



# *Loeys-Dietz Syndrome School Packet*

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Dear Parents and Students,

This school packet is meant to maintain regular communication between you and the educational and social institutions serving your family in regards to how the student is coping at school and at home. It is intended to present relevant information about Loey-Dietz Syndrome (LDS) that should be shared with the appropriate school staff.

The packet contains an area for you to enter important information and emergency contacts. It can be used in conjunction with a doctor's note or a personal note from you for more detailed information that is specific to your child. It is our hope that this will alleviate some of the discomforts of explaining a syndrome as complex as LDS.

Families often ask "how much information is necessary and who needs to know about the diagnosis?" This is an individual choice, but we do recommend that school settings, day care, and others who spend significant time caring for your child know about the diagnosis. They might not need to know all of the details, but it is necessary that they have basic information in case of an emergency. Thus, portions of this packet (including emergency symptoms and instructions) should be copied and given to institutions and those who care for your child. Otherwise, please make changes as necessary for your child's situation.

To get the most of their schooling, students with LDS need ongoing and coordinated support from their families, schools, and medical carers. In Canada, inclusive education is a mandate as it is prohibited to discriminate against children with disabilities. In fact, many provinces and territories have achieved inclusion through Individualized Education Plans (IEPs). IEPs identify the student's specific learning expectations and outlines how the school will address these expectations through appropriate accommodations, program modifications and/or alternative programs as well as specific instructional and assessment strategies. Therefore, it is our desire that every child or adolescent have full access to a rich educational environment and at the same time, is able to easily access the special accommodations that may be needed to allow them to be successful in their educational setting.

We hope you find this to be a helpful tool.

# Letter to the School

Date:

RE:

Dear Educator:

{Student first name, last name} has been diagnosed with Loeys-Dietz syndrome (LDS). The following packet of information is intended to share information, develop a care plan, and keep up good communication between {Student name}, our family and the school. Within this packet, you will find emergency care information for our child, general information and guidelines, accommodations, and extra support.

Thank you for taking the time to familiarize yourself with Loeys-Dietz syndrome on behalf of {Student name}. As a student at your school, {his/her} health should be kept in mind. However, while {he/she} may have some limitations or may need some special assistance in school, {he/she} should be encouraged and supported to fully engage in your school system.

Some children need special accommodations in the classroom setting in order to be successful. We encourage our child to be honest and open about {his/her} needs and any requested support.

Our hope is that our child will be provided the best learning environment in order to empower {him/her} to lead a full and rewarding life during the school years.

If you have any questions about {Student name} or LDS, please don't hesitate to contact us. We look forward to working with you this school year.

Sincerely,

Parent/Guardian Name: \_\_\_\_\_

Parent/Guardian Phone #: \_\_\_\_\_

Parent/Guardian Email: \_\_\_\_\_

# *Inclusive Education in Canada: Know Your Rights*

Canada does not have a national office of education, unlike the United Kingdom and the United States. Instead, each province has the authority to make its own laws concerning education by having an act that governs education in its elementary and secondary schools. Teachers need to become familiar with the laws and policies that govern education in their province or territory.

The Education Act sets in law the powers and responsibilities of the Minister of Education and School Boards, the authority of principals and teachers, and the rights and responsibilities of parents and students.

While inclusion is a part of educational policy in all of Canada's provinces and territories, each province and territory differs in their definition of inclusion:

- **Alberta:** A way of thinking and acting that demonstrates universal acceptance of, and belonging for, all children and students.
- **British Columbia:** The principle that all students are entitled to equitable access to learning, achievement, and the pursuit of excellence in all aspects of their educational programs.
- **Manitoba:** Providing all students with the supports and opportunities they need to become participating members of their school communities.
- **New Brunswick:** A pairing of philosophy and pedagogical practices that allow each student to feel respected, confident and safe so he or she can learn and develop to his or her full potential.
- **Newfoundland:** A philosophy that promotes the right of all students to:
  - attend school with their peers;
  - receive appropriate and quality programming and a continuum of supports and services in the most appropriate setting (large group, small group, individualized) that respects the dignity of the child;
  - experience a welcoming school culture where all members of the school community feel they belong, realize their potential, and contribute to the life of the school;
  - enter a school atmosphere which respects and values the participation of all members of the school community;
  - have a school community which celebrates diversity and is safe and caring.

- **Northwest Territories:** A welcoming and safe common learning environment where all students can learn with their age-appropriate peers.
- **Nova Scotia:** A commitment to ensuring a high-quality, culturally and linguistically responsive, and equitable education to support the well-being and achievement of every student.
- **Nunavut:** Adjustments to the education programs and supports to meet learning needs so students can participate in all aspects of school life and have equal access to an appropriate education program that is inclusive and age-appropriate.
- **Ontario:** Education that is based on the principles of acceptance and inclusion of all students.
- **Prince Edward Island:** When all students attend and are welcomed into their neighbourhood schools in age-appropriate, regular classes and are supported to learn, contribute, and participate in all aspects of the life of the school. When principals, teachers, parents, students, and others work collaboratively to provide a quality education in an inclusive environment.
- **Quebec:** A classroom and school where every child is accepted and supported throughout their education regardless of their diverse learning needs.
- **Saskatchewan:** A needs-based model focused on the strengths, abilities, and needs of individual students.
- **Yukon:** A student-centred approach in which students' strengths and challenges are central to decision-making.

There is one national legislation that has an impact on education across Canada: *The Canadian Charter of Rights and Freedoms*, which is part of the Constitution. Section 15.1 of the Charter outlines the equality provisions that apply to education:

*Every individual is equal before and under the law and has the right to equal protection and equal benefit of the law without discrimination and, in particular, without discrimination based on race, national or ethnic origin, colour, religion, sex, age, or mental or physical disability.*

## **Individualized Education Program (IEP)**

Each student with exceptional learning needs must have an educational program tailored to his or her unique needs. The individualized education program (IEP) is written by a team that includes the student's teacher(s), a qualified school psychologist or special education supervisor, the parent(s) or guardian(s), and (when possible) the student. The program should be reviewed and updated each year and should address the following issues:

1. The student's present level of functioning;
2. Goals for the year and short-term, measurable milestones that help the student progress towards their yearly goals;
3. A schedule detailing how the student's progress towards milestones and goals will be evaluated;
4. A list of specific services to be provided to the student and details of when those services will be provided;
5. A description of the extent to which the student will participate in the general education program;
6. Beginning at the age of 16 (and as young as 14 for some students), a statement of needed transitional services to move the student toward further education or work in adult life.

The Ontario Ministry of Education posts [sample IEPs](#).

# Loeys-Dietz Syndrome: General Information

## What is Loeys-Dietz Syndrome (LDS)?

Loeys-Dietz syndrome (LDS) is a genetic disorder of connective tissue that was identified and named in 2005. At that time doctors realized that even though LDS has some features of other connective tissue disorders, it is a distinct disorder. The other disorders that share features with LDS include Marfan syndrome, VEDS (Vascular Ehlers-Danlos), and Shprintzen-Goldberg syndrome.

LDS is characterized by aneurysms of the aortic root (part of the aorta closest to the heart) and throughout the arterial tree, tortuous (twisting) vessels, hypertelorism (widely spaced eyes) and uvula (piece of flesh that hangs in the back of the mouth) abnormalities.

A vast variety of other craniofacial (head and face), skeletal, skin and cardiac findings have also been described, but because Loeys-Dietz syndrome manifests itself in a number of ways, people with LDS do not have identical medical characteristics.

All those diagnosed with Loeys-Dietz syndrome are at significant risk for dissection and rupture of arteries at sizes that are not thought to be dangerous to the general population or to those with other connective tissue disorders. All individuals with LDS require echocardiography at frequent intervals to monitor the status of the aortic root, ascending aorta, and heart valves. Surgical repair of the aorta is performed long before the individual is deemed to be at high risk for aortic tear or rupture.

A subset of patients have orthopedic concerns, including clubfoot or flat feet, scoliosis, or cervical spine instability that are being medically monitored. The student may have had surgery, braces, and/or limitations to address these problems.

Additionally, a subset of patients have gastrointestinal complaints, including food allergies which affect the foods LDS individuals should be exposed to. Gastrointestinal and allergic concerns can include food allergies leading to allergic responses and/or intestinal concerns including bloody stool, bowel impaction,

abdominal pain and, in rare cases, intestinal or other hollow organ rupture has been reported. Some children have G-tubes for feeding.

Learning problems are not a typical finding in Loeys-Dietz syndrome. However, due to joint laxity, some individuals may have some increased difficulty with balance and fine or gross motor skills. Due to joint laxity or gastrointestinal concerns, a child may have faster fatigue than other students.

In most cases the student should be considered to be at a low risk for a serious event and should be encouraged to participate in school activities to the extent of their ability.

In the event that this student should present with any of the following characteristics his/her emergency contact(s) should be notified immediately and contacting the local emergency room should be considered.

- weak or unusual blood pressure
- severe pain in the head, neck, abdomen or down the back
- weakness of the limbs
- symptoms of a stroke
- dizziness
- loss of consciousness
- shortness of breath and/or difficulty breathing or speaking
- vision disturbances

**Emergency services should be notified that the student has Loeys-Dietz syndrome and is at increased risk for tears of the arteries throughout the arterial tree (head through pelvis) and that imaging (CTA/ MRA or echo cardiogram) should be done promptly. Rarely, rupture or tear of hollow organs (spleen, intestines) may need to be investigated.**

**In the event of an allergic response, Benadryl should be the first line of defense as an Epi-Pen can dramatically increase blood pressure. If an anaphylaxis reaction is occurring, an Epi-Pen to treat allergic response should be used.**

To read more about the characteristics, treatment, diagnosis, and genetics of Loeys-Dietz syndrome, visit our website at [www.loeysdietzcanada.org](http://www.loeysdietzcanada.org).

### **How is LDS diagnosed?**

LDS is a genetic condition, and is diagnosed through medical features and a genetic test.

### **How is LDS managed?**

Students with LDS are under the care of multiple specialists for cardiovascular, vascular, ENT, orthopedics, nutrition, allergic and/or gastrointestinal concerns. They may need to attend appointments for monitoring their symptoms and imaging. Students with LDS may also need physical therapy to treat cervical spine instability.

It is likely this student is on medications to lower blood pressure and heart rate to lessen the strain on body's major arteries as well as treat other symptoms. These may be taken during the school day.

Sometimes, a vascular surgery is needed to prevent the rupture of an aneurysm, in which the student may need to miss school until fully recovered.

### **How does LDS affect education?**

Because of the complexity of the disorder, the student may have absences due to sickness and medical appointments. In order for the student to be successful with their education they may need hospital home bound education at various times.

We thank you in advance for your support and understanding. The student should be held to the same accountability of getting assignments finished even throughout absences when correct accommodations are in place.

Dietary and exercise restrictions may come into play depending on the individual student.

### **What should you do if your student's behaviour changes?**

If teachers or administration have concerns regarding a change in mood or ability, it is important to communicate with the student's family.

# Loeys-Dietz Syndrome: Exercise Restrictions

## General Information

The main goal of restricting the activity of those diagnosed with Loeys-Dietz syndrome (LDS) is to reduce the amount of stress imposed upon the heart and arteries in order to lower the risk of aneurysm growth.

An individual with LDS should be encouraged to remain active with cardiovascular activities that work naturally to lower blood pressure and heart rate and that promote cardiovascular health over the lifespan.

There needs to be frank communication with the student, family and teacher regarding the requirements and intensity of PE to ensure safe student participation

If the student can maintain normal conversation during activity, this is a good indicator that activity is in a safe range.

## Activities that should be avoided

**IT IS A GENERAL RULE TO RECOMMEND THAT THOSE DIAGNOSED WITH LOEYS-DIETZ SYNDROME AVOID:**

- a sustained heart rate of above 140 beats per minute
- exercises that involve straining any muscle group to the point of exhaustion – *vigorous* dynamic (aerobic/anaerobic) and static (isometric) exercise
- heavy weight training and resistance training

**DISCOURAGED ACTIVITIES INCLUDE, BUT ARE NOT LIMITED TO, THE FOLLOWING:**

- competitive exercise performed to the point of exhaustion
- running sprints

- rowing
- strenuous contact sports where there is a high risk of a sharp blow to the body
- isometric exercise (including fitness tests) that involves muscle straining such as weight lifting, pushups, chin ups, rope climbing, sit ups and other activities in which a muscle group is brought to exhaustion
- tumbling and gymnastics due to the risk of cervical spin instability

### Activities that should be encouraged

In LDS, the systolic blood pressure should be lowered to 100mmHg at rest and 120 mmHg on exertion. However, overall, the target blood pressure should always be < 130/80 mmHg. Routine activities in PE programs that encourage **moving performed for fun and in moderation as part of a healthy lifestyle** should be encouraged. These activities naturally lower heart rate and blood pressure over time.

In most circumstances those diagnosed with Loeys-Dietz syndrome are encouraged to participate to the extent of their abilities in any activity that involves movement in the absence of muscle straining or a sustained elevation of blood pressure or heart rate.

If there are questions or concerns about PE activities, please provide the family with an outline of activities that they can get reviewed by their cardiologist for approval.

### ENCOURAGED ACTIVITIES INCLUDE, BUT ARE NOT LIMITED TO, THE FOLLOWING:

- moderate and light aerobic exercise performed in moderation, such as swimming, biking, hiking, jogging and tennis, etc.

## Participation

When participation in physical education is inappropriate, every effort should be made to maximize the potential of the student by allowing them to explore other endeavors. Simply sitting on the side lines may cause a disturbance in their educational and social development and is not a viable option.

# School and LDS: Forms

## GENERAL MEDICAL INFORMATION – FOR STUDENTS WITH LOEYS-DIETZ SYNDROME

Name: \_\_\_\_\_ Date of Birth: \_\_\_\_\_

Primary Emergency Contact: \_\_\_\_\_ Relationship: \_\_\_\_\_

Phone: \_\_\_\_\_ Alternate phone: \_\_\_\_\_

Secondary Emergency Contact: \_\_\_\_\_ Relationship: \_\_\_\_\_

Phone: \_\_\_\_\_ Alternate phone: \_\_\_\_\_

Allergies: \_\_\_\_\_

\_\_\_\_\_

Medications: \_\_\_\_\_

\_\_\_\_\_

Primary Physician: \_\_\_\_\_

Phone: \_\_\_\_\_ Alternate phone: \_\_\_\_\_

Office/Address: \_\_\_\_\_

Specialist: \_\_\_\_\_ Specialty: \_\_\_\_\_

Office/Address: \_\_\_\_\_

Specialist: \_\_\_\_\_ Specialty: \_\_\_\_\_

Office/Address: \_\_\_\_\_

Current Medical Status / Concerns / Notes / Emergency Information:

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

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## EMERGENCY INFORMATION – FOR STUDENTS WITH LOEYS-DIETZ SYNDROME

Name: \_\_\_\_\_ Date of Birth: \_\_\_\_\_

Emergency contact(s): \_\_\_\_\_

Relationship(s): \_\_\_\_\_

Phone: \_\_\_\_\_ Alternate phone: \_\_\_\_\_

Allergies:

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# School and LDS: Accommodations

Name: \_\_\_\_\_ Date of Birth: \_\_\_\_\_

ACCOMODATIONS THAT MAY BE NECESSARY FOR OUR CHILD TO BE SUCCESSFUL IN THEIR EDUCATION ARE AS FOLLOWS:

## Physical Education / Sports Needs

- Modified physical education or alternative health related credit in lieu of PE
- Restrict contact sports
- Restrict tumbling or other activities that place strain on the neck or back
- Cardiovascular activities should be performed in moderation (running, swimming, etc.)
- Avoidance of isometric exercises
- Avoidance of heavy lifting
- Use of splints and strapping as appropriate adjustments during physical activity

## Hallway / Classroom Needs

- Rest periods in the middle of the day for fatigue
- Periods of stretching or walking
- Two sets of books, one for home, one for school (to avoid heavy lifting)
- Preferential seating
- Allow use of a chair or pad instead of floor for circle time
- Use of elevators
- Allow passes for frequent bathroom breaks
- Allow use of book bag on wheels
- Help with note taking or use of laptop
- Provide copies of study guides or class notes
- Allow intake of medications. Ensure there are extra in the classroom if needed
- Extra time to get to and from class (leaving before the bell, if needed)
- Extra time for timed/standardized tests, classroom tests/quizzes, and assignments
- Chunking assignments and schoolwork

- Eliminate handwriting grade in favor of grades for content and effort
- Lockers – assign locker at eye level, allow digital lock instead of combination lock
- Worksheets: provide copies that allow fill-in-the-blanks or underlining in lieu of rewriting existing questions/sentences
- Allow water bottle for excessive hydration
- Allow the student to lie down somewhere for a few minutes if needed
- Allow the student to bring food/nutrients into a classroom or exam (e.g., sugary drinks, salts or a snack – parents can advise)

### Assistive Equipment

- Chair with arms for upper body support
- Provide a foot rest
- Adjust chair/table height as appropriate
- Pad for chair seat or back
- Ergonomic pen/pencil grips
- Pads for wrists at computer keyboard and mouse
- Use of computers with ergonomic and Bluetooth keyboards and mice for extra comfort
- Accessible toilets
- Online communication tools or blended learning to keep in touch in case of absences (e.g., zoom, hybrid schedule, etc.)

### Other

- Use accommodations for specific allergic reactions
- Allow specific snacks or other special dietary needs
- Assignment/test deadline flexibility to accommodate periodic increases in symptoms & absences
- Depending on treatment responses, a reduced class/work load until energy level improves
- Collaborate with the student's family to create an IEP
- Create a separate calendar/course outline for the student to track assignments and due dates
- Encourage the student to use in-school guidance and counselling services, and partnered mental health organizations

- School trips: a risk assessment approach is recommended to help plan for various scenarios
- Managing pain: create a pain management plan by collaborating with parents and health professionals
- Other: \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

Parent/Guardian Signature: \_\_\_\_\_

Principal Signature: \_\_\_\_\_

# School and LDS: General Guidelines

## How you can help

The most important thing you can do to help this student achieve success is to be understanding and informed of the items addressed in this packet, and to offer the necessary support to ensure that this student remains productive and comfortable in their educational and social environments.

## Emergency Situations

In the event that this student presents with certain medical symptoms, parents should be notified immediately and contacting the local emergency room should be considered. For forms through which to communicate emergency information, visit the [\*School and LDS: Forms\*](#) section. All school staff should be aware of these circumstances and information should be made available to emergency medical staff.

## Exercise Restrictions

The major goal of exercise restriction is to reduce the amount of stress imposed upon the heart and other arteries. Exercise regimens that cause a sustained elevation of either heart rate or blood pressure or bring any muscle group to exhaustion should be avoided. Visit the [\*Loeys-Dietz syndrome: Exercise Restrictions\*](#) section for more information.

Ensure that communication of these restrictions is clear to all school staff that have contact with this student. Some children with Loeys-Dietz syndrome will not be able to participate in Physical Education (PE) classes and should be given another option that ensures academic or creative growth. Also, due to medical necessity, not participating should not interfere with graduation requirements.

## Prescription Medications

It may be necessary for medication to be administered at school. In addition, medications may change over time. Parents are encouraged to notify school staff when changes are made and in turn, school staff are encouraged to keep the most up to date information on file.

## Corrective Devices

There may be a need for wheelchair access or student assistance when corrective devices must be worn while attending school. If necessary, the use of an aid or student buddy should be considered when available.

## Allergies

Allergies have been a noted problem for young people diagnosed with Loey-Dietz syndrome. Parents are encouraged to effectively communicate the student's allergies, as well as appropriate restrictions or response actions if the student is exposed to allergens.

As a result of allergies, the student may have gastrointestinal complaints that may require easy and/or more frequent access to bathrooms. Due to some GI symptoms the child may become easily fatigued and need rest periods throughout the school day.

## Orthopedic Concerns

Carrying heavy backpacks can negatively impact scoliosis management. It is essential that students limit the amount of weight carried. This can be achieved by allowing the student to have an additional set of textbooks to leave at home or allowing the use of a rolling book bag.

Because of loose joints causing pain/fatigue, some individuals may require more time for test-taking, shortened assignments, oral responses or access to a computer for note-taking (as typing may be a more efficient and less painful means of note-taking for the student).

## Medical Appointments

Students with LDS may miss a lot of school due to doctor appointments, hospitalizations, and at-home recoveries, all of which are important to maintaining their health. This can lead to:

- Difficulty completing work on time or taking part in exams
- Decreased academic performance
- Difficulty keeping up relationships with school friends
- Difficulty getting around the school environment
- Difficulty participating in some school activities (for e.g., physical education or excursions)
- Feeling less confident and less motivated, also possibly affecting self-esteem

Therefore, planning ahead whenever possible is very important. As well, students and families are encouraged to ask for school work that can be completed during long absences to ensure that the student does not fall behind in class curriculum. Finally, consistent communication is needed to ensure that all parties are on the same page in terms of expectations.

## Participation

As children age they become more cognizant of their physical or medical “differences.” The stress of diagnosis and management may take an emotional and physical toll on this young person. Young people with Loey-Dietz syndrome are encouraged to participate to their full medical ability.

Every effort should be made to ensure that this student remains comfortable in their educational environment. If this student’s behavior or interactions with other students changes it is important that the parents be notified. This will allow everyone to work together to help this student understand his/her genetic condition and achieve their full potential in a healthy environment.

During the course of a student’s learning experience their individual situation may change frequently due to medical circumstance. Families, students and schools should work to together on an ongoing basis to provide the best educational

experience possible. Professionals/specialists can accurately explain the nature of LDS to the school personnel and provide rationale for accommodations critical to increase the student's participation and progress in an academic environment.

### Extra Support

The student's school principal is encouraged to communicate with the parents about the Individualized Education Plan for the student. As well, discussing if there are ways to apply for extra funding or support to accommodate for a student with LDS.

### Bullying

Sometimes, children with LDS may be victims to bullying, especially when it seems like an invisible illness. Bullying can have both long term and short term effects. Children who experience bullying are more likely to exhibit depression, low self-esteem, poor eating, exhaustion, school avoidance, lowered grades, difficulty concentrating and a greater chance of dropping out of school.

Validating and supporting the child may help him/her feel more confident to contribute to school. If bullying is a common occurrence at your school, you can start an anti-bullying campaign. You can make flyers and engage in school activities that promote awareness of bullying. You can also start clubs or support groups dedicated to fighting bullying. School staff is responsible for creating an environment that promotes friendship, good mental health, and well-being. According to the Canadian Survey on Disability (2017), 42 per cent of youth with a disability have experienced bullying at school because of their condition. This increases to 62 per cent among those with a more severe disability.

To help combat bullying and ensure early intervention, training for educators is key.

# Responsibilities for Families, Schools, and Students

Family's Responsibilities	School's Responsibilities	Student's Responsibilities
<ul style="list-style-type: none"> <li><input type="checkbox"/> Notify the school of the student's health management needs and diagnosis</li> <li><input type="checkbox"/> Notify schools as early as possible whenever the student's health needs change</li> <li><input type="checkbox"/> Provide the school packet to the school</li> <li><input type="checkbox"/> Participate in the development of an IEP to implement the student's health needs</li> <li><input type="checkbox"/> Ensure that your child has his/her rescue medication on hand at all times</li> <li><input type="checkbox"/> Identify triggers that make your child's symptoms worse and teach him/her how best to avoid them</li> <li><input type="checkbox"/> Provide an adequate supply of your child's medication, in pharmacy-labeled containers, and other supplies to the designated school staff,</li> </ul>	<ul style="list-style-type: none"> <li><input type="checkbox"/> Identify the student with LDS and review their health records as submitted by families and health care providers</li> <li><input type="checkbox"/> Arrange a meeting with school staff and parents of the student to discuss health accommodations and development of an IEP</li> <li><input type="checkbox"/> Provide nondiscriminatory opportunities to the student with LDS</li> <li><input type="checkbox"/> Clarify the roles and obligations of specific school staff and provide education and communication systems necessary to ensure the student's health and education needs are met in a safe and coordinated manner</li> <li><input type="checkbox"/> Communicate with families regularly</li> <li><input type="checkbox"/> Be prepared to handle health needs and emergencies and to ensure that there is a staff member</li> </ul>	<ul style="list-style-type: none"> <li><input type="checkbox"/> Notify an adult about concerns and needs in managing your symptoms or the school environment (e.g., bullying)</li> <li><input type="checkbox"/> Participate in the care and management of your health as appropriate to your developmental level</li> <li><input type="checkbox"/> Try to make friends in school that can support you and offer reassurance</li> </ul>

<p>and replace medication and supplied as needed</p> <ul style="list-style-type: none"> <li><input type="checkbox"/> Provide the school a means of contacting you or another responsible person at all times in case of an emergency or medical problem</li> <li><input type="checkbox"/> Educate the student to develop age-appropriate self-care skills</li> <li><input type="checkbox"/> Promote good general health, personal care, nutrition, and physical activity</li> </ul>	<p>available who is properly trained to administer medications or other immediate care during the school day and at all school-related activities, regardless of time or location</p> <ul style="list-style-type: none"> <li><input type="checkbox"/> Ensure proper record keeping, including appropriate measures to both protect confidentiality and to share information</li> <li><input type="checkbox"/> Promote a supportive learning environment that views students with chronic illnesses the same as other students except to respond to health needs</li> <li><input type="checkbox"/> Promote good general health, personal care, nutrition, and physical activity.</li> </ul>	
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# Transition to College

Congratulations! You've been accepted to a college! Now what?

**Accommodation** of students with disabilities is governed by the Canadian *Charter of Rights and Freedoms (Charter)*, and by provincial human rights statutes. Post-secondary institutions have developed a wide range of delivery methods and structures to meet these obligations.

The **process of receiving and disclosing accommodations** is often different at a college or university, compared to a high school. The Transition Resource Guide provides an overview of these differences in the chart below. For more information about the accommodation process at a specific college or university, contact the school's office for students with disabilities.



TRANSITION RESOURCE GUIDE

## Differences between High School and College/University

Points to Consider	High School	College/University
Access to education for students with disabilities is regulated by ...	The Education Act	The Charter of Rights and Freedoms and Accessibility for Ontarians with Disabilities Act
To show that a student has a disability, they must ...	Have an IEP that can be based on a formal diagnosis or an informal identification	Have recent documentation (3-5 years old) of their disability (for students with a Learning Disorder/Disability, a full Psychoeducational Assessment is often required)
The decision to disclose one's disability is made by ...	Your parent or guardian (until you're 18)	You
To decide which accommodations students need ...	Teachers can recommend various accommodations to students, often all students with learning difficulties have access to the same accommodations	Accessibility Services advisors will review your documentation and only choose specific accommodations that address your areas of functional impairment
To inform teachers/professors of accommodations ...	The special education teacher provides each classroom teacher with IEPs for appropriate students	Accessibility Services develops a letter of appropriate accommodations that is communicated to professors/instructors
Teachers/professors will know your specific disability ...	Always – your identification/diagnosis is written right on your IEP beside your list of accommodations	Only if you specifically tell them – otherwise they will only know which accommodations you receive, but not why
The cost of assessments is provided by ...	The school board (due to limited availability many seek private assessments)	You (funds may also be available via private health insurance and/or OSAP)
The cost of assistive technology is provided by ...	The school board via SEA application	You (unless you qualify for the BSWD)

## To **access accommodations** at a college or university:

- Register with the college's disability services office or program
  - Contact the campus office
  - Provide disability documentation that is current & meets college guidelines
  - Request the accommodations you will need (e.g., note-taking, assistive devices, testing modifications, extra time, etc.)
  - Ensure to request the accommodations before scheduled placement tests
  
- Search for extra support
  - Go over your health insurance plan provided by the school and learn what it includes
  - Go over your personal health insurance plan (if you are covered by a plan outside of your school) and learn what it includes
  - Counselling (can sometimes be offered by the school)
  - Medication arrangement
  - Find out how medical appointments interfere with your schedule and plan ahead to stay on track
  - If you choose to live in residence, contact the housing department for living accommodations
  - Inform your Residence Assistant about your condition to ensure you get the appropriate accommodations
  - Learn about any additional services that schools may offer (e.g., clubs, peer tutoring/mentoring, workshops, etc.)
  
- Self-advocate (speaking or acting for yourself)
  - When you need additional accommodations
  - When you don't have access to an activity on the campus and you need to have that barrier removed
  - When you are having disability-related difficulty in a class and need extra assistance

# *Additional Resources*

1. [Primary Student Profile – for elementary students to introduce themselves](#)
2. [Secondary Student Profile - for secondary students to introduce themselves](#)
3. [Canada Student Grant for Students with Permanent Disabilities](#)
4. [Disability Tax Credit](#)
5. [Child Disability Benefit](#)
6. [Assistance for Children with Severe Disabilities Program \(Ontario\)](#)
7. [Financial assistance programs for handicapped children \(Quebec\)](#)
8. [Transition resource guide for students with disabilities](#)
9. [Bullying support service - Canada](#)

For more resources, please visit the resource directory on our website OR contact our support centre: 1-888-LDS-FCAN / [info@loeysdietzcanada.org](mailto:info@loeysdietzcanada.org).

## *Contact Us*

### **Loeys-Dietz Syndrome Foundation Canada**

**Website:** <http://www.loeysdietzcanada.org/>

**Email:** [info@loeysdietzcanada.org](mailto:info@loeysdietzcanada.org)

**Phone:** 1-888-LDS-FCAN

**Facebook:** <https://www.facebook.com/loeysdietzcanada>

**Instagram:** <https://www.instagram.com/loeysdietzcanada/>

**Twitter:** <https://twitter.com/LDSFCanada>

**LinkedIn:** <https://www.linkedin.com/company/49091111/>

**Youtube:** <https://www.youtube.com/channel/UChGdysxLGznn2pbSZUtj8hA>

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This school packet aims to foster a safe, educational, and social school experience for students with Loeys-Dietz syndrome. If you would like to contribute to this effort, please contact us.

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