



Loeys Dietz Syndrome (LDS) Workplace Booklet: Employee Rights, Accommodations and Legislation



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Understanding Disability, Rights and Legal Context

What is Disability?

A disability is a physical or mental impairment that has an impact on a person's life to engage in certain tasks or activities. When talking about LDS, there can be a large range of different disabilities, for example:

- high risk of arterial rupture
- flat feet / clubfoot
- scoliosis
- cervical spine instability
- gastrointestinal issues etc.

What is Discrimination?

Discrimination is defined as any practise that results in an unfair or prejudiced treatment of a person on the basis of their "individual characteristics". In a workplace, discrimination can take many forms, including discriminatory job advertising, refusing employment, unequal pay or disrespectful language.

Understanding Disability, Rights and Legal Context

Anti-Discrimination Legislation in Canada

Federal anti-discrimination legislation in Canada can be traced back to the 1960 Canadian Bill of Rights. Consequently, the first version of the Canadian Human Rights Act was passed in 1977 and later on amended to include more protected characteristics.

The Canadian Human Rights Act prohibits discrimination on the basis of the following characteristics:¹

1. Race
2. National/ ethnic origin
3. Colour
4. Religion
5. Age
6. Sex/pregnancy
7. Family status & marital status
8. Sexual orientation, Gender identity and expression
9. Genetic characteristics
10. Disability
11. Record of offence

In terms of the process of applying for a job, the Canadian Human Rights Act prohibits discrimination- some examples include during

- the hiring process: an employer cannot refuse to hire or disregard an application solely on the basis of a protected characteristic
- The participation/ full membership in an organisation (eg a trade union)
- The career span, limiting the employee's opportunities

Understanding Disability, Rights and Legal Context

Anti-Discrimination Legislation in Canada

The Employment Equity Act (1995) requires all federally regulated organizations/ employers to reasonably remove barriers and allow full participation.^{2,3} Federally-regulated sectors include people working for the federal government, post offices, television and radio stations, interprovincial buses and railways, as well as certain airlines and banks.⁴ The 4 protected groups include aboriginal, visible minorities, people with disabilities and women. This makes discrimination for employment opportunities for disabled people illegal.

Also, this Employment Equity Act requires organizations to create an Equity Employment plan which would explain offered accommodations, awareness training, sensitivity training etc. Accommodations can be addressed in system (i.e. softwares), process (i.e. onboarding) or facilities (i.e. workhouse) to allow the full participation of people with disabilities in the workplace.

However, it must be noted that if any of the above actions are based on a bona fide occupational requirement, they do not classify as discrimination. For example, for a warehouse assistant physical strength for extended periods is necessary to complete the work. As such, people who cannot undertake strenuous exercise due to a heightened risk from cardiovascular disease/ risk might not be hired on this basis.⁵

Understanding Disability, Rights and Legal Context

Genetic Discrimination

Genetic discrimination is the unfair treatment of individuals or groups of people based on real or perceived genetic conditions, genetic predispositions, genetic risk factors related to health and disease traits, or ancestry.⁶ Concern about genetic discrimination is largely concentrated on the realms of insurance and employment, as certain mutations increase the risk of hereditary disorders.

Why might employers refuse to hire on the basis of genetic characteristics?

- to avoid higher disability insurance costs
- to reduce absenteeism and employee turnover
- protect their investments in employee training

The Genetic Non-Discrimination Act (GNDA, May 4th 2017) is Canada's first federal anti-genetic discrimination statute.⁷ Along with amendments in the Canadian Labour Code and the Canadian Human Rights Act, the Act prohibits any person from requiring genetic test results when providing goods or services, entering contractual agreements or offering specific terms or conditions in a contract.

The supreme court rejected the appeal of the insurance industry to use genetic testing or predictive genetic illness information for insurance purposes, particularly under the guise of lower premiums.⁸

Important to note that the genetic non-discrimination act does not apply to physicians, pharmacists or other health practitioners who are providing health services. This exception is to allow health care professionals to recommend genetic testing as well as receive results to guide care.⁷ The GNDA also does not apply to pharmaceutical or scientific researchers acting in the course of their studies, as they ensure that they can get a declaration of genetic condition for study purposes while also collecting and using genetic data provided with consent for research purposes.⁷

Understanding Disability, Rights and Legal Context

Genetic Discrimination

Living with LDS, you are not required to share your diagnosis with your employer. However, it is important to learn what you will disclose to receive the treatment and accommodations you deserve. This can be based on your comfort level and needs, you can choose what your employer needs to know. You can also choose whether or not you would like to share your diagnosis with your insurance provider.

Barring cases of bona fide occupational requirement, nobody is allowed to require information relating to your genetic make-up from you.

Federally, many bills and regulations comprehensively cover genetic discrimination however provincial legislation is lacking. Please see our [additional resources page](#) for more information on genetics related legislation.

Understanding Disability, Rights and Legal Context

Federal and Provincial Human Rights Regulations

Both the federal and provincial government is concerned with human rights issues. The Canadian Human Rights Act applies **only** to federally-regulated companies, while **provinces and territories have their own human rights legislation**.

Broadly, the content of the legislatures will be very similar. Disability is a protected characteristic and duty to accommodate is present in all provinces and territories.¹ Provincial and territorial regulations are applicable to private companies, as well as schools, hospitals etc.

The following page contains a table with resources for legislative applicable to individual provinces and territories.

Understanding Disability, Rights and Legal Context

Federal and Provincial Human Rights Regulations

Province	Human Rights Commission	Link
Alberta	Alberta Human Rights Commission	www.albertahumanrights.ab.ca
British Columbia	BC Human Rights Tribunal	www.bchrt.bc.ca
Manitoba	MA Human Rights Commission	www.gov.mb.ca/hrc
New Brunswick	NB Human Rights Commission	www.gnb.ca/hrc-cdp
Newfoundland & Labrador	N&L Human Rights Commission	https://thinkhumanrights.ca/
Nova Scotia	NS Human Rights Commission	www.gov.ns.ca/humanrights
Ontario	ON Human Rights Tribunal of Ontario ON Human Rights Legal Support Center	www.hrto.ca http://www.hrlsc.on.ca/
Prince Edward Island	PEI Human Rights Commission	www.gov.pe.ca/humanrights
Quebec	Commission des droits de la personne et des droits de la jeunesse	www.cdpcdj.qc.ca/en
Saskatchewan	Saskatchewan Human Rights Commission	https://saskhrc.ca/
Northwest Territories	NT Human Rights Commission	www.nwthumanrights.ca
Nunavut	N Human Rights Tribunal	www.nhrt.ca
Yukon	Yukon Human Rights Commission	https://yukonhumanrights.ca/

Understanding Disability, Rights and Legal Context

International Legislation

There also are international laws applicable to Canada; in particular United Nations Human Rights Conventions which had been ratified by Canada.

- International Covenant on Economic, Social and Cultural Rights (1976): addressing the right to work
- Convention on the Rights of Persons with Disabilities (2017): Specifically, Article 27 addresses disabilities in relation to work and employment. It addresses issues such as inclusive working environment, workspace accessibility and accommodations.
- Optional Protocol to the Conventions on the Rights of Persons with Disabilities (2018): the way in which people with disabilities can make a human rights complaint if their rights have been denied or violated, or the respective authorities have not resolved the claim

Understanding Disability, Rights and Legal Context

Employees Rights in the Workplace

Employee rights and standards will vary by province or territory. Here is a [resource](#) which outlines all the employment standards acts. Use this to refer to specific employee rights pertaining to disability, type of work, age limits, critical illness leave etc.

Consider the Type of Work

Before beginning to look for work consider skills, limitations, working hours as well as how work may affect any funding requirements (income support, disability benefits etc.). Below find some resources and additional questions to help guide research for various jobs.

Strengths, Skills and Interests

Reflecting upon strength, skills and interest can help to narrow down some possible industries or careers that can be further explored. These [series of quizzes](#) from the government of Canada can help to further guide reflection and exploration of job options. ¹⁰

Self-Reflection and Career Planning

Limitations

While researching potential careers or jobs it is necessary to consider possible limitations. Not all of these may apply to you at this moment or even in the future, however these are common limitations experienced by individuals living with LDS. Using the [Loeys Dietz Syndrome Head to Toe Document](#), you can search for specific conditions in the [Job Accommodations Network](#) to review specific limitations that already exist or alternatively reflect on your own experience with work.^{9,10} While this resource does not have a direct source to Loeys- Dietz Syndrome, other connective tissues disorders with similar manifestations like Marfan Syndrome or Ehlers-Danlos Syndrome can be used to consider limitations.

**please note that LDSFC is not in affiliation or endorses the Job Accommodation Network, however is proposing a resource that can better help to understand limitations and their associated accommodations.*

Health	Task	Other
• ADD/ADHD • Allergies • Arthritis • Dermatological conditions • Heart conditions (aneurysm etc.) • Hernias • Hypermobility • IBS • Menstruation • Mental health challenges • Oral anomalies • Orthopedic challenges • Osteoporosis • Seizures • Spine malformation or instability • Vascular anomalies • Vision deficiencies	• Balancing • Decreased Stamina/ Fatigue • Lifting • Medication schedule • Respiratory Distress/ Breathing Problems • Standing • Stress intolerance • Temperature sensitivity • Toileting • Walking	• Air quality/irritants • Commute • Parking Stress • Telework

Self-Reflection and Career Planning

Working Hours

Working hours by job can be variable and flexible. Depending on the jobs during certain hours staff may be required to maintain presence or shift work is the accepted work structure. Another possible work consideration can be full time versus part time work.

Full Time

There is no strict definition of full time hours, as it will vary by organization and industry, however close to 40 is generally considered 'full time work'.¹³ The explanations of the advantages and disadvantages may not reflect all companies however can provide more information of the possible offerings of companies in different work structures.

Advantages

- Health insurance or other benefit offered through company that are fully covered or co-paid (percentage by employee and the remainder covered by employer) (verify with your HR)
- Registered Retirement Saving Plan (RRSP) contribution by employer
- Job security: Potentially more security if you need an extended leave or possibility to get paid during the time off. (verify with your HR)
- Paid time off including sick leave
- Higher earnings therefore providing financial independence
- Profit sharing and bonuses

Disadvantages

- Less flexibility if frequent medical appointments or time off required, especially for extended periods off work (once sick days run out, individuals are taking days off without compensation)
- Greater chance of burnout due to working more hours and responsibilities at work
- Disability benefits: full-time work may violate the amount offered by disability benefits in different provinces and territories, please refer to the table below in funding to learn more about the possible limitation.

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Part Time

Part-time work is generally less than 30 hours, but depends on the company and the type of work. Once again, not all advantages and disadvantages apply to all jobs, please use this list with caution

Advantages

- Flexible schedule allowing for attendance of regular medical appointments or time off between work

Disadvantages

- No benefits, insurance or RRSP contribution offered
- Limited Job Security
 - As a contractor, or seasonal worker, work is reliant upon economic conditions therefore during a time of recessions hours may be cut significantly unless other specified that you are guaranteed a certain amount of hours of work per week
- Sporadic Scheduling
 - This does not offer true flexibility, as you cannot plan ahead, if your schedule is not released ahead of time (such as a monthly basis). Also swapping shifts may be a difficult task if no one is able to take over your work.

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Funding

Funding options and amounts will vary by provinces and territory, find your respective location below (if offered):

Location	Funding Name	Link
Alberta	Assured Income for the Severely Handicapped (AISH)	https://www.alberta.ca/aish
British Columbia	Disability Assistance	https://bc.support.services
Manitoba	Employment and Income Assistance (EIA)	https://www.gov.mb.ca
New Brunswick	Disability Support Program	https://socialsupportsnb.ca https://nbsocialdevelopment.ca
Newfoundland & Labrador	Newfoundland and Labrador Disability Benefit	https://www.gov.nl.ca
Northwest Territories	Income Assistance for Senior and Persons with Disabilities	https://www.ece.gov.nt.ca
Nova Scotia	Standard Household Rate	https://novascotia.ca
Nunavut	Income Assistance	https://www.gov.nu.ca
Ontario	Ontario Disability Support Program	https://www.ontario.ca
Prince Edward Island	Assured Income	https://www.princeedwardisland.ca
Quebec	Disability Pension	https://www.retraitequebec.gouv.qc.ca
Saskatchewan	Saskatchewan Assured Income Disability	https://www.saskatchewan.ca
Yukon	Yukon Supplementary Allowance	https://yukon.ca
Federal Funding	Canada Disability Benefit	https://www.canada.ca/

Self-Reflection and Career Planning

Job Search and Workplace Integration

A diagnosis can come at any age- when you are just beginning to search for a job or you may be well established in your career or even looking to change jobs. This next section is dedicated to exploring new possible careers that work with your current capabilities.

Grief

Grief after losing a job due to new health circumstances or even leaving willfully as you can no longer perform your tasks can be equally devastating. It is normal to feel an array of emotions after not being able to have a job, considering how much of our time and energy is dedicated to a job.¹¹ Some tangibles like income and other intangibles like friends, social networks, sense of control and social identity are all linked to work. Grief will worsen when it does not acknowledge the values the loss (job) had in your life or even how the circumstances of loss (surgery, health etc) may put you in a stigmatizing position of having a limitation.¹²

Know that there is no one form of grief. Though many have defined the stages as shock, denial, anger, bargaining, depression and acceptance there is no linear, no one way to grieve. You may find yourself in varying stages of grief at any given point and may return if your health worsens, imposing more limitations.

However, the support of friends, family, your work network and even professional mental health guidance can help to allow time and space for grieving. A LDS specific support network is our [Loeys-Dietz Families](#) which can serve as an additional source of support. Once you are ready and would like to explore work with renewed energy, this guide can help you on your journey to finding work and work accommodations.

Even after accepting your new capabilities and limitations, your job search may begin with renewed hope, energy and often expectations of finding work quickly. If you are searching for a long period, you may experience grief, frustration and even anger during your job search process. However, know that there is always support from the people around you.

Self-Reflection and Career Planning

Finding a New Job

Figuring out where to begin your job search or even finding suitable careers can be difficult to imagine. Using powerful tools like the internet, especially AI with its capabilities.

Some prompts for AI resources can look like

I am currently a _(insert role)_____, and I have some physical limitations ____(list limitations). What are some possible career options for me?

I have the following skills (insert skills) and knowledge of (put in softwares, techniques etc.). What are some possible career options for me?

Once you have found some career options. You may want to look into how your current skills can transfer as well as any new certifications or knowledge that may be good to have to pursue new roles.

I want to change jobs from ____ (insert previous role)____ to this new role ____ (insert new role)____. Give me a step by step plan of how to find jobs for the new role and what skills and certificates can I get to help me land this new role.

Disclaimer: Loeys- Dietz Syndrome Foundation is not in affiliation or endorses any specific artificial intelligence tool, however is proposing a resource that can assist with brainstorming. Please use the results with discretion as artificial intelligence can make errors.

Self-Reflection and Career Planning

Explaining Gaps

Gaps in professional experiences and on resumes can be perceived negatively. However, acknowledging that a medical leave is an incredibly personal experience can support the decision to limit disclosure. There is a fine balance between being transparent while also strategic about disclosure.¹³

Consider the contents of disclosure whether they are current and relevant to the job. Also, consider how the time off there may have been unique experiences and skills that you have learned that can demonstrate strength and adaptability.^{14,15}

When to disclose can also be a choice; whether it is done on your resume as a brief highlight, on a cover letter providing more capacity to explain the context and transferable skills or even in an interview to show that you are capable of taking on a new job.¹⁶ Strategic framing using neutral language to explain a break or even adding a positive declaration that you are ready to re-enter the workforce can be effective.

Tracking Information due to Frequent Breaks

Health, illness and recovery are not a linear process nor will breaks taken from work be consistent. As such keeping record of when breaks begin and end as well as experiences during these times may help to reflect and share details of the break. It can also take away the stress of having to recall what you did during this time from reading to new experiences that can help when revising your resume and cover letter.

Self-Reflection and Career Planning

Hiring Process

When to Disclose Health Limitations

There is no consensus about the best time to disclose accommodations or task limitations due to health. Each company and recruiting team will have different opinions on this, however transparency and clear communication are key to establishing a reliable and dependable presence.

Please see the table below on when it is possible to disclose and the respective benefits and drawbacks.^{18,19}

When to disclose	Who will you be disclosing to?	Benefit	Drawbacks
Cover letter/ Resume	• HR professionals who maintain confidentiality and have the power to grant accommodations • Hiring manager or team lead, that can provide further clarity on the roles' bona fide occupational requirements and how the team can be modified to work with accommodations	• If accommodations are needed for the interview • Transparency that avoids misunderstanding in the later phases of hiring or hinders trust with employer • Display openness about your health condition • Employer may be looking for individuals with diverse experiences • Employee may be more comfortable disclosing in writing than verbally within an interview for the first time	• Limited space to discuss condition • May not address all of employers questions • Could be screened out

Self-Reflection and Career Planning

When to Disclose Health Limitations

When to disclose	Who will you be disclosing to?	Benefit	Drawbacks
Through a reference	• HR professional or hiring manager, bound by confidentiality with accommodation capacity	• Employer is giving a level of trust to this person to recommend your capabilities • Employer is aware of disability and reference can advocate for your capabilities	• Cannot control what is said which may create misunderstandings • Possibility of being screened out³⁵
Prior to an Interview	• Hiring group may include team members to whom you may not want to disclose your disability or accommodation for fear of bias and knowledge of personal information	• Can give employer time to think about your disability and possible support means • Allows a candid conversation about your disability • Demonstrates an employer's interest in your candidacy • Can ask for the presence of HR at the end of the interview to discuss accommodations	• Employer may consider you unsuitable for the job

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When to Disclose Health Limitations

When to disclose	Who will you be disclosing to?	Benefit	Drawbacks
During an Interview	Hiring group may include team members to whom you may not want to disclose your disability or accommodation for fear of bias and knowledge of personal information	Employer can ask for clarification and discuss their questions	- Unpredictable reactions - Difficult to disclose to strangers or even a group of strangers - Focus may be directed to disability rather than skills
After receiving a job offer		Employer is responsible for making accommodations and may be more inclined to find supports in an employee which they would like to invest their time and resources	Employer may be displeased with not having knowledge prior to hiring

Self-Reflection and Career Planning

Why Disclosure is Important

The decision to disclose a disability or job limitation is grounded in transparency and clear communication. It also means the capacity to live authentically¹⁹ and get the accommodations needed to be successful at work. However there is a fear of discrimination or bias especially in the case where the disability is invisible or otherwise physically obvious. Know that disclosure is always your choice, and allows you to be the expert about your health and advocate for yourself.

While the employer holds legal responsibility for accommodations, the initial informing step must be initiated by the employee. This is especially necessary in the case of rare disease where there is often overestimation of limitations when an employer is not familiar with the condition. This also provides an opportunity to highlight more of your skills and capabilities.

Another consideration is a reference potentially disclosing your condition.²⁰ This may be used in an example to demonstrate your capacity rather than highlight your limitations, however the reference provider is the first person to mention your health condition as opposed to transparent communication from you, the potential employee. However, if the disability is disclosed ahead of time the reference can provide credibility by reaffirming your capacity to work and skills that make you a successful employee.

What to Disclose

As an employee you have no obligation to disclose your disability, and there can be some hesitation about discussing private information. Disclosing a disability, may increase stigmatization or discrimination, result in being passed over for opportunities. Knowing what to disclose is difficult as every company and recruiting team has different values and understandings of disability and accommodations.

However, you can begin by thinking about questions that a prospective employer may ask to better understand your condition. Also know that employers may not always know the right questions to ask, so guiding the conversation can help to find the right accommodations for your capabilities.

If you have a diagnosis, name your disability clearly and how it impacts the job tasks. This can help to identify the accommodation the employer can offer. However, know that accommodations will evolve with your health and may change over time and ultimately you are responsible for identifying the needs to support your work.

To help with what to disclose as well as a general overview of LDS please provide the following General LDS Info sheet to your employer, HR and other involved parties.

General Information on Loeys-Dietz Syndrome

What is 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. As such, the employee might require medical leave for checks to be performed. 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 employee may have had surgery, braces, and/or limitations to address these problems. As such, the workplace need to be accessible to account for limited mobility.

Additionally, a subset of patients have gastrointestinal complaints. 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.

Due to joint laxity, some individuals may have some increased difficulty with balance and fine or gross motor skills. As such, they might require ergonomic tools to perform their work responsibilities.

General Information on Loeys-Dietz Syndrome

In most cases the employee should be considered to be at a low risk for a serious event. As such, the employee should be included in regular workspace activities as much as possible.

In the event that the employee 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 employee 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.

How is LDS Managed?

Employees with LDS are under the care of multiple specialists for cardiovascular, vascular, ENT, orthopedics, nutrition, pain management, allergic and/or gastrointestinal concerns. They may need to attend appointments for monitoring their symptoms and imaging. Employees with LDS may also need physical therapy to treat cervical spine instability. Therefore, employees will likely occasionally need to take medical leave to attend their appointments or an extended medical leave should more serious issues arise.

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

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Who to Disclose to?

At any point in the hiring process you may be engaged with people from varying positions and power to help identify accommodations. The hiring team during the interview may consist of co-worker, HR professionals, and team leads. You may not want to share your disability with co-workers, consequently, asking who will be present within the interview will allow private disclosure to the appropriate individuals like HR/ team lead.

Disclosure Support

Disclosure may be accompanied with a formal doctors or professional note. There is also the option to refer the company to another person for support like an employment specialist, recruiter, rehab counselor or other individual that can help to better support the accommodation process or even provide clarity on your current capabilities.

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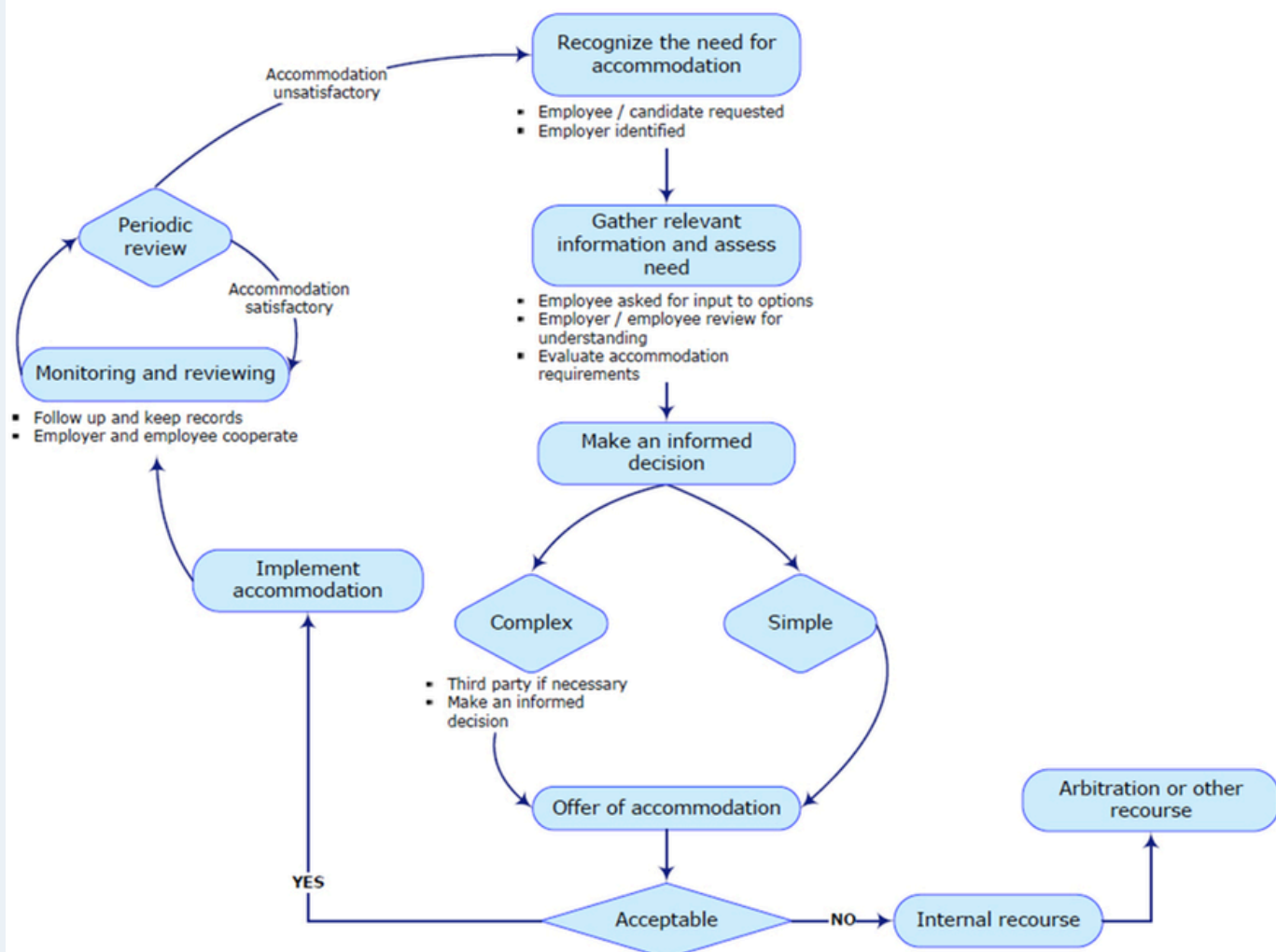
Accommodation

The accommodations process is one that takes time however clear communication is a key to ensuring that your needs are met to address the dynamic nature of health.

Employers have a duty to accommodate under both of the federal and provincial laws. It is a continuous process that includes reviewing of accommodations efficiency and adjustments, if necessary.²¹

The Government of Canada flowchart below explains the general process of accommodation.²¹

Figure 1: Accommodation Process Diagram



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Accommodation

Accommodation needs should be met at all points of your interaction with the company, starting with job advertising and recruitment (e.g. ensure interviews are accessible). If you have any accommodation needs, you should reach out to the recruiting agent or HR, your supervisor, your disability management advisor or your union representative.

In general, the steps the employer should follow when implementing an accommodation are:

1. recognise need for accommodation
2. gather information relevant to the disability in question
3. make an informed decision
4. implement the accommodation
5. regularly review and monitor the accommodation efficiency

If you are working in a federally-regulated company, you can choose to use the Government of Canada Workplace Accessibility Passport. This is a tool that allows you to keep track of potential barriers encountered in workspaces as well as possible solutions to accommodate your needs. It is meant to make the communication between employee and employer easier and the process of accommodating faster.

It is important to keep in mind that the duty to accommodate is meant to ensure an accessible workplace, and not concerned with your personal preferences in terms of accommodations. As such, you can't refuse a reasonable accommodation only because you had in mind a different one.

Self-Reflection and Career Planning

Suggested Accommodations

There are different types of accommodation that might be helpful depending on the situation.

1. Adjustments to the work schedule
 - a modified/flexible schedule (eg allowing for more remote working hours)
 - longer or more frequent breaks - eg if work includes physical exercise, it is important to provide breaks
2. Adjustments to job duties
 - allowing for additional time to learn new responsibilities
 - providing a mentor
 - adjusting duties as to not include undue intense physical exercise
 - reduce the amount of standing necessary and allow for opportunities to sit down.
 - supportive shoes for orthotic insoles could be helpful with joint laxity induced pain and flat feet.
3. Example of adjustments to work environment
 - use of adaptive technology devices
 - use of ergonomic equipment
 - ergonomic chairs or sitting cushions can be very helpful for scoliosis, providing additional support and alleviating discomfort. Generally, a chair with a high back, posture curved seat and adjustable neck and arms rests are preferable. A good option is the Aeron chair, or the Murray range. It is also possible to get a specialist scoliosis chair for more severe cases. Good support while seating can also alleviate discomfort from cervical spine instability^[1]
 - adjustable table height
 - foot rests
 - use of elevators
 - ensure office corridors are wide and without obstacles - allows for passage of wheelchair or other walking aids
 - accessible bathrooms
 - use of computers for typing instead of handwriting
 - typing instead of handwriting will put less stress on fingers & hands, or alternatively consider verbal transcription instead of typing

Self-Reflection and Career Planning

Suggested Accommodations

Accommodations will vary for people with the same condition. Some other possible accommodations are suggested on the Job Accommodation Network[1] website. However, there is no specific page dedicated to the LDS, similar connective tissues disorders such as Ehler-Danlos Syndrome and Marfan Syndrome.

**please note that LDSFC is not in affiliation or endorses the Job Accommodation Network, however is proposing a resource that can better help to understand limitations and their associated accommodations*

There might be several alternative accommodations proposed. In these cases, it is important to consider the maintenance of the employee's dignity, autonomy, privacy, and try to achieve a high inclusion of the person in the workspace. It is also crucial to minimise any inconveniences, and address the employee's needs in a timely manner.

Also note that employers are responsible for bearing the cost of accommodations. Establishing a central accommodation fund will allow employers to plan for the financial aspect of accommodations.

The employer can refuse to accommodate the disability if doing so would result in significant cost, or would compromise the safety of either the individual requiring the accommodation or others. For example, a small business employer may refuse to install an elevator in the building as the cost to the business would be untenable. Furthermore, an employer can refuse to hire an applicant if the required accommodations for that individual resulted in safety risks for other employees. This principle is referred to as the accommodation causing **undue hardship**.

It is also worth noting that an employee with a disability may not refuse a reasonable accommodation proposed by the employer simply because they would prefer a different one.

In some provinces, employers also have a **duty to inquire** beside the **duty to accommodate**. This means that if they suspect an undisclosed disability affecting the employee's performance, they have to ask for further details in order to create a plan to accommodate the disability.

Self-Reflection and Career Planning

Roles and Responsibilities in the Accommodations Process

To ensure efficient communication, both the employee and the employer have to work together, completing their responsibilities. These include:²²

Employer	Employee
Be aware when a person may need an accommodation even if they have not requested one	Communicate the need for accommodation and not assume that the manager knows or should have known about the need
Accept a person's request in good faith	Cooperate with the organization by providing relevant and appropriate information to support the request for accommodation
Obtain the opinion of an expert or further advice, if needed	Work with the manager to find the appropriate accommodation solutions
Only request information related to the nature of the limitations mentioned	Advise the manager if accommodation measures need to be changed or if the agreed-upon solution has not worked as it was intended
Examine alternative approaches and possible accommodation solutions	Consider all proposals that effectively respond to the needs
Establish a central accommodation fund	Discuss your accommodation needs only with persons who need to know
Keep a record of accommodation requests and document what actions were taken	Seek for a workplace representative, if needed
Maintain confidentiality and respect the dignity of the person requesting the accommodation	
Process and implement accommodation requests in a timely manner	
Cover the cost of any medical information or documentation being requested	

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Roles and Responsibilities in the Accommodations Process

The trade union also has responsibilities, which may include facilitating the communication between employee and employer, representing the employee (if requested), as well as cooperating on finding a reasonable accommodation.

Medical Leave

Laws for guaranteed sick leave vary from province to province. In all federally regulated private sector workplaces, there are 10 days of guaranteed paid sick leave. Workers who have been continuously employed for at least 30 days have access to 3 days of sick leave, accumulating one additional day at the start of every following month.²³

With employment insurance, sickness leave benefits can provide up to 26 weeks of paid leave within a year. It is possible to receive up to 55% of earnings to a limit of \$668 per week.²⁴

To be eligible:

- unable to work for medical reasons
- need to provide a medical certificate
- weekly earnings have decreased by at least 40% in the last week
- accumulated 600 insured hours of work in the 52 weeks since the start of the sickness leave claim
- remain otherwise available for work, if it weren't for the medical condition, while receiving sickness benefits²⁵

Unpaid medical leave can be taken to up to 27 weeks.²³

Self-Reflection and Career Planning

Accommodations Template

Preparing for an accommodation discussion can make the process more efficient and productive. This section provides templates and resources that can help you organize your accommodation needs, identify workplace barriers, and communicate practical solutions with your employer. These tools are designed to facilitate collaborative discussions and ensure that accommodation requests are clear, well documented, and focused on supporting your ability to perform your job successfully.

[Accommodation Plan Template](#)

[Sample Accommodation Process and Plan](#)

Complaints

If you are being discriminated against or your needs for accommodations aren't being taken into consideration:

- try and resolve the issue internally, ie by speaking or raising a complaint to the employer
- reach out to the trade union, if applicable
- submit a formal complaint to the relevant human rights protection body — either at a federal or provincial level, depending on the employment

A formal complaint usually has three parts:

- stating the protected ground of discrimination which was affected
- explaining the negative effects arising from the discriminatory action
- outlining the connection between the discriminatory act, and its negative consequences²⁶

If you are planning to submit an official complaint, first review:

- the goals of submitting the complaint (monetary compensation, change of workplace policy)
- how long willing you are willing to wait for result
- cost of complaint (usually none for tribunal or board, but fees for court)
- strength of evidence showcasing the issue you are submitting a complaint about

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Complaints

Depending on the province, there are different human rights bodies you can submit complaints to - please see the [table of human right bodies](#) for more information. Do note that [complaints](#) to the Canadian Human Rights commission must be submitted within 12 months of the incident. This timeframe may not be applicable to provincial legislations, consult the provincial and territorial tribunals for more information.

For federally regulated companies, you can find more information and submit a complaint under the Canadian Human Rights Act (or the Accessible Canada Act) to the [Canadian human rights commission](#).

It is advisable to get legal help before submitting a complain²⁷. You may try to contact some of the sources listed below, or reach out of LDS Foundation Canada for further help.

Additional Resources

Some additional bills of further interest and research may include:

- [Bill C-508](#)- amend human rights to protect Canadians from discrimination on the basis of genetic characteristics (not passed)
- [Bill C-536](#)- "genetic characteristics: prohibited grounds of discrimination in the Canadian Human Rights Code (not passed)
- [Bill 127](#)- Human Rights Code Amendment
- [Bill S-201](#)-(Non-Genetic Discrimination Act)

Legal resources:

1. [ARCH](#) – help with providing free over-the-phone legal advice
2. [Lawyer Locate](#) – find a human rights lawyer + free referral service
3. [Pro Bono Resources in Canada](#) – A list of law-based organizations that help low-income families and individuals
4. [Pro Bono Ontario](#) – Free legal advice by phone

Financial resources:

1. [Disability Tax Credit](#)
2. [Canada Pension Plan Disability Benefit](#)
3. [Employment Insurance Sickness Benefit](#)
4. British Columbia - [Fuel Tax Refund](#)
5. British Columbia - [Employment and Assistance for persons with Disabilities](#)
6. New Brunswick - [Disability Tax Credit](#)

Additional Resources Linked in the Booklet:

1. [Canadian Association for Supported Employment- Accommodations](#)
2. [Disability Management: Employee Wellness Resource](#)
3. [Employment Standards Across Canada](#)
4. [LDS Facebook Support Group](#)
5. [EI Sickness Benefits](#)
6. [Government of Canada Workplace Accessibility Passport](#)
7. [Job Accommodations Network](#)
8. [Accommodation Plan Template](#)

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

Glossary

Bona fide occupational requirement: necessary skills or capacity that is essential for a job

Canadian Bill of Rights: the first federal statute that protected human rights and fundamental freedoms

Canadian Human Rights Act¹: anti-discrimination act passed by the Canadian Parliament to allow equal opportunity to receive services and employment.

Canadian Labour Code: applicable to federally regulated private sectors, federally regulated public sector and private sector firms and municipalities. It outlines workplace relations, collective bargaining, workplace health and safety, and labour standards.

Disability: physical or mental impairment that has an impact on a person's life to engage in certain tasks or activities.

Discrimination is defined as any practice that results in an unfair or prejudiced treatment of a person on the basis of their "individual characteristics".

Employment Equity Act: requires all federally regulated organizations/ employers to reasonably remove barriers and allow full participation of aboriginal, visible minority, people with disability and women

Genetic discrimination: is the unfair treatment of individuals or groups of people based on real or perceived genetic conditions, genetic predispositions, genetic risk factors related to health and disease traits, or ancestry.

Genetic Non-Discrimination Act: First Canadian legislation specifically outlining genetics as grounds for discrimination

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