



FIRST STEPS WITH KIDS

Nothing can prepare you for your child receiving a diagnosis of mito. Those first few appointments can be extremely emotional and you may find it hard to absorb all the information you are given.

As a parent, you naturally want to seek the best course of action to find the best treatment plan for your child. This fact sheet can help to guide you in some of the first steps you may want to take after receiving a diagnosis and aims to help you develop a plan for the future.

EARLY INTERVENTION

Whilst there are currently no cures for mito, early intervention can make a big difference to your child's clinical outcomes and symptom management. Engaging in a multidisciplinary approach to your child's health can help keep their disease progression at bay.

Your GP should be able to provide you with guidance on everyday symptom management. Providing them with the [AMDf Information Booklet for Medical Practitioners](#) may help you with this process. You can access this resource online or the Mito Foundation can send you a copy in the mail. Contact the Mito Foundation to organise this. Your GP should also be able to refer you to a paediatrician who can guide you in symptom management.

The Australian Government Department of Social Services provides funding for early intervention for children of different age groups. An overview and further information about applying for funding can be accessed via their [Early Intervention Services and Supports](#) or [Early Intervention Services for Children with Disability](#) websites.

Some of the early intervention services you may want to consider include:

1. Physiotherapy (PT)/Exercise Therapy (ET)

Depending on your child's diagnosis and individual needs, PT or ET can provide many benefits to their physical and mental health. A qualified PT or ET professional can work with you and your family to tailor a plan that suits their individual needs. Intervening early can help make exercise fun for your child and help manage their symptoms. See your GP or specialist for a referral to a physio or exercise therapist.

2. Occupational Therapy (OT)

An OT is able to work with your family in assessing your child's home and learning environment and tailoring it to their needs. They can recommend and guide you and your child in the use of assistive devices and how to implement them. An OT will be able to help you enhance your child's skills in everyday life. See your GP or specialist for a referral to an Occupational Therapist.

3. Dietician/Nutritionist

Adequate nutrition is essential for the growth and development of any child. Children with mito will benefit from a diet that supports their mitochondrial function. A dietician or nutritionist can help you create a plan that will suit their individual needs, including allergy prevention and intolerances. See your GP or specialist for a referral to a dietician/nutritionist. Click [here](#) for a link to a Mito Foundation factsheet on nutrition and mitochondrial disease.

4. Speech Therapy

A speech therapist will work with your child to assist them in developing and improving their communication abilities. They may also be able to assess and guide you in any swallowing issues your child may have. See your GP or specialist for a referral to a speech therapist.

5. Supplements

As there are no specific or curative treatments, many variations of mito are responsive to a combination of supplements. A combination of these supplements is sometimes referred to as the "Mito Cocktail" and is a unique combination of supplements that are dependent on your child's diagnosis and symptoms. Your GP or specialist should be able to give you more in-depth information on which supplements are right for your child. For more information on supplements, click [here](#).

"I can't stress how important early intervention has been for our family, particularly physio, speech therapy, occupational therapy and also very early medical intervention when my child is unwell. These have been an amazing help in keeping my child's disease at bay and giving him the best quality of life possible."

- Belinda, mother of Alex (age 4)

SHARING YOUR CHILD'S DIAGNOSIS WITH FAMILY AND FRIENDS

Sharing your child's diagnosis with family and friends is a personal choice. If you do decide to share this information with those in your support network, it can be difficult to explain what a diagnosis of mito means for your child's future health. The Mito Foundation can provide you with resources to make this process easier. The [Medical Information page](#) on the Mito Foundation website can be a good place to direct people to in order to facilitate their understanding, so you don't have to be the one to explain the medical terminology.

The Mito Foundation can also send you its Information Pack which includes the [Mitochondrial Disease Fact Sheet](#), a great resource in providing an overview of what it means to have mito. You can use the resources in this pack to give to others to read, if you don't feel up to explaining the details yourself. Telling your support network as a group can ease the process and ensure you can explain all the relevant information at the one time. You may want to ask that people save any questions they may have for a later time when you feel ready to answer, so you don't become overwhelmed.

“My family was very up to date with our journey, however we didn't explain possible diagnoses with them as they didn't really understand what Aidan had. The first thing I did was go to the Mito Foundation website and sent the link to medical information to my whole family. My mum gathered my siblings together so I could tell them at the same time. I asked that they leave any questions about Aiden's diagnosis and prognosis until later on. I just wanted them to listen. I did not want to have to help them through their grief whilst things were so raw for me”

- Belinda, mother of Alex (age 4)

TALKING TO YOUR CHILD ABOUT MITO

The best way to talk to your child about their diagnosis will differ depending on their age and stage of development. To gain insight into the best way to approach your child at their developmental level, your family may consider seeking the advice of a family counsellor. Your GP should be able to refer you to a counsellor who specialises in patients with chronic illnesses. If you have a younger child, the Mito Foundation “Little Book of Mito” is a great way of explaining mito in a child-friendly way. Click [here](#) for an online copy or contact the Mito Foundation to get one sent out to you.

GENETIC COUNSELLING

If you are planning on expanding your family in the future, you may want to consider looking into genetic counselling. A genetic counsellor can provide you with support and information on the process of genetic testing and the implications of the results on your future decisions.

Your genetic counsellor may work as part of a multidisciplinary team and be able to give you further insight into reproductive options. Click [here](#) for more information on genetic counselling.

SUPPORTING YOUR CHILD AT SCHOOL

School can be challenging for any child, particularly those suffering from mito. In order to support your child in having a positive school experience, you may want to inform the school of their recent diagnosis of mito.

Each school will differ in their understanding of chronic illnesses and most will not have had a student with mito before. Providing a letter to the school is a great way

of keeping this information on their record and ideally preventing you from explaining your child's condition to every teacher.

You may also want to provide a medical plan to your child's school that they are able to implement if your child becomes unwell at school. This medical plan should be constructed with the assistance of your child's specialist or GP. Your child's school should have a Support Officer who is responsible for managing student welfare and this is a great person to get in touch with for more in-depth advice. Click [here](#) for the Mito Foundation's [Parent and Teacher Resources](#).

COPING STRATEGIES AND EMOTIONAL SUPPORT

The way you and your family cope with the diagnosis of your child will differ for every individual. Whilst your child will require emotional support, taking care of your own emotional and physical health is essential in helping you cope with your situation.

A counsellor, psychologist or social worker will be able to provide you with coping strategies and provide advice for how to best support your child and other family members. If you ever feel like you're struggling with your situation and it's all too much, there are organisations that are able to provide you with further support in times of crisis. Access information about these [here](#).

The Mito Foundation also provides support services for you and your family to gain information and advice about mito. Click [here](#) for more information on support services.

“The way you cope will be different for every family. In many ways you just have to roll with the highs and the lows. Celebrate achievements as much as you can – even if they are small. No achievement is small when dealing with mito. For our son, doing everyday things takes much more time for him than his peers. You learn to be patient and not to worry about what others may be thinking. You plan things in advance, and have sheets of medical and sick day plans to take on holidays and to give to school and carers. Using apps and technology to keep track of medications and supplements is a good way to help you stay in control. When you live with mito, you need to learn to accept and seek help. Seeking counselling early on after a diagnosis is extremely important in helping you understand you are not alone. Although you may feel like you have to be superhuman to help your loved one, you aren't. You need to be as kind to yourself as you can be”

- Belinda, mother of Alex (age 4)

EQUIPMENT

Children with mito can have special needs with regards to assistive equipment. You may want to consider aids and devices for your children if necessary that suit their individual needs. Various organisations can provide your family with funding that enables you to access these resources. [Variety Children's Charity](#), and the [Steve Waugh Foundation](#) can provide financial support for equipment.

Individual State Health Services will differ with regards to their funding for medical devices. Click on your state below for a link to their policy.

- [Western Australia](#)
- [Victoria](#)
- [Tasmania](#)
- [South Australia](#)
- [Queensland](#)
- [Northern Territory](#)
- [New South Wales](#)
- [Australian Capital Territory](#)

The Mito Foundation also facilitates an equipment exchange program that allows community members to donate or sell equipment. This can be a good place to find equipment at a more affordable price. Click [here](#) for a link to the exchange page.

For more information about how to manage your first steps with mito, click [here](#). For more information on the Mito Foundation support services and patient resources, call the Mito Foundation Helpline on 1300 977 180 or email helpline@mito.org.au

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.

REFERENCE LIST

Early Intervention

1. AMDF Information Booklet for Medical Practitioners:
www.amdf.org.au/wp-content/uploads/2014/05/Mito-Medical-Info-Booklet-201405-web.pdf
2. Early Intervention Services & Support:
www.dss.gov.au/our-responsibilities/disability-and-carers/program-services/for-people-with-disability/overview-of-early-intervention-services-and-supports
3. Early Intervention Services for Children with a Disability:
www.dss.gov.au/our-responsibilities/disability-and-carers/program-services/for-people-with-disability/early-intervention-services-for-children-with-disability
4. Nutrition for Mitochondrial Disease:
www.amdf.org.au/wp-content/uploads/2017/03/Nutrition-for-Mitochondrial-Disease.pdf
5. Supplements & Mitochondrial Disease:
www.amdf.org.au/wp-content/uploads/2017/03/Supplements-in-Mitochondrial-disease_Dr-Christina-Liang.pdf

Talking to your child about Mito

1. A Little Book about Mito:
www.amdf.org.au/wp-content/uploads/2017/03/A-Little-Book-About-Mito-for-print_24042017.pdf

Genetics Counselling

1. Genetic Counselling for Mitochondrial Disease:
www.amdf.org.au/wp-content/uploads/2017/03/Genetics-Counselling_Fact-Sheet.pdf

Supporting your Child at School

1. Parent & Teacher Resources:
www.amdf.org.au/parent-teacher-resources/

Coping Strategies and Emotional Support

1. Third Party Support:
www.amdf.org.au/third-party-support/
2. Support Services:
www.amdf.org.au/support-services/

Equipment

1. Variety Children's Charity:
www.variety.org.au/qld/how-we-help/support-programs/
2. Steve Waugh Foundation:
www.stevewaughfoundation.com.au/
3. Western Australia Equipment Funding:
www.disability.wa.gov.au/services-support-and-eligibility/services-supports-and-eligibility-new/services/services-provided-by-the-commission/equipment-and-technology/community-aids-and-equipment-program-caep-/
4. Victoria Funding:
<https://services.dhhs.vic.gov.au/aids-and-equipment>
5. Tasmania Funding:
www.dhhs.tas.gov.au/service_information/services_files/RHH/treatments_and_services/tasequip
6. South Australia Funding:
www.des.sa.gov.au/
7. Queensland Funding:
www.health.qld.gov.au/masshttp:
8. Northern Territory Funding:
<https://nt.gov.au/wellbeing/disability-services/disability-equipment/apply-for-disability-equipment-program>
9. New South Wales Funding:
www.enable.health.nsw.gov.au/services/aep
10. Australian Capital Territory Funding:
www.health.act.gov.au/our-services/rehabilitation-aged-and-community-care/oxygen-and-equipment-services
11. Mito Community Equipment Exchange:
www.amdf.org.au/community-equipment-exchange/