



FIRST STEPS WITH MITO GUIDE

The diagnostic journey for those affected by mito often takes years and can be extremely distressing and isolating. This checklist aims to help you navigate information about mito and the health system, and provide an overview of considerations for the future. All the resources mentioned in this guide are available to download on the AMDF website.

It is important to remember that whilst there is no cure for mito, there are treatments and methods to help manage your symptoms.

1) WHAT SHOULD I ASK MY SPECIALIST?

- Is it appropriate to have further testing, for example genetic testing? ([Find out more](#) about the benefits of a genetic diagnosis)
- Are you able to provide me with a management plan based on the [Patient Care Standards for Primary Mitochondrial Disease](#)?
- How can I get in touch with the clinic between visits if I have questions about medications or symptoms?

AMDF has developed a fact sheet about preparing for specialist appointments which can be downloaded [here](#).

Our [Mito Professionals Directory](#) lists health care providers who have experience in diagnosing, treating and managing patients with mito. Please contact us to be directed to health professionals who best suit your individual needs.

2) WHERE CAN I LEARN MORE ABOUT MITO?

AMDF has information about mito, as well as resources for patients and families, published on its website. This information has been reviewed by its [Scientific and Medical Advisory Panel](#).

The following resources may be helpful:

- [Mitochondrial Disease Fact Sheet](#) – overview of mito.
- [Information Booklet for Medical Practitioners](#) – in-depth guide about mito.
- [The Genetics of Mitochondrial Disease](#) – overview of genetics and mito.

You can also call or email the [AMDF Helpline](#) on 1300 977 180 or Helpline@amdf.org.au, if you have any questions or to request a Mito Information Pack.

“The Mito Information Days that AMDF organise are a great source of support. I can access more information whilst making supportive contacts.”

Pam - Mito Community Member

3) HOW CAN I ACCESS EMOTIONAL SUPPORT?

It can be helpful to work with a health professional such as a social worker, psychologist or genetic counsellor to support you through coming to terms with your diagnosis. Your GP or specialist clinic will be able to provide a referral for these services.

There are a number of organisations which provide counselling and other support services, which are appropriate for people with mito and their carers. Access more information about these [here](#).

AMDF facilitates a peer support program called Mito Connect. Mito Connect includes:

- The [AMDF Facebook Group](#) for people with a close connection to mito. Here you can seek support and advice from other members of the community.
- The [AMDF Support Network](#) is a contact list of people with a close connection to mito who are happy to be contacted by people in a similar situation.
- Support groups located in each state that connect you with other community members.
- Mito Connect Calls which are similar to support groups but take place over the phone.
- Mito Information Days in your state where you can hear the latest updates on mito.

You can join Mito Connect [here](#) on the AMDF website.

“If things become increasingly difficult emotionally, I recommend accessing a counsellor or psychologist with experience in chronic illness. Your GP can refer you”

Pam - mito community member

Mito Community Tip:

Take a trusted family member or friend to your appointment to help take notes of any information you need and to provide support.

4) WHAT SHOULD I TELL FAMILY AND FRIENDS?

Talking to others about mito may seem overwhelming, particularly because many people have never heard of mito. You don't have to share your diagnosis, however it may be helpful to let loved ones know so that they can support you. Often people with mito have been unwell for a long time, so sharing your diagnosis can help others understand your symptoms. If you find it too overwhelming, you might like to ask a loved one to help you tell others or to tell others on your behalf.

AMDF can post you copies of the [Mitochondrial Disease Fact Sheet](#) or brochures for you to provide to family and friends to help them understand mito. AMDF also has resources for children to help them understand mito. You can download a copy of [A Little Book About Mito](#) from the AMDF website or request one to be posted to you.

A genetic diagnosis of mito has implications for family members, as the genetic changes that can cause mito often run in families. Before discussing your diagnosis with your relatives, it is important to consider how family members may be impacted by any results from a genetic test.

AMDF recommends speaking to a genetics counsellor to help you understand the implications for family members, and to support you in communicating this. Find out more about [genetic counselling](#).

5) HOW CAN I FIND OUT ABOUT AND GET INVOLVED IN RESEARCH?

Mitochondrial research is a rapidly growing field. AMDF has established the Australian Mitochondrial Disease Patient Registry (Mito Registry) to support the international research effort. This is a database which contains a limited amount of personal information about people with diagnosed or suspected mito.

Being part of the Mito Registry means that:

- You will have the earliest opportunity to find out about clinical trials and research in Australia.
- You will be helping AMDF and researchers understand the number of people with mito in Australia, what diagnosis they have and what type of mito they have.
- You will be supporting the effort to increase mito research in Australia by demonstrating to researchers that there is a patient community in Australia willing to take part.

You can join the Mito Registry [here](#) or by calling 1300 977 180.

6) WHAT SHOULD I CONSIDER WHEN THINKING ABOUT THE FUTURE?

Financial considerations

Mito can affect many aspects of a person's life including their finances. Some people with mito may need to reduce their working hours or stop working altogether, depending on their symptoms and the demands of their job. There may also be increased costs related to healthcare and management of symptoms for example medications, medical tests and supplements.

AMDF has information about government support including [Centrelink](#), the [National Disability Insurance Scheme](#) and [concessions](#) available to patients, parents, and carers.

You may also like to look into your options for life insurance and total permanent disability (TPD) insurance. If you are working, you may already have TPD cover through your superannuation fund. [Click here](#) to read Melissa's story about accessing her TPD when she was no longer able to work.

Advance Care Planning

When you feel ready, it can be a good idea to think about your wishes for future medical care and discuss these with your healthcare team and family members. An advanced care plan can guide the delivery of care that reflects your own personal health values, beliefs and preferences. Find out more about making health and medical decisions, including advance care planning [here](#).

Reproductive Options

Preconception genetic counselling is recommended for all couples where there is a diagnosis or family history of mito, to enable couples to make informed decisions about family planning. Depending on the genetic diagnosis, and the couple's individual preferences, reproductive options may include prenatal diagnostic testing, prenatal genetic diagnosis (PGD), or egg or embryo donation through in vitro fertilization (IVF). [Click here for more information](#).

Information contained in this document is intended for use as a guide of a general nature only. Individual advice should be sought from a patient's mitochondrial disease specialist. Please be aware that the AMDF support team are not medically trained and cannot offer medical advice.

FIRST STEPS GUIDE: REFERENCE LIST

1. What Should I ask my Specialist?

- Benefits of a Genetic Diagnosis Factsheet
<http://www.amdf.org.au/wp-content/uploads/2017/03/Benefits-of-a-Genetic-Diagnosis-of-Mitochondrial-Disease.pdf>
- Patient Care Standards for Primary Mitochondrial Disease
<http://www.amdf.org.au/patient-standards-of-care/>
- Mito Professionals Directory
<http://www.amdf.org.au/mito-professionals-directory/>

2. Where Can I Learn More about Mito?

- Scientific and Medical Advisory Panel
www.amdf.org.au/smap/
- Mitochondrial Disease Factsheet
www.amdf.org.au/wp-content/uploads/2017/03/Fact-Sheet-Mitochondrial-Disease-AMDF-March-2017.pdf
- Information booklet for Medical Practitioners
www.amdf.org.au/wp-content/uploads/2014/05/Mito-Medical-Info-Booklet-201405-web.pdf
- The Genetics of Mitochondrial Disease
www.amdf.org.au/wp-content/uploads/2018/03/The-Genetics-of-Mitochondrial-Diseases.pdf

3. How Can I Access Emotional Support?

- AMDF Facebook Group
www.facebook.com/groups/44299119727/
- AMDF Support Network
www.amdf.org.au/amdf-support-network/
- Mito Connect
www.amdf.org.au/amdf-support-network/

4. What should I tell family and friends

- Mitochondrial Disease Fact Sheet
www.amdf.org.au/wp-content/uploads/2017/03/Fact-Sheet-Mitochondrial-Disease-AMDF-March-2017.pdf
- A Little Book About Mito
www.amdf.org.au/parent-teacher-resources/
- Genetic Counselling
www.amdf.org.au/parent-teacher-resources/

5. How can I find out about and get involved in research?

- Mito Registry
app.etapestry.com/onlineforms/AUSTRALIANMITOCHONDRIALDISEAS/mitoregistry.html

6. What should I consider when thinking about the future?

- Centrelink
www.amdf.org.au/government-payments/
- NDIS
www.amdf.org.au/ndis/
- Concessions
www.amdf.org.au/state-concessions/
- Melissa's Story
www.amdf.org.au/melissa-armstrong-case-study/
- Advanced Care Planning
www.amdf.org.au/wp-content/uploads/2017/02/Making-health-and-medical-decisions.pdf