

Marfan Syndrome



Marfan syndrome is a rare hereditary disorder that affects the connective tissue in many body systems, including the skeleton, eyes (symptoms may include glaucoma or detached retina), heart and blood vessels, nervous system, skin and lungs. Individuals with Marfan syndrome are typically very tall, slender and loose jointed. Marfan syndrome can cause a number of complications that may require medical attention, including breathlessness and chest pain (and in some cases spontaneous collapse of the lungs), dislocation of knees and shoulders, and sudden changes or disturbances in vision, including painful eyes.

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 Marfan syndrome. 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 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.
- Work with the parents to carry out a risk assessment before field trips to check for steep hills, stairs or other potential hazards, and to plan for the student's safe and successful participation.
- Collaborate with the parents and student to consider if, and how, they would like to share specific information on Marfan syndrome 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 Marfan syndrome 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.

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



- Collaborate with the school and/or jurisdictional team to identify and coordinate any needed consultation and services, such as physical or occupational therapy.
- 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.
- 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

- Talk and smile within the student's comfortable viewing distance, as recognizing facial expressions can often be difficult.
- Make accommodations for vision difficulties, as needed, such as sitting the student at the front of the class and using large print if the student's vision is impaired.
- Provide adapted tools and materials (e.g., slant boards, adapted writing paper and pencils, large print books, specialized computer software, low vision aids).
- Adjust desk height and seating to make the student comfortable and safe.
- Encourage the student to use prescription glasses or contact lenses throughout the school day.
- Encourage the student to wear a hat or sunglasses in class if bright light causes discomfort or vision problems.
- Provide additional time for transitions between classes, particularly in large schools. A trolley may assist in transporting books, laptop computers or other heavy items from room-to-room.
- In collaboration with the student and parents, discuss the appropriate level and types of physical activity for the student. Alternatives to regular physical education may need to be considered.
- Be cautious of the student's involvement in contact sports due to the danger of retinal detachment.

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" or mentor the student can check in with on a weekly (or daily basis) to assist with any planning and/or problem solving that may arise.
- Provide clear expectations, consistency, structure and routine for the entire class. Rules should be specific, direct, written down and applied consistently.

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.



- 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.

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 strengths and needs? Yes No
2. Do I need targeted professional learning? Yes No
If yes, what specific topics and strategies would I explore?
3. Is consultation with jurisdictional staff required? Yes No
If yes, what issues and questions would we explore?
4. Is consultation with external service providers required (e.g., Regional Educational Consulting Services, Student Health Partnership, Alberta Children’s Hospital, Glenrose Hospital)? Yes No
If yes, what issues and questions would we explore?
5. Are further assessments required to assist with planning for this student? Yes No
If yes, what questions do I need answered?
6. Is service to the student from an external provider required? Yes No
If yes, what outcomes would be anticipated?

Links for further information:

Genetic Aortic Disorders Association Canada. Marfan Syndrome.
<http://www.gadacanada.ca/marfan-syndrome/>
National Marfan Foundation. “Resources and Answers: Patients and Families.”
<http://www.marfan.org/resources/patients>

Please note:

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

