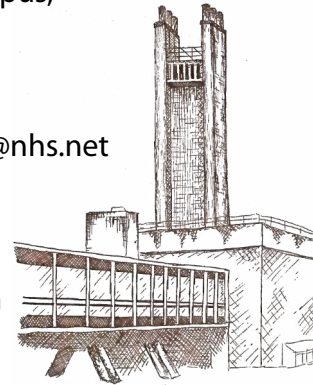
The Wellcome Centre for mitochondrial research has resources for patients, family and clinicians:
<http://www.newcastle-mitochondria.com>

Please do not hesitate to take a copy of this leaflet for your GP too!

MitoCamb Clinic contact details
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MitoCamb mitochondrial disease clinics are usually held on Friday afternoons in Clinic 43 at Addenbrooke's Hospital in Cambridge.



Mitochondrial disease: Information and support

<https://mitocamb.medschl.cam.ac.uk/>
<https://www.thelilyfoundation.org.uk/>

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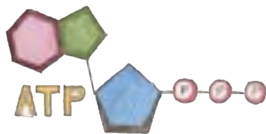
We understand that being diagnosed with a mitochondrial disease can be a confusing and worrying time. That is why we have put together this information sheet to explain what mitochondria and mitochondrial diseases are, and to point to useful sources of information and support.

Please do not hesitate to contact the MitoCamb clinical team or the Lily Foundation with any further questions you might have, using the contact details on the other side of this leaflet.



What are mitochondria?

Mitochondria are small structures ('organelles') in almost all the cells of our bodies. They are sometimes called the **powerhouses** of our cells, since they turn our food into something called 'ATP', which is the **energy** that our cells need.



What is mitochondrial disease?

Mitochondrial diseases are genetic conditions that affect energy production in the mitochondria. A **genetic condition** means that the disease is caused by damage to one of our genes, a '**mutation**'. In mitochondrial disease, the mutation affects a gene involved in energy production. Cells that require lots of energy, such as muscle cells, are frequently affected by mitochondrial disease. **This may lead to many different symptoms**, including muscle weakness, fatigue, blurry vision, hearing difficulties, diabetes, epilepsy, heart problems etc. More common symptoms like migraine or constipation may also be experienced by patients with mitochondrial disease.



Although mitochondrial disease can cause many different symptoms, **this does not mean that everyone will have these symptoms**. Some people who are diagnosed with a mitochondrial disease may find it affects their life and health in various ways, while others do not experience any symptoms at all. Your doctor will explain to you which symptoms you might experience, and how or whether this could affect your daily life. However, it is very **difficult to predict** how mitochondrial disease will progress. Therefore, your doctor may advise you to be tested regularly for symptoms that, when detected early, could be treated effectively. Examples are regular blood tests for diabetes, hearing tests, heart rhythm tests ('ECG') and heart ultrasound tests.

Opportunities to contribute to research

If you attend one of our clinics, you may be approached by a member of our team to ask if you would like to take part in research. **All research is voluntary**, and it is up to you to decide if you would like to take part or not.

The aims of our research are **to better understand the causes of mitochondrial diseases**, so that we can find new and better ways to diagnose these diseases, as well as measure how these diseases respond to therapy and develop new treatments.



To see which studies/trials are running across the UK and elsewhere in the world, please visit the following page on the **Lily Foundation website**: www.thelilyfoundation.org.uk/lily-research/what-research-going-world

To find out more about research in Cambridge, you can look on our **MitoCamb website** to see the studies/trials that we currently have running: www-neurosciences.medschl.cam.ac.uk/mitocamb

You can also contact the **research team** directly by email: add-tr.mitoteam@nhs.net