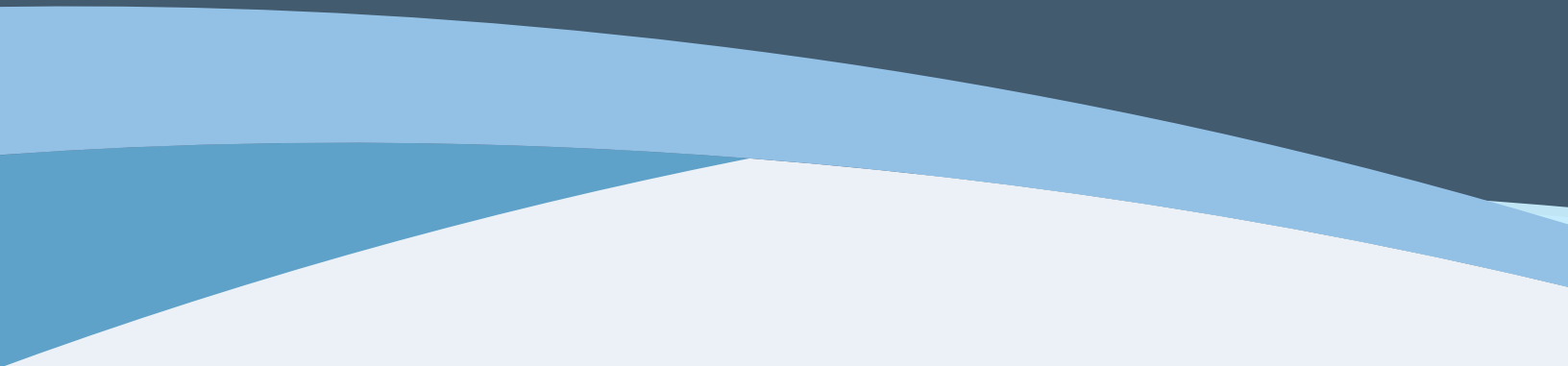




Loeys Dietz Syndrome (LDS) Workplace Booklet: Employee Rights, Accommodations and Legislation *Executive Summary*





About This Executive Summary

This Executive Summary provides a concise overview of the key information from our "Loeys Dietz Syndrome (LDS) Workplace Booklet: Employee Rights, Accommodations and Legislation".

It is designed as a quick-reference resource for individuals with Loeys-Dietz syndrome, employers, managers, and workplace teams. For more comprehensive information and practical guidance, we encourage you to consult the full Workplace Guide, which explores topics such as workplace rights, disclosure, career planning, accommodations, and available supports and resources.

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Understanding Disability, Rights and Legal Context

Living with Loeys-Dietz Syndrome (LDS), a rare connective tissue disorder, can present unique and ongoing health challenges that impact many aspects of daily life, including the pursuit of meaningful employment. This booklet is designed to support individuals with LDS in navigating the world of work. It offers a comprehensive overview of disability rights, workplace accommodations, and anti-discrimination legislation in Canada. In addition, this guide encourages self-reflection on your strengths, interests, and limitations, while addressing important emotional experiences such as grief and resilience. Whether you are entering the workforce for the first time, returning after a break, or seeking more suitable employment, this booklet aims to equip you with the knowledge and tools needed to make informed decisions and advocate for your needs in the workplace.

What is Disability?

Disability is more than a medical diagnosis—it refers to a physical, mental, or cognitive condition that may affect a person's ability to perform certain activities. Because Loeys-Dietz Syndrome presents differently in every individual, the impact on work can vary significantly. Understanding how disability is defined can help you recognize your rights and identify when workplace accommodations may be appropriate.

What is Discrimination?

Discrimination occurs when a person is treated unfairly because of a protected characteristic, such as disability or genetic characteristics. It can happen during hiring, promotions, workplace interactions, or termination. Recognizing discrimination is the first step toward protecting your rights and seeking appropriate support when needed.

Understanding Disability, Rights and Legal Context

Anti-Discrimination Legislation in Canada

Canadian laws protect people with disabilities from discrimination in employment and require employers to provide reasonable accommodations whenever possible. This section in the *Full Workplace Booklet document* introduces the key federal legislation and explains how these laws help create more equitable and inclusive workplaces.

Genetic Discrimination

Many people living with rare genetic conditions worry about how genetic information could affect employment or insurance. Canadian legislation protects individuals from being required to disclose genetic test results in most circumstances. Understanding these protections can help you make informed decisions about sharing personal health information.

Understanding Disability, Rights and Legal Context

Federal and Provincial Human Rights Regulations

Human rights protections exist across Canada, although the legislation differs depending on whether your employer falls under federal or provincial jurisdiction. This section in the *Full Workplace Booklet document* provides an overview of the organizations responsible for protecting workplace rights in each province and territory.

International Legislation

Canada is also committed to international agreements that promote equal rights for people with disabilities. These conventions reinforce the importance of accessibility, workplace inclusion, and equal employment opportunities for individuals living with chronic health conditions.

Employees Rights in the Workplace

Employees with disabilities have the right to work in an environment free from discrimination and to request reasonable accommodations that enable them to perform their job safely and effectively. Understanding these rights can help you advocate for yourself throughout your career.

Self-Reflection and Career Planning

Consider the Type of Work

Finding the right job is about more than matching your qualifications to a job description—it is about finding a role that supports both your career aspirations and your health. Before beginning your job search or considering a career change, take time to reflect on the physical, cognitive, and emotional demands of different occupations. Think about the work environment, schedule, travel requirements, physical expectations, and opportunities for flexibility. Choosing a career that aligns with your abilities and long-term health can improve job satisfaction, reduce stress, and help you build a sustainable career while living with Loeys-Dietz Syndrome.

Strengths, Skills and Interests

Your diagnosis does not define your potential. Identifying your strengths, transferable skills, interests, and personal values can help you focus your job search on careers where you are most likely to succeed. Whether you are entering the workforce, returning after medical leave, or changing careers, understanding what you enjoy and where your talents lie can help you find meaningful work that aligns with both your professional goals and your health needs. Career assessment tools can also provide valuable guidance as you explore different opportunities.

Limitations

Every person living with Loeys-Dietz Syndrome experiences different health challenges, and limitations may change over time. Understanding how your condition affects your ability to perform certain tasks is an important step in choosing an appropriate career and identifying workplace accommodations. Consider your physical, cognitive, and environmental limitations, as well as factors such as fatigue, pain, mobility, medication schedules, and medical appointments. Recognizing your limitations is not about focusing on what you cannot do—it is about understanding what support you need to work safely, comfortably, and successfully.

Self-Reflection and Career Planning

Working Hours

Work schedules can have a significant impact on your health, quality of life, and ability to manage a chronic condition. Some individuals with LDS may benefit from flexible hours, reduced schedules, or remote work to better balance employment with medical appointments, treatment, and recovery. Before accepting a position, consider how different work schedules, shift work, overtime, and commuting requirements may affect your physical and mental well-being. Choosing a schedule that supports your health can contribute to long-term career success and reduce the risk of burnout.

Full Time

Full-time employment often provides greater financial stability, access to health benefits, retirement savings plans, paid leave, and other workplace benefits. However, working full-time may also present challenges for individuals who require frequent medical appointments, extended recovery periods, or greater flexibility due to fluctuating health. Carefully consider whether the demands of a full-time schedule are compatible with your current health needs and discuss potential accommodations with your employer if additional flexibility is required.

Part Time

Part-time employment may offer greater flexibility and a better work-life balance, making it an attractive option for individuals who require regular medical appointments or experience fluctuating symptoms. While part-time work can reduce physical demands and provide more time for self-care, it may also come with trade-offs such as reduced income, fewer benefits, limited job security, and unpredictable schedules. Weighing these advantages and disadvantages can help you determine whether part-time employment is the right choice for your circumstances.

Self-Reflection and Career Planning

Funding

Employment may affect your eligibility for disability benefits, income assistance, or other financial support programs. Before accepting a new job or changing your work hours, it is important to understand how your earnings could impact provincial or federal benefits. This section in the *Full Workplace Booklet document* provides an overview of disability income programs available across Canada and encourages you to research the eligibility requirements in your province or territory. Being informed can help you make employment decisions that support both your financial security and your long-term health.

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

Receiving a diagnosis, experiencing health changes, or leaving a job because of your condition can bring feelings of grief, frustration, uncertainty, or loss. These emotions are a normal response to significant life changes and may resurface throughout your journey as your health evolves. This section in the *Full Workplace Booklet document* acknowledges the emotional impact of career transitions and encourages you to give yourself time to adjust, seek support when needed, and recognize that your value extends far beyond your ability to work. Healing and moving forward are gradual processes, and with time, it is possible to build a fulfilling and meaningful career that aligns with your current abilities.

Finding a New Job

Beginning a job search can feel overwhelming, especially if your health circumstances have changed or you are considering a new career path. This section in the *Full Workplace Booklet document* provides practical strategies for exploring careers that match your interests, strengths, and physical abilities. It also highlights tools, including career planning resources and artificial intelligence, that can help you identify transferable skills, discover new opportunities, and develop a plan for entering or re-entering the workforce with confidence.

Self-Reflection and Career Planning

Explaining Gaps

Employment gaps due to illness, surgery, or recovery are more common than many people realize. While you are not required to disclose personal medical details, you may choose to briefly explain periods away from work in a way that is honest, professional, and focused on your readiness to return. This section in the *Full Workplace Booklet document* offers guidance on how to address employment gaps on your résumé, cover letter, or during interviews while emphasizing the skills, resilience, and personal growth you developed during that time.

Tracking Information due to Frequent Breaks

Managing a chronic health condition often means taking intermittent breaks from work for medical appointments, treatments, surgeries, or recovery. Keeping a personal record of these periods, along with any courses, volunteer work, certifications, or other meaningful experiences, can make it easier to update your résumé, prepare for interviews, and reflect on your accomplishments. Maintaining organized records can also reduce stress when explaining employment history in the future.

Finding an Employer who Prioritizes Accessibility

Not all workplaces offer the same level of support for employees with disabilities. As you search for employment, consider looking beyond the job description to assess an organization's commitment to accessibility, diversity, equity, and inclusion. Reviewing company policies, employee benefits, accessibility statements, public reports, and employee experiences can help you identify employers that value inclusive workplaces and are more likely to support your long-term success.

Self-Reflection and Career Planning

Hiring Process

The hiring process involves several stages, each presenting opportunities to demonstrate your skills and determine whether an employer is a good fit for your needs. This section in the *Full Workplace Booklet document* discusses how to navigate interviews, communicate professionally, and prepare for conversations about accommodations if necessary. It also encourages you to evaluate potential employers just as they evaluate you, ensuring that the workplace aligns with your values, career goals, and health requirements.

When to Disclose Health Limitations

Choosing when to disclose your health condition or accommodation needs is a personal decision with no universally correct answer. Some individuals disclose before an interview to request accommodations, while others wait until after receiving a job offer or beginning employment. This section in the *Full Workplace Booklet document* explores the potential benefits and challenges of disclosure at different stages of the hiring process, helping you make an informed decision based on your comfort level, workplace needs, and the specific role you are pursuing.

Why Disclosure is Important

While disclosure is voluntary in most situations, it can play an important role in ensuring that you receive the workplace accommodations you need to perform your job safely and effectively. Open communication can help employers better understand your functional limitations, reduce misunderstandings, and foster a collaborative approach to problem-solving. This section in the *Full Workplace Booklet document* discusses the reasons why some individuals choose to disclose their condition and how thoughtful communication can support both workplace success and personal well-being.

What to Disclose

If you choose to disclose your condition, focus on sharing information that is relevant to your job and accommodation needs rather than every aspect of your medical history. Explaining how your condition affects specific work tasks, what accommodations may be helpful, and any important work restrictions can help employers understand how to best support you. This section in the *Full Workplace Booklet document* also introduces an Employer Information Sheet that you can share with Human Resources or your manager to provide a clear overview of Loeyes-Dietz syndrome and workplace considerations.

General Information on Loeys-Dietz Syndrome

What is LDS?

Many employers have never heard of Loeys-Dietz syndrome and may not understand how it affects an individual's daily life or ability to work. This section in the *Full Workplace Booklet document* provides a concise overview of the condition, including common health considerations, medical monitoring, emergency situations, and potential workplace implications. It is intended to improve awareness, reduce misconceptions, and support productive conversations between employees, employers, and Human Resources about reasonable accommodations and workplace safety.

Self-Reflection and Career Planning

Who to Disclose to?

Not everyone in the workplace needs to know about your health condition. This section in the *Full Workplace Booklet document* explains who may need information about your disability, such as Human Resources, your supervisor, or a hiring manager, depending on your circumstances. Sharing information only with individuals who are responsible for implementing accommodations helps protect your privacy while ensuring that the appropriate supports are in place.

Disclosure Support

You do not have to navigate disclosure on your own. Depending on your situation, your healthcare provider, occupational therapist, rehabilitation specialist, employment counsellor, or another professional may be able to provide documentation or assist with workplace conversations. This section in the *Full Workplace Booklet document* outlines the types of support available and explains how involving knowledgeable professionals can help facilitate effective communication and successful workplace accommodations.

Self-Reflection and Career Planning

Accommodation

Requesting workplace accommodations is a collaborative process that begins with open communication between the employee and employer. Under Canadian human rights legislation, employers have a duty to provide reasonable accommodations that allow employees with disabilities to perform the essential duties of their job, unless doing so would cause undue hardship. This section in the *Full Workplace Booklet document* explains how the accommodation process works, what information may be required, and the steps employers and employees can take to develop effective, individualized solutions. It also emphasizes that accommodations should be reviewed regularly, as health needs and job responsibilities may change over time.

Suggested Accommodations

There is no one-size-fits-all accommodation for individuals living with Loeys-Dietz syndrome. Workplace supports should be tailored to each person's health needs, job responsibilities, and work environment. This section in the *Full Workplace Booklet document* provides examples of common accommodations, including flexible scheduling, remote work, ergonomic workstations, modified duties, adaptive equipment, accessible workspaces, and adjustments to physical tasks. These examples are intended to help employees and employers begin productive conversations about creating a safe, accessible, and supportive workplace.

Roles and Responsibilities in the Accommodations

Process

Successful accommodations rely on collaboration and shared responsibility. Employees are responsible for communicating their accommodation needs, participating in discussions, and providing relevant information when appropriate. Employers are responsible for considering accommodation requests in good faith, maintaining confidentiality, implementing reasonable accommodations, and reviewing their effectiveness over time. In some workplaces, Human Resources, union representatives, healthcare providers, or disability management professionals may also play an important role in supporting the accommodation process.

Self-Reflection and Career Planning

Medical Leave

Living with Loeys-Dietz syndrome may require time away from work for specialist appointments, diagnostic imaging, surgery, treatment, or recovery. Understanding your options before leave becomes necessary can reduce uncertainty and help you plan ahead. This section in the *Full Workplace Booklet document* provides an overview of paid and unpaid medical leave, Employment Insurance sickness benefits, eligibility requirements, and workplace considerations. Knowing your rights and communicating proactively with your employer can help ensure that your health needs are supported while maintaining your employment whenever possible.

Complaints

If you believe you have experienced discrimination or your accommodation needs have not been appropriately addressed, there are formal processes available to protect your rights. This section in the *Full Workplace Booklet document* outlines the steps you can take, from raising concerns internally with your employer or Human Resources to seeking assistance from your union or filing a complaint with the appropriate provincial or federal human rights body. It also provides practical considerations to help you determine whether pursuing a complaint is the right course of action for your situation.

Self-Reflection and Career Planning

Additional Resources

Navigating employment while living with a rare disease can be challenging, but you do not have to do it alone. This section brings together trusted legal, financial, employment, and accommodation resources from across Canada to support you throughout your employment journey. Whether you are looking for information on workplace rights, disability benefits, accommodation strategies, or legal assistance, these resources can help you make informed decisions. The Loeys-Dietz Syndrome Foundation Canada is also available to provide educational resources and connect you with additional support when needed.

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