



# SUPPORTING YOUR CHILD AT SCHOOL: MITO COMMUNITY TOP TIPS!

## MANAGING THE SCHOOL DAY

### Managing Fatigue

Almost every child with mitochondrial disease (mito) will experience fatigue. Your child may find it difficult to finish their schoolwork or may zone out during class. Making a plan for your child's fatigue with their teacher is essential to helping them get the most out of their day. Organising an area in the classroom where they can rest will help children have a break and return to their work refreshed. This space could include pillows or even a tent, so they are removed from sensory input to fully relax.

If your child finds sitting on the floor painful and difficult, work with the teacher to ensure there are comfortable pillows or a chair available. It can be helpful to make sure these alternatives are planned for when children sit on the floor for long periods, such as school assemblies. They may need to be taken for a walk or sit on a chair, so they can participate. Sometimes having an Occupational Therapist (OT) review your child in the classroom can provide strategies for them to get the most out of their day.

### Nutrition

Making sure they have regular snacks with good nutritional content can make a difference to how they manage their fatigue and workload. Most schools will have regular food breaks throughout the day and supplying the right food at this time is essential. Your child may benefit from more substantial snacks such as full fat yoghurt, cheese, milk or snack-sized deli meats. Communicating these needs with their teacher and explaining the benefits to your child may enable them to facilitate this throughout the day as they see your child's energy levels dropping. You can teach the teacher how to notice when their energy levels are dropping and when they might consider providing an extra snack.

### After School Activities

Although most primary school-aged children are keen to keep up with their peers and attend after school activities such as sports, it's important to consider the effect that this will have on their health and energy levels. Liaising with your specialist to find the right plan for your child is essential. This may mean involving a physiotherapist or an exercise therapist and really observing the way your child responds to these activities to work out the right plan for them.

## COMMUNICATING WITH YOUR CHILD'S SCHOOL

If your child requires alterations to their school day, it's essential to communicate this to the school. Most Australian schools will be able to implement a plan such as an *Individual Education Plan* or a *Negotiated Education Plan* to support children with additional learning needs and ensure their equal participation in the school day. It's a good idea to bring along a support person when attending these meetings. This person could be a family member, friend or someone provided by a service such as the National Disability Insurance Agency (NDIA). The plan should include a description of your child's diagnosis, their symptoms, where more information can be accessed in addition to any accommodations your child requires during the day. It's a great idea to make sure there's a formal document in place which covers necessary communication between yourself and the school, for example circumstances in which the school must contact you.

The Mito Foundation has online resources such as fact sheets on how to communicate with your child's school, [click here](#) for the link to our school education resources.

## CHANGES TO ROUTINE

Changes to your child's routine may be difficult to manage as some activities may increase their fatigue and affect their health for the following period of time. Having a plan around any significant changes can help maintain your normal routine.

**Sports Days:** Athletics, swimming carnivals and other sports days may involve strenuous activity which can leave children with mito feeling sick, exhausted and isolated from their peer groups. Plans can be made for younger children to start races closer to the finish line so they can still participate. If sports days leave your child feeling unwell and fatigued for days afterwards, you might consider talking to them and the school about other ways they can participate.

**Excursions:** Make sure you speak with the school about your child's requirements for out of school excursions where they might require lots of energy i.e. walking for long distances. There may need to be provision for physical assistance such as mobility strollers or wheelchairs. If children are required to walk to the excursion venue, it can be arranged to drop your child off from school. Make sure the chaperone takes some high energy snacks to hand out throughout the journey.

It may be difficult for your child to understand why they need special considerations for activities their peers are able to do. It's important to have a conversation in your own way about why it's OK for them to be different. If your child is struggling emotionally and feeling isolated from their peers, it's essential to get assistance developing strategies for managing their emotional and mental health. Accessing an organisation like [Headspace](#) can provide early intervention mental health services to young people and their families for little to no cost.

## MEDICAL PLAN

Making a plan for your child's medical care at school can help put your mind at ease. It can be helpful to put together a document for the school outlining any relevant medical contact details, such as their family doctor or specialist, information about their diagnosis and what to do in certain medical situations.

Make sure you explain to the school what to do if your child becomes acutely unwell. Explain the process and how to recognise their deterioration. You may need to do this individually with each teacher or as a group depending on the school's process. Explain that any medical emergency, even one that isn't a direct result of the child's illness, should still result in the involvement of the relevant medical contacts. Including a letter from your specialist can be very helpful in conveying your child's needs.

It's important to explain that your child is immunosuppressed and how serious the implications of common illnesses, such as the flu, are for their health and wellbeing. Some schools may also be willing to pass this communication to other students' parents to explain that sending their children to school when sick can be potentially dangerous for your child.

## SELF-CARE

It's not uncommon to feel drained and burnt out as a parent caring for a young child with a chronic illness. It's essential to practice self-care in order to maintain your own physical, emotional and mental health and wellbeing to be the best possible parent to your child.

Some suggestions for managing stress and practising self-care can come from a GP referral to a counsellor or the Mito Foundation's Support Network or Mito Connect program. Through these services, you can be put in touch with other parents in the community. This can reduce the sense of isolation and allow you to share ideas about managing your child's care.

*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.*