

# Mitochondrial Disorders



**Mitochondrial disorders arise from genetic mutation of the mitochondria (the parts of the cells that produce energy for cell function). Almost any tissue can be affected. The ones most commonly affected are those with the highest energy demands, such as the heart, central nervous system, eye, stomach and skeletal muscles. Particular syndromes may be accompanied by a cluster of clinical symptoms. The most common symptoms are seizures, fatigue, cardiac complications and gastrointestinal symptoms, including frequent vomiting. Mitochondrial disorders range in severity, from very mild to severe.**

## Implications for Planning and Awareness

- Meet with the student and parents early in the school year to discuss how the school can support this student's needs related to Mitochondria. This could include finding out about:
  - the student's strengths, interests and areas of need
  - the student's specific symptoms
  - successful strategies used at home or in the community that could be used at school.
- In collaboration with parents and health care professionals, develop a written management plan that aligns with related jurisdictional policies and protocols. This plan should include specific information, such as:
  - symptoms that may affect the student at school and may require monitoring
  - the role of school staff
  - equipment and environmental modifications
  - when and what emergency measures should be taken.
- If the student is taking medications during the school day, discuss with the parents possible side effects. Follow school and/or jurisdictional policies and protocols in storing and administering medication.
- Collaborate with the parents and student to consider if, and how, they would like to share specific information on Mitochondrial disorders with peers. If they wish to do this, consultation with health care providers, such as school or community health nurses, may be helpful.
- Learn as much as you can about how this condition may affect learning and social and emotional well-being. Reading, asking questions and talking to qualified professionals will build your understanding and help you make decisions to support the student's success at school.
- Collaborate with the school and/or jurisdictional team to identify and coordinate any needed consultation and supports.

Your awareness needs to begin with conversations with the student's parents.



- Determine and arrange for any equipment or classroom modifications that might be needed. This may include accommodations for mobility equipment (e.g., wheelchairs, standing frames, walkers), supportive seating, supportive toilet seats and/or mechanical lifts.
- Make arrangements for the student to avoid heat and cold (if this is an issue). This may impact recess, as well as activities where students have to leave the school (e.g., field trips, fire drills).
- Determine if any changes to school timetables or schedules will have to be made to accommodate the student's equipment and/or travel time from class-to-class.
- Develop a system for sharing information with relevant staff members about the student's condition and successful strategies.

### Implications for Instruction

- Provide supports and accommodations, as needed, to manage any cognitive, visual or hearing impairment the student may have. Consult with a teacher of the deaf and hard-of-hearing or a teacher of the visually impaired, if needed.
- Be aware that students with Mitochondrial disorders may have numerous absences due to medical appointments, or treatments, or fatigue.
- Develop a communication strategy between the home and school to stay informed about absences, and to keep the student and family connected to classroom learning.
- Seat the student in the classroom with thought given to any hearing or vision difficulties.
- Schedule breaks, as needed, throughout the day to help the student cope with fatigue and to allow for frequent small meals.
- Consult with an adapted physical education specialist or physical therapist, as required.

### Implications for Social and Emotional Well-being

- Engage the student and parents in planning for transitions between grade levels and different schools.
- Consider having a “key person” the student can check in with on a weekly (or daily basis) to assist with any planning, self-monitoring and/or problem solving that may arise.
- Take steps to ensure the student does not feel left out during recess, intramural or other school activities; for example:
  - provide an alternative role, such as referee during physical education or intramural activities
  - provide alternative activities during recess, such as a friendship bench to sit on and meet with peers.
- Recognize that the student may have dietary restrictions (e.g., avoiding MSG). Help the student feel included in the classroom by considering this when foods are served for special events or brought into the classroom.
- Encourage peers to engage the student in activities on the playground that require limited physical demands.

Parents know their children well and can offer insights on how to support their social and emotional well-being. There is strength in collaborating on strategies that could be used at home, at school and in the community.



**As you consider the implications for this medical condition, think about the following questions:**

1. Do I need further conversations with the parents to better understand this student's medical needs?  Yes  No
2. Do I need targeted professional learning?  
If yes, what specific topics and strategies would I explore?  Yes  No
3. Is consultation with jurisdictional staff required?  
If yes, what issues and questions would we explore?  Yes  No
4. Is consultation with external service providers required (e.g., Regional Educational Consulting Services, Student Health Partnership, Alberta Children's Hospital, Glenrose Hospital)?  
If yes, what issues and questions would we explore?  Yes  No
5. Is service to the student from an external provider required?  Yes  No  
If yes, what outcomes would be anticipated?

**Links for further information:**

Mito Action. About Mitochondrial Disease – Mito FAQ. <http://www.mitoaction.org/mito-faq>  
United Mitochondrial Disease Foundation. <http://www.umdf.org/>

**Please note:**

These websites are for information only and the user is responsible for evaluating the content and appropriate uses of the information.

