Working it Out

A report on the experiences of people with psoriatic disease in the Canadian workplace

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Canadian Psoriasis Network
Réseau canadien du psoriasis

CAPP ACPP
Canadian Association of Psoriasis Patients
Association canadienne des patients atteints de psoriasis

Unmasking PSORIASIS

Contents

Executive Summary

In the late spring of 2021, the Canadian Psoriasis Network (CPN), the Canadian Association of Psoriasis Patients (CAPP) and Unmasking Psoriasis, an awareness group in Saskatchewan, collaborated to develop an online survey to better understand and address the workplace challenges and needs of people living with psoriasis and psoriatic arthritis (PsA).

The aim of the survey was to learn about the experiences of people living with psoriasis and PsA to better understand their needs and priorities regarding accommodation in the workplace, access to private and public health benefits, and the impact of their health on their experiences in the workplace. The survey had responses from 190 individuals. Responses came from all provinces with Ontario (36%) and British Columbia (17%) having the greatest number of respondents. Sixty-five percent of those who filled out the survey identified as female and almost three-quarters of all respondents were greater than 50 years of age. The survey population overwhelmingly self-identified as white (89%) although a number of other ethnic groups were also represented (see full survey demographics).

While about three-quarters of those responding to the survey said they had medications and other health benefits paid for through a public plan or an employer benefit plan for themselves or their spouse, 27% said they had to pay for medications and other health services themselves.

Many of those who answered the survey clearly felt their psoriasis or PsA was having or, if they were retired, used to have a significant impact on their work. More than half of respondents agreed or strongly agreed that:

- Psoriasis or PsA had a negative impact on them at work.
- They felt self-conscious in a way that impacted their performance at work.
- They felt worried to a degree that it had an impact on their job performance.
- They had difficulty performing physical tasks such as standing for long periods of time.
- They had difficulty staying focused because of fatigue.
- The location of psoriasis plaques affected them at work.
- They were worried about how psoriasis and/or PsA will affect their ability to stay employed.
- They were upset or angry about how psoriasis and/or PsA affects them at work.

Just over half of the respondents agreed or strongly agreed that they had to reduce social activities in order to maintain the energy to work and a similar but slightly smaller percentage felt the same about family activities.

Only a minority of those individuals who responded to the workplace survey felt they could make use of workplace accommodations. Only a third of those polled agreed that they could access needed workplace adaptations or accommodations.

Two-thirds of respondents indicated they had made use of one or more of a variety of workplace accommodations. Opinions were mixed on the helpfulness or effectiveness of the accommodations that people had used. Paid time away from work to attend medical appointments, flexible work hours, and the ability to work from home were seen as the most useful.

While most people who did not use workplace accommodations felt they did not need them, a significant minority of respondents said they did not want their employer to know about their health situation or they felt others would think they were getting preferential treatment.

More than half of those responding to the survey said COVID-19 had affected their employment a great deal (30%) or quite a bit (21%). Sixty-three percent reported working in an environment where they could have been exposed to COVID-19. However only one respondent said they had ever been diagnosed with

COVID-19.The pandemic has had a variable impact on the work lives of those who responded to the survey:

- 72% feel they can access necessary tools (e.g., PPE) to carry out their work safely.
- 63% have felt more work stress during the pandemic.
- 59% worry about their health because they could be exposed to COVID-19 through their work.
- 43% agree or strongly agree that working from home is now the norm.

Respondents were evenly divided on whether the pandemic had changed the need for workplace accommodations. Similarly, they had varied opinions on the impact of the changes in the workplace that had occurred during the pandemic although about a third of those polled who answered this question felt this was not applicable to their own situation. A significant proportion of respondents felt:

- Not having to commute to and from work helped them save energy.
- Working from home had a positive impact on their psoriasis or PsA.
- They could control the pace of their workday better.

As a result of the survey findings and analysis of the current status of psoriasis care and the workplace environment, CPN, CAPP and Unmasking Psoriasis propose the following recommendations to support people with psoriasis and PsA.

Recommendations

Disability Recommendations

- Employers and policy makers should clearly acknowledge psoriasis and PsA as episodic, chronic conditions that can result in disability.
- All those who have psoriasis and PsA should have timely access to medical care and the best available treatment to minimize the disabilities these conditions might cause.
- Employers should strive to offer benefits such as health and extended health benefits and auxiliary supports (e.g., mental health programs) to all employees.
- Initiatives are required to better educate employers, human resources staff, and unions about psoriasis and PsA and the potential impact of these diseases on individuals and their families.

Accommodation Recommendations

- Workplaces and patient organizations should provide people living with psoriasis and PsA with information, tools and resources to better understand the workplace accommodation process.
- Employers should seek information about psoriasis and PsA disabilities so that they are better equipped to be flexible and responsive when developing workplace accommodation plans with employees.
- Employers should ensure that employees are confident their personal information is protected by clearly outlining who has access to what types of information when considering or developing workplace accommodation plans in human resources policies and communications with staff.

COVID-19 Recommendations

- Individuals with psoriasis and PsA should have access to the most timely and accurate information concerning COVID-19.
- Based on clinical guidance, patients with psoriasis and PsA should be vaccinated against COVID-19 with vaccines approved for use in Canada in accordance with medical guidance.
- Employers should maintain accommodations made during the COVID-19 pandemic for employees with psoriasis and PsA for whom these accommodations would be beneficial, such as working from home.

Virtual Care Recommendations

- All patients should have the option of receiving care either in-person or virtually based on the nature of the visit, physician advice, and personal circumstances.
- Policy makers should ensure that inequitable physician remuneration is not a deterrent to the use of virtual visits.
- Virtual care should be available through the publicly funded health care system and patients should not have to pay privately for such care.

Getting to Know You

Having psoriasis or psoriatic arthritis (PsA) can have an impact on all aspects of a person's life including their career and work experience. In the late spring of 2021, the Canadian Psoriasis Network (CPN), the Canadian Association of Psoriasis Patients (CAPP) and Unmasking Psoriasis, an awareness group in Saskatchewan, collaborated to develop an online survey to better understand and address the workplace challenges and needs of people living with psoriasis and PsA.

The aim of the survey was to learn about the experiences of people living with psoriasis and PsA to better understand their needs and priorities regarding accommodation in the workplace, access to private and public health benefits, and the impact of their health on their experiences in the workplace. Survey questions evaluated these issues in the context of the current COVID-19 pandemic and how adaptations to create more flexible workplace policies to accommodate virtual work as a result of COVID-19 may have helped or hindered the psoriasis and PsA community.

This report discusses the findings of that survey and broader issues concerning the rights of those with psoriasis and PsA who may experience disability or seek workplace accommodations. The report begins by providing a snapshot of the current state of care and management of psoriasis and PsA in Canada in 2021 and issues facing this community.

The workplace survey concluded August 3, 2021 with responses from 190 individuals. Responses came from all provinces with Ontario (36%) and British Columbia (17%) having the greatest number of respondents. Sixty-five percent of those who filled out the survey identified as female and almost three-quarters of all survey respondents were greater than 50 years of age.

The survey population overwhelmingly self-identified as white (89%) although a number of other ethnic groups were also represented (see full survey demographics).

Seventy-six percent of respondents said they were living with plaque psoriasis and 57% said they had PsA. Just over half of the survey population said they were living with moderate disease with 26% saying they had mild disease and 16% describing the current severity of psoriasis or PsA as being severe. These figures are not representative of the general psoriasis population in Canada (see Figure 1) but most likely reflect the fact that those who completed the survey were more motivated to participate because their condition was not as well controlled (see Figure 2).

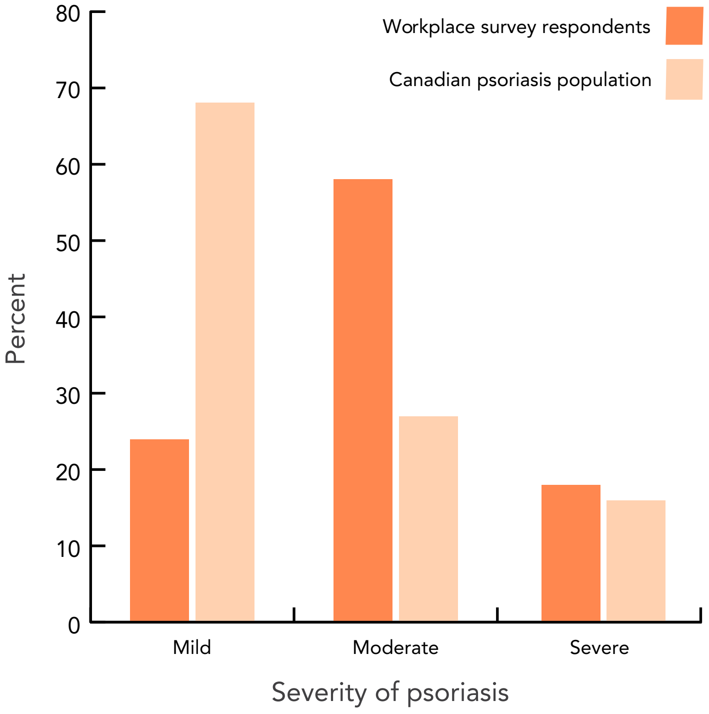

Figure 1: Workplace survey respondents' severity of psoriasis compared to a (2011) report on general psoriasis population in Canada.

A slight majority (55%) said the symptoms associated with their psoriasis or PsA were somewhat well managed while the same percentage (22%) said their symptoms were either very well managed or not well managed at all.

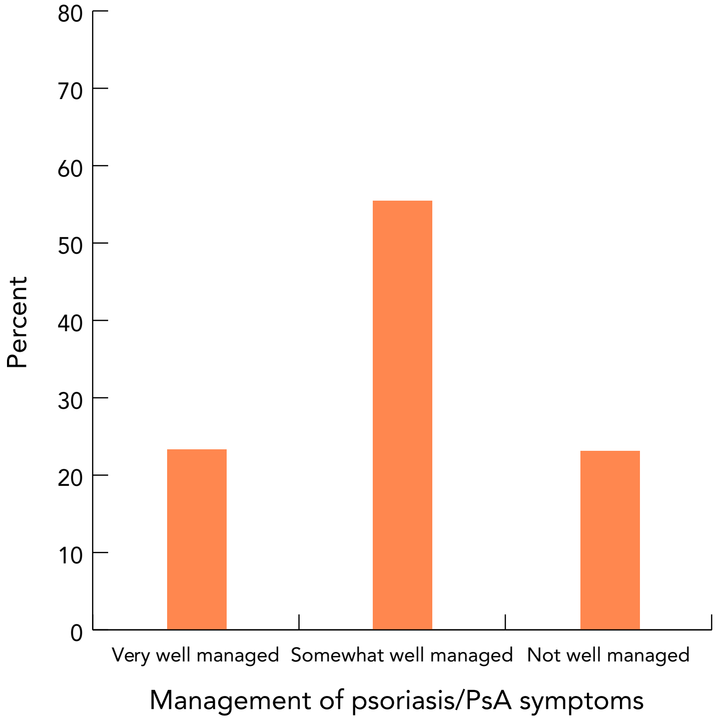

Figure 2: Survey respondents' self-report of symptom management

Survey respondents reported having a number of other comorbidities including:

- Anxiety (38%)
- Depression (30%)
- Cardiovascular disease (23%)
- Diabetes (21%)

The survey findings confirmed results from earlier polls of Canadians showing the significant impact of psoriasis and/or PSA on a person's quality of life. The survey found:

- 86% said they were worried about their psoriasis and/or PsA.
- 71% agreed or strongly agreed they had trouble managing fatigue and this impacted daily activities.
- 71% agreed or strongly agreed that they had difficulty sleeping.
- 62% said they were worried about their finances and long-term financial situation.
- Only 25% of respondents said they felt good about themselves and their bodies.

Psoriasis Supplement

Psoriasis is a persistent chronic inflammatory skin condition with severity that can range from a few dandruff-like scales to widespread patches that cover large areas of skin. Psoriasis may flare up then go into remission. During flare-ups, psoriasis causes itchiness and pain in the inflamed skin.

Psoriasis affects up to an estimated 1 million Canadians and 125 million people globally. There is no cure for psoriasis but advances in treatment mean many people with psoriasis can control their symptoms.

Psoriasis affects the regeneration of skin cells. In psoriasis, overactive signals in the body's immune system trigger new skin cells to form in three to four days instead of the usual cycle that takes 28 to 30 days. These new skin cells accumulate on the skin surface creating painful and itchy red lesions called plaques, which can form silvery scales.

While psoriasis can appear anywhere on the body, the most common sites include the elbows, knees and scalp, but can also occur on the palms of the hands, soles of the feet, nails, genitals and torso. There are five main forms of psoriasis with the most common being plaque psoriasis that affects an estimated 90% of people with psoriasis.

Psoriasis can develop at any age, although it is typically seen in adults with onset commonly being seen between the ages of 15 and 25.

Psoriasis occurs equally among men and women.

Psoriasis has a genetic basis and about one-third of people with psoriasis have at least one family member with the disease. While the exact cause of psoriasis has not yet been determined, researchers believe it involves a combination of genetic, environmental and immune factors.

Up to 30% of patients with psoriasis will develop psoriatic arthritis (PsA), a chronic form of arthritis that causes joint inflammation.

People with psoriasis and PsA are at risk of other health conditions including metabolic disease, cardiovascular disease, and depression.

Psoriasis has a broad impact on patients that extends beyond the cosmetic or physical aspects. It can negatively affect a person's quality of life due to physical pain and discomfort. Psoriatic lesions can be itchy, painful and bleed, making it difficult to sleep, dress or engage in various daily activities. If the person has PsA with joint involvement, the pain can also make it challenging for the individual to function physically. People with psoriasis have an increased risk of depression, anxiety and suicide.

Access to Psoriasis Care

Access to specialists (dermatologists and rheumatologists) to help manage their psoriasis or PsA is an ongoing concern for patients. Access to phototherapy services and to new medications are also ongoing challenges.

A report from CAPP published in 2018—PsoSerious—documented that there are still problems with access, but many Canadian dermatologists interviewed for the report indicated that, in their view, patients with psoriasis who have moderate or severe disease can usually be seen in a timely manner especially if referred by a family physician.

The number of dermatologists and rheumatologists per capita in Canada has remained stable over the past quarter of a century, according to statistics from the Canadian Medical Association. However, the number of dermatologists being trained at Canadian medical schools continues to increase. In 2020/2021 there were 189 funded postgraduate training positions in dermatology in Canada. This is an increase from 177 in 2017/18 and 155 who were in training in 2014/15.

The Canadian Skin Patient Alliance (CSPA) recommends a five-week benchmark for initial non-urgent consultation for dermatologic services based on the national median wait time. In 2012 the CPSA found that 11 out of 13 provinces struggled to meet the five-week benchmark, with 12 out of 13 having wait times double this standard. The Journey to Stability report from CAPP and CPN found that wait times to see dermatologists reported by patients were on average one to three months for 47% of respondents, followed by 20% taking four to six months. Thirteen percent took more than seven months for their first appointment.

Access to Psoriasis Treatments

Treatment for psoriasis and PsA requires a proper diagnosis and appropriate management.

A wide spectrum of treatments is available depending on the severity of the condition and individual patient characteristics. Many patients with mild or moderate psoriasis can manage their condition well with lifestyle strategies and the use of topical ointments and creams. A number of oral drugs can help to manage psoriasis systemically and are usually reserved for the treatment of more severe and/or widespread symptoms. Phototherapy is another option for treating psoriasis.

Patients with psoriasis and PsA whose condition is not well controlled by topical treatments, systemic drugs or phototherapy may be eligible for biologics (including biosimilars). Given either by injection or infusion, these medications are large molecules that block very specific inflammation pathways and can be highly effective for more serious psoriasis. In Canada, patients cannot receive biologics for psoriasis or PsA through the publicly funded system or through private insurance unless they have failed to improve with other types of treatment. Biosimilar policies have been introduced in a number of jurisdictions in Canada and among private insurers that prioritize the use of biosimilars to save money.

Patient Support Programs (PSPs) are designed by pharmaceutical companies to help patients who have been prescribed a particular medication or treatment. These programs exist for biologics for various diseases including psoriasis and PsA.

Workplace Experiences and Environment

Of the survey respondents, 45% said they were employed and working full-time. Another 24% said they were retired. The same number of respondents (10%) said they were either working part-time or were self-employed. About 11% of those who answered the survey said they were on either short- or long-term disability or leave from work. Respondents indicated they worked in a wide variety of industries or sectors with the largest proportion being in healthcare or social assistance (22%). Of those who said they were employed, 41% indicated their work involved quite a bit or a great deal of physical activity or movement. Forty-four percent said they had been working or managing a business while they had psoriasis or PsA for more than twenty years.

Many of those who answered the survey clearly felt their psoriasis or PsA was having or used to have a significant impact on their work. More than half of respondents agreed or strongly agreed that:

- Psoriasis or PsA had a negative impact on them at work.
- They felt self-conscious in a way that impacted their performance at work.
- They felt worried to a degree that it had an impact on their job performance.
- They had difficulty in performing physical tasks such as standing for long periods of time.
- They had difficulty staying focused because of fatigue.
- The location of psoriasis plaques affected them at work.
- They were worried about how psoriasis and/or PsA will affect their ability to stay employed.
- They were upset or angry about how psoriasis and/or PsA affects them at work.

Just over half of the respondents agreed or strongly agreed that they had to reduce social activities in order to maintain the energy to work and a similar but slightly smaller percentage felt the same about family activities. Asked to rank the relative importance of having information on a variety of workplace related topics, the following areas received top ranking:

- The type of workplace accommodations that might be useful.
- Understanding what my employer can ask me about my health.
- Understanding the steps involved in requesting and receiving workplace accommodation.

In ranking the relative importance of having access to certain services through work, the poll showed these to be the top services:

- Employee Assistance Program
- Support from an independent human resources specialist

Asked who they would refer to when they had questions about workplace issues, respondents listed the following as their top options:

- Supervisor (48%)
- A trusted colleague (36%)
- Human resources department (34%)
- Other people with psoriasis or PsA (27%)

Psoriasis and the workplace: International context

The World Health Organization Global Report on Psoriasis published in 2016 stated "the lost opportunities and the burden from disease (psoriasis) over a significant portion of a lifetime can be cumulative and in many cases are irreversible." The report also said that "In patients with psoriasis, functional impairment, lost opportunities in professional life and elevated economic burden for treatment expenses can add to significant socioeconomic burden on an individual level."

"Inability to work due to psoriasis increases with psoriasis severity," the report goes on. A US study quoted in the WHO report found 68% of people said psoriasis had a negative impact on their professional live with the percentage being higher for those with PsA.

An Italian survey of 787 patients with moderate to severe psoriasis from 29 dermatology centres published in 2013 found 55% of patients had limited expectations of career progression and 25% said limitations due to their condition had caused them to quit their job

Because of joint involvement, PsA is often more likely to impact a person's working life. A review of 49 studies (including Canadian studies) conducted between 1998 and 2009 looking at the direct and indirect costs of PsA found disability and lost productivity were substantial components of the economic burden of PsA.

A recent large U.S. analysis of several thousand patients with psoriasis and PsA and controls without these conditions found annual work absenteeism and short-term disability were consistently greater among patients with PsA and psoriasis than controls, "highlighting the substantial economic burden of psoriatic disease."

This report provides a Canadian perspective on the issues relating to the workplace explored in the articles referenced above through survey findings and the individual perspectives of patients with psoriasis and/or PsA in Canada.

When asked about their satisfaction with the answers they received from these sources, respondents indicated they were more satisfied with information from a supervisor, trusted colleague, or others with psoriasis or PsA than from a human resources department.

Those with psoriasis and PsA can experience challenges obtaining and maintaining employment—despite the numerous safeguards put in place under Canadian law to protect them. This has been well documented in studies published in medical journals and reports from medical organizations *(see sidebar—Psoriasis and the workplace: International context–for a summary of peer-reviewed articles and reports that have reported this).*

Dr. Vinod Chandran, an associate professor of rheumatology at the University of Toronto and co-director of the psoriatic arthritis program at the University Health Network said that with the advent of biologics, people with PsA may be more functional and have fewer issues with work than these earlier studies indicate. However, he said, he was not aware of any long-term studies that could confirm this. To a degree, Dr. Chandran said, it depends on how quickly a person is diagnosed and how well they respond to treatment.

Margaret, the founder of Unmasking Psoriasis, can speak from personal experience about the impact of psoriasis on work life:

> *"I couldn't work for the longest time because I couldn't walk, I couldn't stand. My hands and my feet were both so terrible that there were days I couldn't type on a computer, I couldn't hold a pen. I couldn't walk more than 10 steps without my feet bleeding. It was not good for an awful long time."*

Margaret talks about taking casual work to accommodate the intermittent nature of her disease and that was when she experienced the stigma which caused her to start Unmasking Psoriasis. As described on the organization's website, Margaret was bar tending an event when a customer saw her hands and refused to accept his drink. Devastated, she spoke with

Dr. Hawkins, her dermatologist, about the consequences of this lack of understanding. Together they decided they could make an effort to change this reality by fundraising to raise awareness. She founded Unmasking Psoriasis to raise awareness and meets frequently with employers in her home province of Saskatchewan to help them understand how to better support their workers.

Margaret describes the incident referenced on the Unmasking Psoriasis website:

> *"This person came up to me and ordered a drink. I mixed it and handed it to him. And he looks at me and says, 'You're contagious, I'm not taking a drink from you." I said, 'It's psoriasis and I'm not contagious." He wouldn't believe me, and he went to management. They let me go that day and I never returned."*

Brenda, who has had psoriasis since age five, had a similar experience while working at a pizza restaurant as a teenager.

> *"We have uniforms that we had to wear, and you could see the rash on my arm. I worked there for probably four years. The manager actually cried when he had to let me go because the owners came in and had seen my arms. I explained to them what it was and that it was not contagious. But eventually the management staff decided it wasn't a good idea and I was let go."*

Brenda says she also feels having psoriasis influenced her choice of career. She had wanted to be an emergency nurse but was advised by a career counsellor in college to choose a career other than nursing because the psoriasis on her arms was visible and not under control. Brenda said she hoped the situation would be different now with the ability of biologics to control her psoriasis. "If my marks were good, and they were happy with the disposition and everything I cannot see for a second why I wouldn't be able to do it."

Andrew, the founder of the Canadian Psoriasis Network, who has been selling real estate since 1994, said while having psoriasis did not influence his choice of career, it has had an impact on his work when psoriasis lesions were very visible. "You have to understand if you didn't have psoriasis and you saw somebody with it, the first thing you'd think is: 'I don't want to catch that'. I remember for instance going to pass my pen to someone and they would recoil. If you have these sort of crusted, bleeding, white scaly hands I can see why somebody would not be comfortable with that."

Andrew talked about masking his psoriasis by putting bandages over his fingernails. "I went through a lot of years of misery and trying to hide the disease." However even when his flares were very bad, Andrew said he would "soldier through" and continue with house showings. With his psoriasis now well-managed with biologic therapy, Andrew said, his career has taken off and he is now able to exercise and sleep well which was not an option when his psoriasis was not controlled. "If you can sleep, you can think more clearly and you can be more diligent in your work."

Simon, who has psoriasis and who started his career as a banker and is now an independent financial consultant said he was always self-conscious about his condition when selling mutual funds directly to clients and he made a conscious decision to move into a role which did not involve so much direct interaction with people. "No one told me they were uncomfortable, but you can't tell, and I was thinking ahead to consciously get into a role where appearance doesn't matter." In his current role he said "the client needs you more than you need your client. The client comes to you, and it doesn't matter what you look like." Simon is a board member of the Canadian Association of Psoriasis Patients.

Laurie Proulx, who is a consultant in human resources and a patient advocate for those with disabilities, said she believes there is now more awareness among both employers and patients about disability management compared to a decade ago. She specifically referenced the *Accessible Canada Act* implemented in 2019 for federal employees and provincial legislation such as the *Accessibility for Ontarians with Disabilities Act.*

Proulx also talked about the importance of ongoing work by a diverse group of disability advocates. She noted that it was disability activists who coined the phrase "nothing about us without us" which has become the slogan of patient advocates in general. In addition, she said, there is an expectation from society that employers will respect disability rights.

"But I think there's more work to be done," she adds.

Rights for those with disabilities

When it comes to the workplace, Wade Poziomka, a Hamilton-based human rights lawyer and chair of the Ontario Bar Association human rights section, says some industries and activities such as transportation and publication transportation are federally regulated and subject to the *Canadian Human Rights Act.* Other industries fall under provincial legislation. Kim Holland, a Calgary-based employment lawyer says "it is a common misconception within employment law, that one law applies to everyone. But it really goes back to the *Constitution Act* that states that the federal government has jurisdiction over certain industries, and everything else is for the provinces to oversee."

"The legislation from province to province as well as federally is pretty much the same," Holland adds.

Protection for those who are disabled is strongly laid out by human rights commissions in various jurisdictions across Canada. The language used by the Ontario Human Rights Commission in its policy on ableism and discrimination based on disability is representative and described by Poziomka as the single most comprehensive policy he has seen in Canada *(see sidebar—Ontario Human Rights Commission Policy on Ableism and Discrimination excerpt).*

The International Federation of Psoriasis Association notes that World Health Organization countries acknowledge that psoriasis and PsA can be disabling because they can cause long-term physical and/or psychosocial impairment. It is also important to

Ontario Human Rights Commission Policy on Ableism and Discrimination (excerpt)

In Canada and across the world, people with disabilities have long experienced abuse, neglect, exclusion, marginalization and discrimination.

This negative treatment has included:

- *Restrictive immigration policies preventing people with disabilities from entering the country;*
- *Involuntary sterilization to prevent people with disabilities from having children;*
- *Inappropriate and harmful institutionalization, seclusion and restraint; and*
- *Major barriers to accessing educational opportunities, employment opportunities and fairly paid work.*

While there have been some significant gains for people with disabilities in recent years, serious barriers to equality continue to exist throughout society. Statistics Canada reports that Ontarians with disabilities continue to have lower educational achievement levels, a higher unemployment rate, are more likely to have low-income status, and are less likely to live in adequate, affordable housing than people without disabilities. It is clear that people with disabilities continue to experience difficulties accessing employment, housing and various services throughout Ontario. "Disability" continues to be the most frequently cited ground of discrimination under the Ontario Human Rights Code (Code) in human rights claims made to the Human Rights Tribunal of Ontario.

People with disabilities are a diverse group, and experience disability, impairment and societal barriers in many different ways. Disabilities are often "invisible" and episodic, with people sometimes experiencing periods of wellness and periods of disability. All people with disabilities have the same rights to equal opportunities under the Code, whether their disabilities are visible or not.

acknowledge that given the variability of these conditions, while some people with psoriasis or PsA may identify with having a disability, others may not. The needs for accommodations or disability supports may also vary throughout the course of one's condition.

Many people with psoriasis and PsA can find the paperwork that is required to claim disability insurance to be overwhelming. "I had to claim disability with my insurer for my mortgage," said Margaret. "It probably took three, four letters from my doctor and I had to fight to get [my] disability [claim] with them [approved]."

Dr. Catherine McCuaig, president of the Canadian Dermatology Association (CDA) notes it to be difficult for people without a group insurance plan to obtain disability insurance or life insurance once a diagnosis is made.

"We could write many letters to the (insurance) company and it wouldn't make a difference once that diagnosis has been made. They might ask for higher premiums or refuse to cover individuals."

Proulx notes that insurance companies can sometimes request more information about a person's health than is required or is appropriate for their disability coverage. She said that ideally a physician will obtain a patient's consent every time they share information but admits this is not always the case. Physicians also sometimes request an additional fee from the patient to provide a note to an insurance company.

For all the list of rights and protections for those with physical disabilities such as psoriasis or PsA, Margaret still feels there really are no protections in the workplace. She said she does a lot of speaking to companies to raise awareness about psoriasis and many still do not understand it all. "One employer actually said to me, 'Oh, my goodness, I fired somebody because of it' and that was just five years ago."

In contrast, Morris, a tenured professor at the University of Toronto with PsA said he is "golden" as every effort has been made to accommodate his disability. "During the time when I had to lay in bed for four months, I basically just worked on papers," he said. "I possibly have the one profession on the planet where I can lay in bed and be productive."

Organizations with responsibilities under the Code should be aware that new and emerging disabilities may not yet be well-understood. In general, the meaning of disability should be interpreted broadly. It may be more challenging for a person with a less-recognized disability to have their disability verified by their family doctor, for example. It may be necessary for an employer … to consult with a specialist with expertise in the disability in question. The focus should always be on the needs and limitations of the person requesting the accommodation, rather than on a specific diagnosis.

The ultimate responsibility for maintaining an environment free from discrimination and harassment rests with employers, housing providers, service providers and other responsible parties covered by the Code.

Read the full policy here.

The Commission notes in another document that on average, 30 – 50% of human rights claims cite the ground of disability with most being in the area of employment.

Brenda feels that while much has been done by groups such as CPN and CAPP to inform people about psoriasis, the potential seriousness of the condition compared to other diseases is often not appreciated.

Dr. David Adam, president of the Dermatology Association of Ontario and the Chair of the Medical Advisory Board for CAPP has a different perspective on disability and psoriasis. His view is that if a person's psoriasis or PsA is so serious as to be disabling then that patient urgently requires effective therapy with a systemic agent. Given the high level of efficacy of current systemic agents, disability due to psoriasis should not be a long-term issue.

However, accessing treatments for psoriasis and PsA can be an onerous process with significant paperwork required by public and private health benefit plans. Morris admits that the volume of paperwork needed to make sure he gets the biologics he needs for treatment of his PsA can be overwhelming. He says he is very lucky because the clinic he attends deals with all this paperwork.

Dr. McCuaig acknowledges "there is quite a bit of paperwork to be filled out" to prescribe biologics to a patient with psoriasis and/or PsA but from her perspective "that's fair enough, when you're talking about the cost of these medications."

If a person with psoriasis is requesting or receiving long-term disability in 2021, Dr. Adam said, the inference is that it is a possibility that their disease is not being adequately treated. While short-term disability may be appropriate for patients until their psoriasis is brought under control, Dr. Adam, said longer-term support is not usually required for patients under his care as disease control is usually achieved with the highly effective treatments available today. The circumstances may be different from those with PsA which, if not diagnosed and treated early, can result in irreversible joint damage. Those with other, associated health conditions may also require access to disability benefits.

When it comes to dealing with discrimination in the workplace, Holland says "there's a lot of opportunity for growth and awareness. I would like to see my job [as a disability and human rights lawyer] not be required but that certainly isn't going to happen anytime soon." Poziomka said "I think there's a lot of people in our community that are racist, that are homophobic, that will judge people on the basis of disability. I just think for the most part that they're more hidden now. But they're still there."

Disability Recommendations

- Employers and policy makers should clearly acknowledge psoriasis and PsA as episodic, chronic conditions that can result in disability.
- All those who have psoriasis and PsA should have timely access to medical care and the best available treatment to minimize the disabilities these conditions might cause.
- Employers should strive to offer benefits such as health and extended health benefits and auxiliary supports (e.g., mental health programs) to all employees.
- Initiatives are required to better educate employers, human resources staff, and unions about psoriasis and PsA and the potential impact of these diseases on individuals and their families.

Workplace Accommodation

A minority of those individuals who responded to the workplace survey felt they could make use of workplace accommodations. Only 33% agreed that they could access needed workplace adaptations or accommodations.

Two-thirds of respondents indicated they had made use of one or more of a variety of workplace accommodations (see Figure 3). Opinions were mixed on the helpfulness or effectiveness of the accommodations that people had used. Paid time away from work to attend medical appointments, flexible work hours, and the ability to work from home being seen as the most useful.

While most people who did not use workplace accommodations did so because they felt they did not need them, a significant minority of respondents said they did not want their employer to know about their health situation or they felt others would think they were getting preferential treatment.

An Employment Assistance Program was the most likely mental health resource that survey respondents said they could access although reimbursement for counselling through an employer benefit plan and the use of free self-directed programs or resources

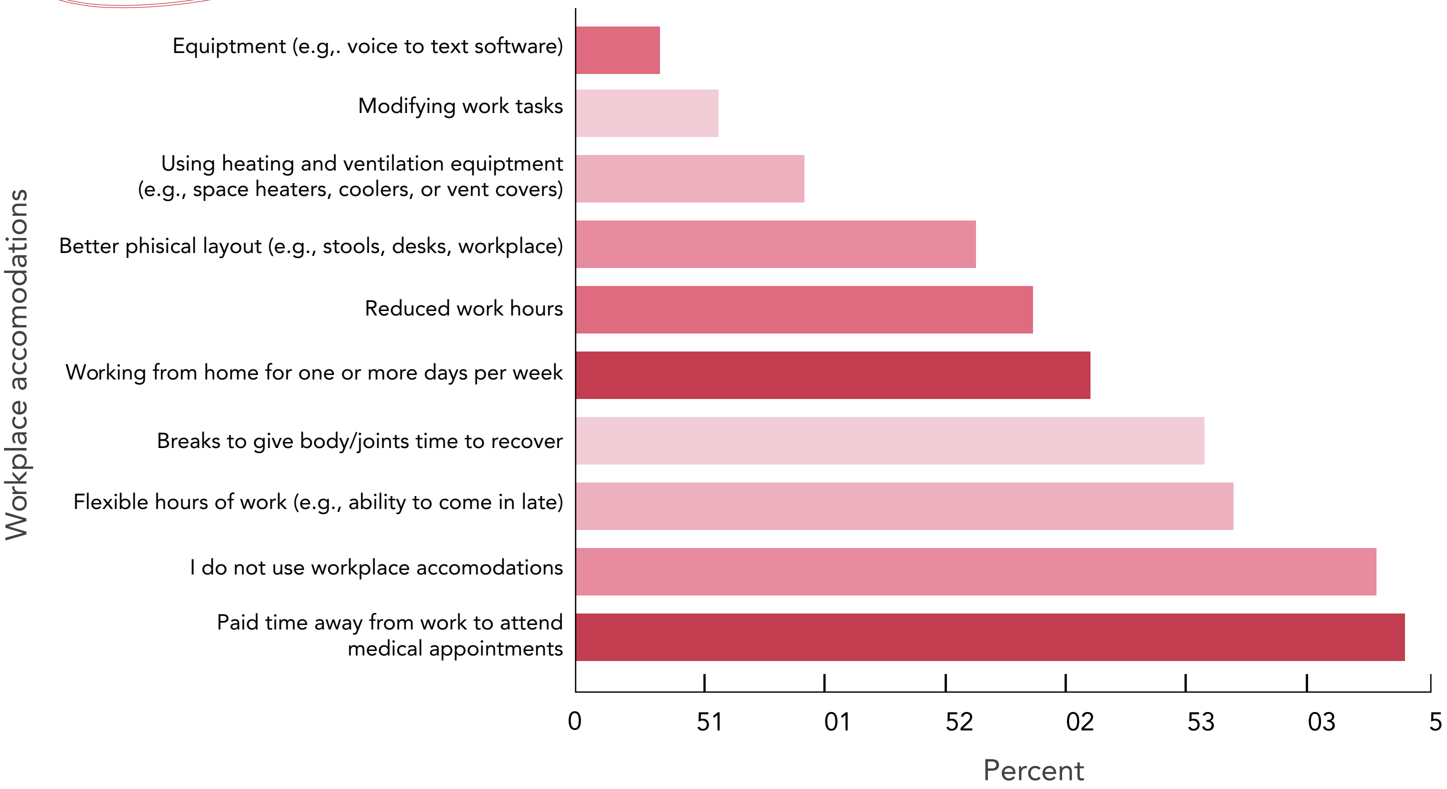

Figure 3: Workplace accommodations used by survey respondents.

offered through work were also mentioned.

Accommodating those with disabilities in the workplace, including those caused by diseases such as psoriasis and PsA are core principles for protecting the ability of these individuals to work productively.

Poziomka provides an example of what workplace accommodation is and how it works:

> *Let's assume that somebody has depression which is often a chronic disability and cyclical in nature. As a result of their depression, they miss work and they're away from work for 10 out of 20 workdays. Normally, the employer would fire them because their absenteeism rate is so poor, but they're only absent from work because of their disability, because of the depression. That triggers that duty to accommodate. Rather than terminate someone or discipline them, you'd ask questions to see if the disability was part of the reason for their absence. You look at what steps can you take as the employer to facilitate them coming to work, notwithstanding that depression.*

As the Canadian Union of Public Employees (CUPE) states in discussing disability rights in the workplace, "the duty to accommodate is a broad equality concept that applies to all grounds of discrimination covered under human rights legislation and the Canadian Charter of Rights and Freedoms. CUPE adds that workplace accommodation "usually involves treating that worker differently, so he or she can be treated equally and maintains dignity."

Proulx said while employers still feel workplace accommodation can involve a lot of work, especially if they are a smaller company, "a lot of the time, it can be just small changes that are done in the workplace to include people and make it so they can also manage their health and make those important contributions at work."

Poziomka describes it as "levelling the playing field" for someone who has a disability of any sort. "Flexibility and adaptability are key and recognizing that we can include people without causing a lot of rigamarole for the organization."

"In terms of what is required, we usually defer to the treating physician in determining exactly what those accommodations should look like and what is required," said Holland.

Proulx noted that a person with psoriasis or PsA can ask for some sort of accommodation during the hiring process for a job if they feel they might need it. But she admitted it can be "scary" to ask for any sort of accommodation when in the process of being hired.

Holland adds there are some circumstances when an employer can discriminate against people who do not have a certain physical ability required to carry out their duties—for work in emergency response and health care settings, for example. "With that being said," she adds, "I cannot conceive of a condition such as psoriasis getting in the way in the majority of work settings."

From a human resources perspective, Proulx said while an employer may notice a change in performance with someone who has an episodic condition such as psoriasis and may introduce changes to accommodate that person, in most instances such requests come from the employee when their health impacts their work.

To help those with psoriasis and PsA understand workplace accommodation-related issues, CPN, CAPP and Unmasking Psoriasis have developed three tools to assist them and their physicians:

1. A guide for patients on how to have conversations with employers about workplace accommodations
2. Privacy expectations when discussing workplace accommodations with employers
3. A tool for patients and physicians when filling out forms related to accommodations and disability

For those with psoriasis or PsA, the reality of workplace accommodation can still differ from the ideal. "I was let go from a job because my fingers were bleeding and I couldn't handle luggage," said Margaret. She added that there was "absolutely no" effort made to accommodate her.

Many with psoriasis or PsA have never or rarely sought accommodation in the workplace and have managed their condition on their own.

Simmie, who is president of CPN, is one such person. She talked about masking her condition at work and not asking for any accommodation in order to avoid discrimination and being labelled that she was not able to do her job. "I grew up in a culture where you don't tell anybody you have this." She said now she realizes all this does is perpetuate pain and suffering.

"I learned to deal with it at a very young age," said Brenda who has worked as a pharmacy technician for 30 years. "I took very little time off work. When it irritated me or bothered me, I would go in the bathroom on my break or lunch and disrobe, put on ointment or cream, let it soak in, then put my clothes back on and go back to work. That was the way I dealt with it."

Brenda said the one time she did need to seek time off to be hospitalized because the rash on her hand was so bad, the assistant manager of the pharmacy "was absolutely marvelous. He had no problem and said take all the time you need to be off." Despite this favorable environment, Brenda said that she has masked her condition at work as "I didn't want that to define who I was."

Simmie said she feels attitudes towards workplace accommodations have changed now for the positive.

> *"I would say there's definitely a change in attitude. I think the workplace is more welcoming. But I also think what's happened is when you think about the number of lawsuits of people who have been discriminated against, for various reasons, I think there is more knowledge within workplaces about the responsibility you have around accommodation. Whether it's forced openness or just people are coming in and being more open about it, it's just respecting the fact that a person needs time off."*

Regarding respect for patient confidentiality, Proulx discussed the "disclosure dance" where an employee has to decide how much information about their personal health to share when requesting any workplace accommodation. While employees are not required to share their diagnosis with their employer, they can be asked to provide medical evidence of their disability. She said in large organizations, the human resources departments should have policies in place to deal with this situation.

Holland described the situation as a "back and forth consultation process." She added "privacy is very important, and all employers have an obligation to maintain the privacy of their employees and they do not have the blanket right to know exactly what a person's diagnosis is."

Asked what changes in the workplace they would like to see to better accommodate them, survey respondents had a number of responses such as:

- Make hours more flexible.
- Trust that employees are more productive when they work from home.
- There isn't much for those with illnesses.
- Support each employee individually.
- I know you are concerned. Please do not ask, every time you see me, how I am doing.
- Sensitivity training for colleagues.
- Please do not assume I am looking for an excuse not to work.
- Don't be judgmental.

Asked what advice they would give to others with psoriasis or PsA regarding workplace issues, survey respondents provided a wide spectrum of advice including these examples:

- Do what is right for you.
- Listen to your body and rest whenever possible.
- Find a less stressful job with flexible hours.
- Don't be shy to ask for help.

Accommodation Recommendations

- Workplaces and patient organizations should provide people living with psoriasis and PsA with information, tools and resources to better understand the workplace accommodation process.
- Employers should seek information about psoriasis and PsA disabilities so that they are better equipped to be flexible and responsive when developing workplace accommodation plans with employees.
- Employers should ensure that employees are confident their personal information is protected by clearly outlining who has access to what types of information when considering or developing workplace accommodation plans in human resources policies and communications with staff.

Impact of the COVID-19 Pandemic

More than half of those responding to the survey said COVID-19 had affected their employment a great deal (30%) or quite a bit (21%). Sixty-three percent reported working in an environment where they could have been exposed to COVID-19. However only one respondent said they had ever been diagnosed with COVID-19.

The pandemic has had a variable impact on the work lives of those who responded to the survey:

- 72% feel they can access necessary tools (e.g., PPE) to carry out their work safely.
- 63% have felt more work stress during the pandemic.
- 59% worry about their health because they could be exposed to COVID-19 through their work.
- 43% agree or strongly agree that working from home is now the norm.

Respondents were evenly divided on whether the pandemic had changed the need for workplace accommodations. Similarly, they had varied opinions on the impact of the changes in the workplace that had occurred during the pandemic although about a third of those polled felt this was not applicable to their own situation. A significant proportion of respondents felt:

- Not having to commute to and from work helped them save energy.
- Working from home had a positive impact on their psoriasis or PsA.
- They could control the pace of their workday better.

However, few felt strongly that their employer or business would make the needed accommodations for psoriasis or PsA after the pandemic is over.

Just as it has impacted all of society and people requiring medical care, so the COVID-19 pandemic has had a significant effect on patients with psoriasis and PsA. To better understand this impact in Canada, in Sept. and Oct. 2020 the CPN, CAPP and Unmasking Psoriasis surveyed 830 patients with psoriasis and/or PsA. They found that:

- 68% had a virtual medical appointment.
- 57% reported feeling anxiety as a result of the pandemic.
- 45% of respondents had avoided seeking care with a physician or hospital because of COVID-19.
- 40% reported being depressed.
- 25% felt they had worse or much worse access to employment because of the pandemic.
- 13% had to change treatment to manage new flares.
- 10% said their treatment plan was impacted because of the pandemic.

Margaret talked about being very concerned when the COVID-19 pandemic struck. "The doctors here had no idea what to do." Because of her concerns about COVID-19 and caring for her mother, Margaret said she went into isolation and was unable to work.

In contrast, Morris said "I have honestly never felt threatened or scared," by COVID-19. However, he works in an academic environment as a scientist and so was able to keep very up to date on what information was available as the pandemic evolved.

Andrew talked about sharing everybody's concerns about COVID-19 when it first struck but then being told by his physician that people with psoriasis who were taking biologics like himself actually did better if they contracted COVID.

Dr. Adam said he did have a few patients who stopped taking their medication when the COVID-19 pandemic struck and flared as a result, but this was not a major trend. In addition, he said, there were probably patients who did not seek care when it was needed because of fears of becoming infected in the doctor's office or clinic. "I think some people with psoriasis were affected but not to the same degree as those who had a heart attack or who had cancer and the window of opportunity to treat them was missed because they avoided an appointment."

Dr. Chandran said without rigorous survey data from patients it has been hard to assess exactly what the impact of the pandemic has been. He noted that the Toronto Western Hospital clinic where rheumatologists and dermatologists jointly manage patients with psoriasis ceased in-person care when the pandemic began. However, he said, he and his colleagues had been able to maintain communications virtually in order to continue to provide coordinated care.

Simon said COVID-19 has been a huge benefit for him in the workplace because it has given him a reason to hold meetings on the video platform Zoom which allows you to filter your appearance. However, he said, now that his psoriasis is clearing due to therapy, he "can't wait" to get back to more direct meetings.

Morris is another example of someone with psoriatic arthritis who has benefitted with the changes in the workplace due to the pandemic. "My knees have never ever been in such good shape in six years," he said. "because I don't have to (go into) work. I walked up my steps to a little office in the attic and I'm done." He added that during the pandemic the university specifically said, "unless there is a compelling reason that you must work to come to the office, we want you to be at home."

Kim was in the unique position of being someone with psoriasis who was also a new mother and who has been working on the front-line as a nurse in Quebec providing care to COVID-19 patients. While understandably feeling ongoing anxiety, Kim says she has weathered the pandemic well as a result of having strong support from her spouse, her support network and her colleagues.

"The only thing that has been an issue," said Kim "is that because of the pandemic, we had to wear those almost plastic gowns over our uniforms when we're working in COVID units, and you sweat like crazy. I would get super itchy. But they understood that, and I would just leave the area a little bit more often just to get some air and put on a new gown."

Organizational culture has also played a part in determining to what degree organizations have offered accommodations to their employees during the pandemic, said Proulx. She noted, some companies had not allowed their employees to work at home before the pandemic if it was feasible as they want to be able to "keep an eye" on them. She said she hopes some of the workplace changes made to deal with the pandemic will remain post-pandemic thereby benefitting those with psoriasis and PsA. But she admitted making such permanent changes in the workplace environment can be difficult and many might return to requiring people to work in an office when the pandemic is over.

Holland said what organizations can do regarding accommodation made during the pandemic when the pandemic ends is a hotly debated topic in legal circles. "If an individual is finding that they're more productive at home, that in and of itself is not grounds to maintain remote work as a right," she said. "However, if there is a genuine requirement for accommodation, that individual would need to visit their doctor and actually provide medical documentation that the accommodation is required."

COVID-19 Recommendations

- Individuals with psoriasis and PsA should have access to the most timely and accurate information concerning COVID-19.
- Based on clinical guidance, patients with psoriasis and PsA should be vaccinated against COVID-19 with vaccines approved for use in Canada in accordance with medical guidance.
- Employers should maintain accommodations made during the COVID-19 pandemic for employees with psoriasis and PsA for whom these accommodations would be beneficial, such as working from home.

Tele-dermatology and Virtual Care

Morris said his clinicians have adopted a hybrid approach during the pandemic using both virtual and in-person visits for his care and he said this has worked flawlessly. He said some procedures such as corticosteroid injections were done in-person in the clinic whereas other routine issues could be handled with telephone calls.

Having been involved in advocacy for patients with psoriasis and PsA through CAPP, Morris said the organization has argued for years that many dermatology services could be delivered virtually but the government consistently refused to pay for this approach. "This is one of the COVID silver linings—that the government is paying for what we argued for 10 years ago."

Dr. McCuaig agreed that the COVID-19 pandemic has escalated the use of virtual care by dermatologists and has quickly moved physicians away from being "dinosaurs" in the adoption of the new virtual means of communicating with patients. While technological advances make it possible for skin lesions to be photographed and shared virtually with dermatologists, physicians remain divided on the value of doing this. "We may not receive clear and close enough photos including all the areas of the skin, hair and nails that are pertinent to making a proper diagnosis," said Dr. McCuaig.

"For many illnesses it is better to see a patient in person at least for the first consultation, but routine follow-up care and communication of results can be done virtually," she said. For patients with psoriasis in rural areas, she said, this means they would not need to travel as much for care.

Dr. Adam agrees virtual visits can be perfectly appropriate for those with psoriasis or PsA whose disease is well controlled with systemic therapies or biologics. He said while it may be counter-intuitive, it is patients with more mild or moderate disease who are more likely to require in-person visits as they might require more direct monitoring as they search for the best treatment to control their condition.

For patients with PsA requiring care from a rheumatologist, virtual visits can be more problematic because of the challenges in assessing joint health remotely. "People have tried joint counts online and I don't think that's reliable," said Dr. Chandran. He said he has tried to persuade patients to maintain in-person visits noting that hospital clinics have actually been very safe spaces during the pandemic.

For others with psoriasis such as Kim and Brenda, virtual care has not been a factor in their visits with their physicians since COVID-19 started as in-person care has been maintained throughout the pandemic. "Not all dermatologists are the same," said Brenda, "and having a good dermatologist who works with their patient and will basically do anything to try and help them especially during a time like COVID is so important. And I feel like I've gotten that support."

Simon said he would not have minded having access to virtual care during the pandemic "but it wasn't an option."

Virtual Care Recommendations

- All patients should have the option of receiving care either in-person or virtually based on the nature of the visit, physician advice, and personal circumstances.
- Policy makers should ensure that inequitable physician remuneration is not a deterrent to the use of virtual visits.
- Virtual care should be available through the publicly funded health care system and patients should not have to pay privately for such care.

Acknowledgements

CPN, CAPP and Unmasking Psoriasis would like to thank all survey participants and all of those who gave their time to be interviewed for this report. They also thank Pat Rich for his assistance in writing the report, and Laurie Proulx & Kim Holland for developing tools to support people living with psoriatic disease navigate workplace impacts.

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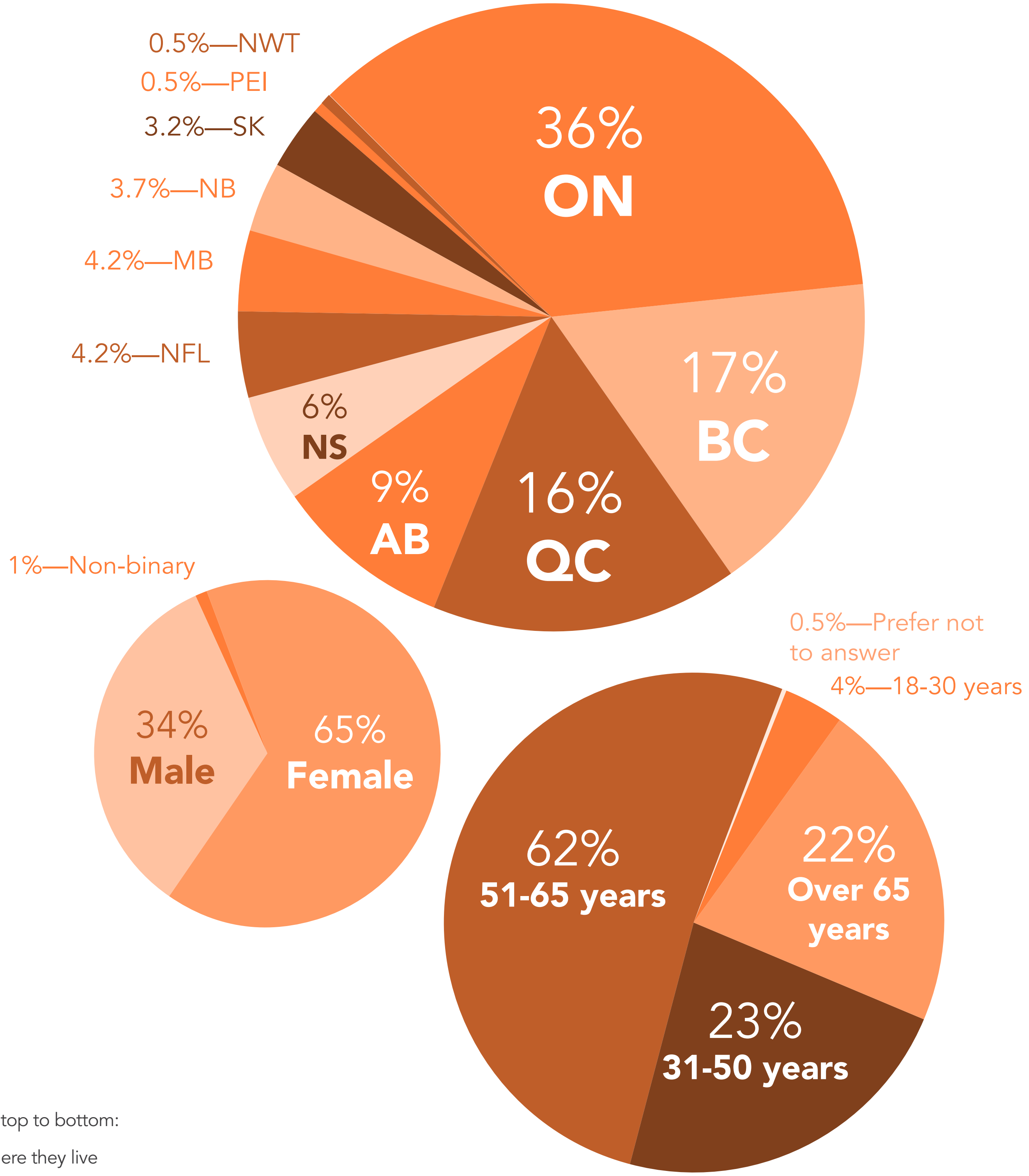
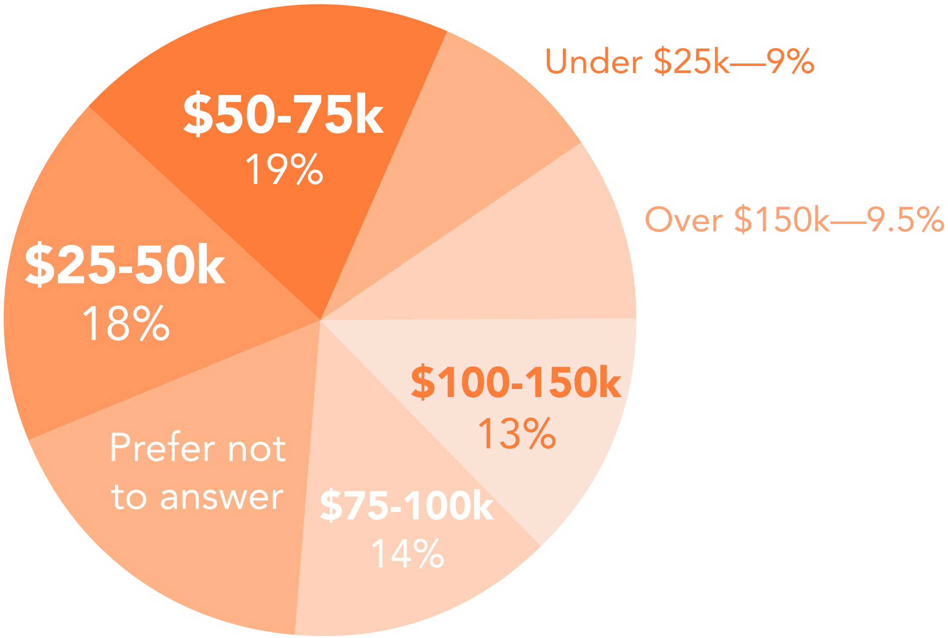
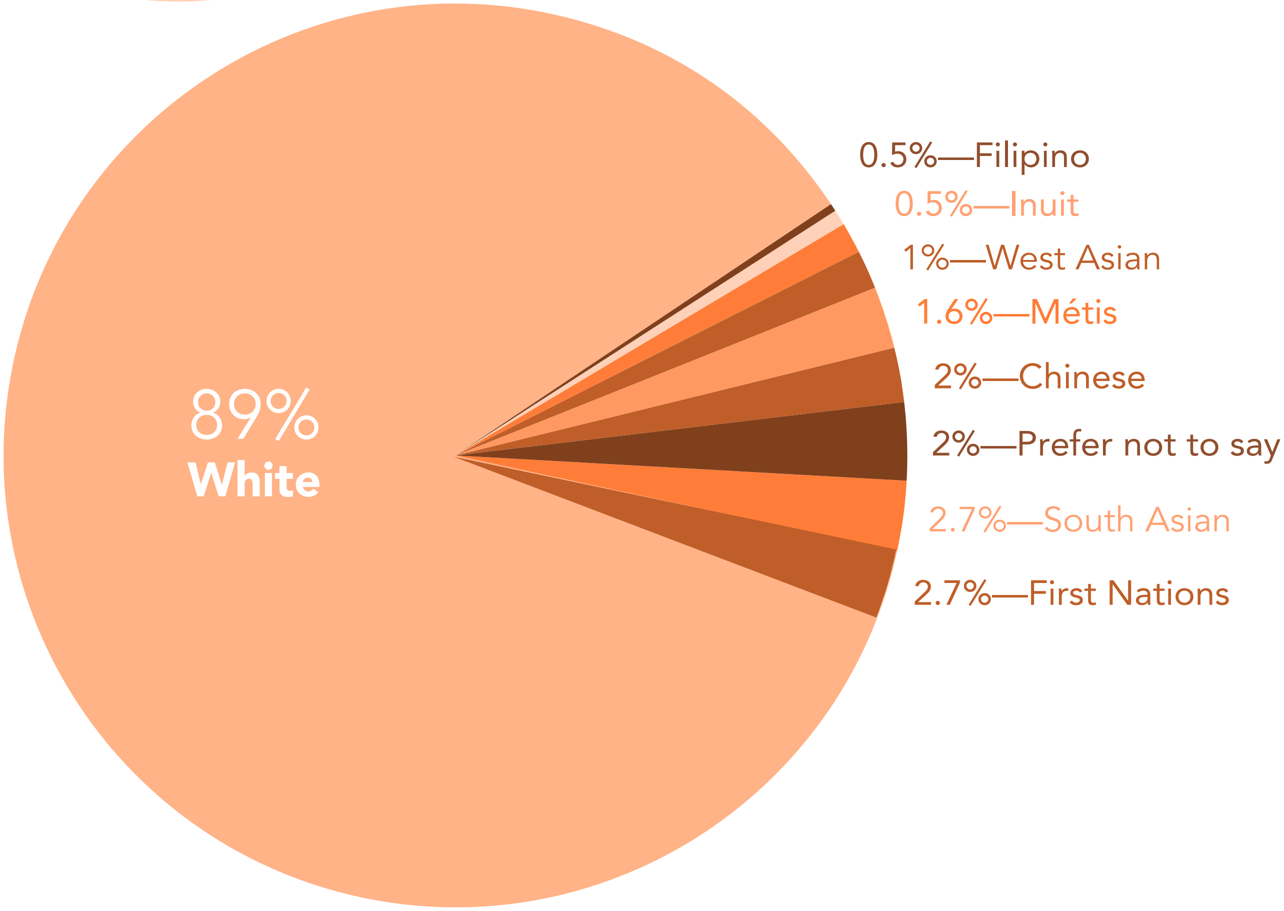
Survey Demographics



From top to bottom:

1. Where they live
2. Gender
3. Age range





From top to bottom:

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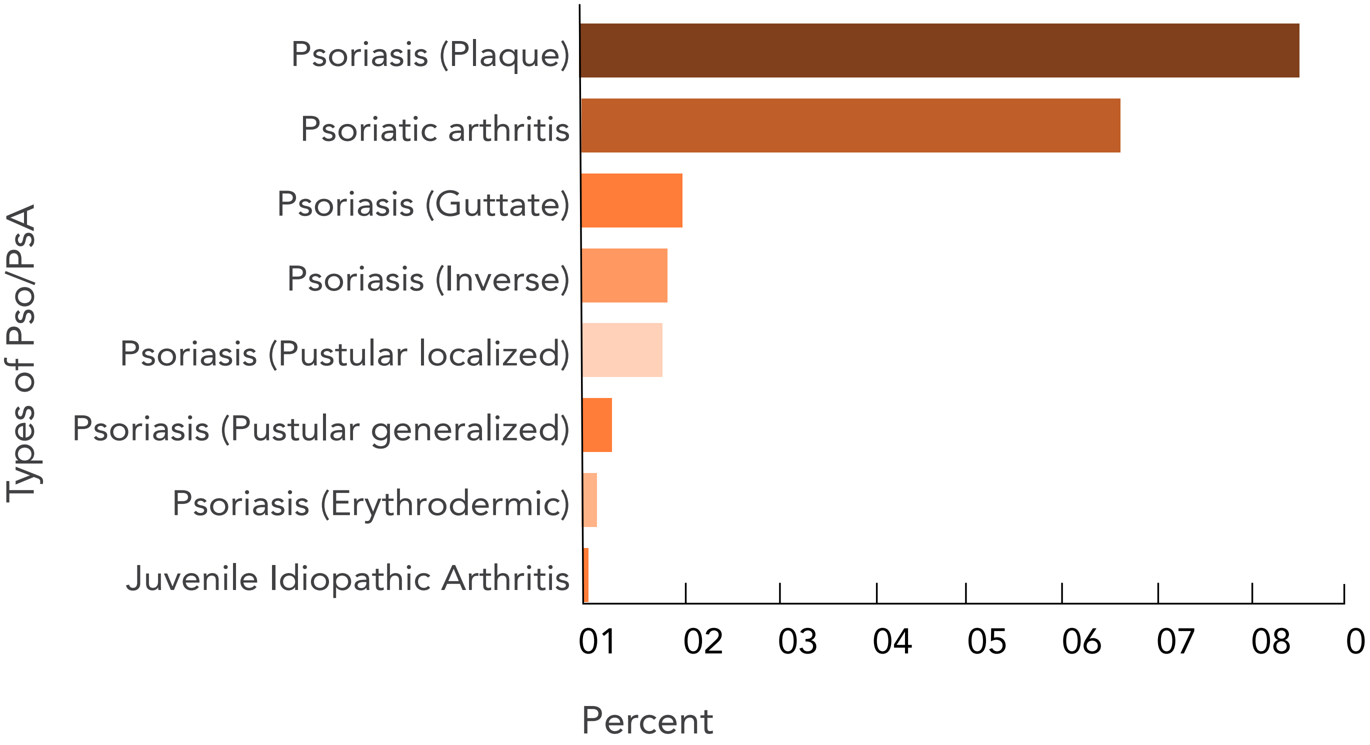
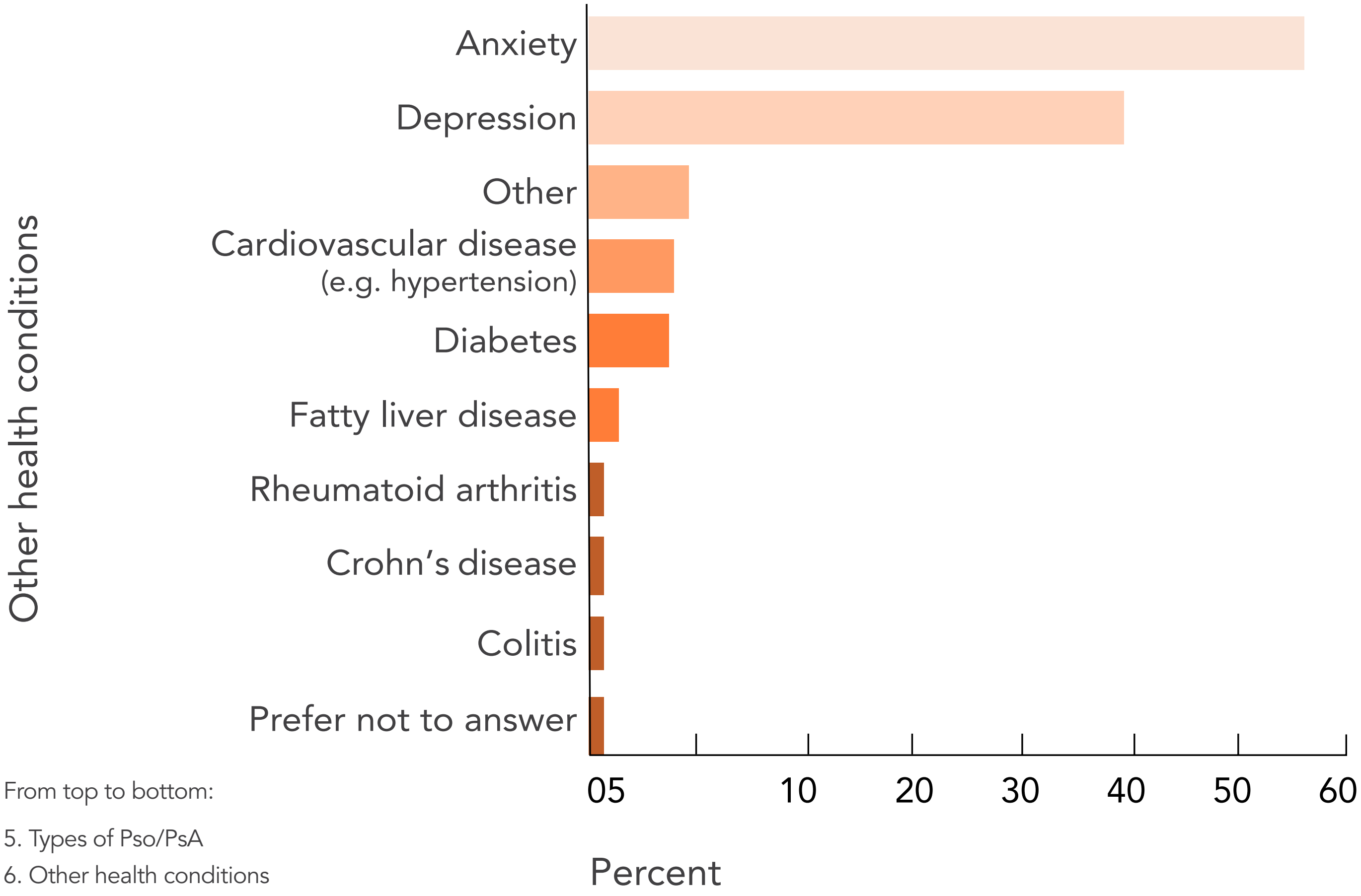
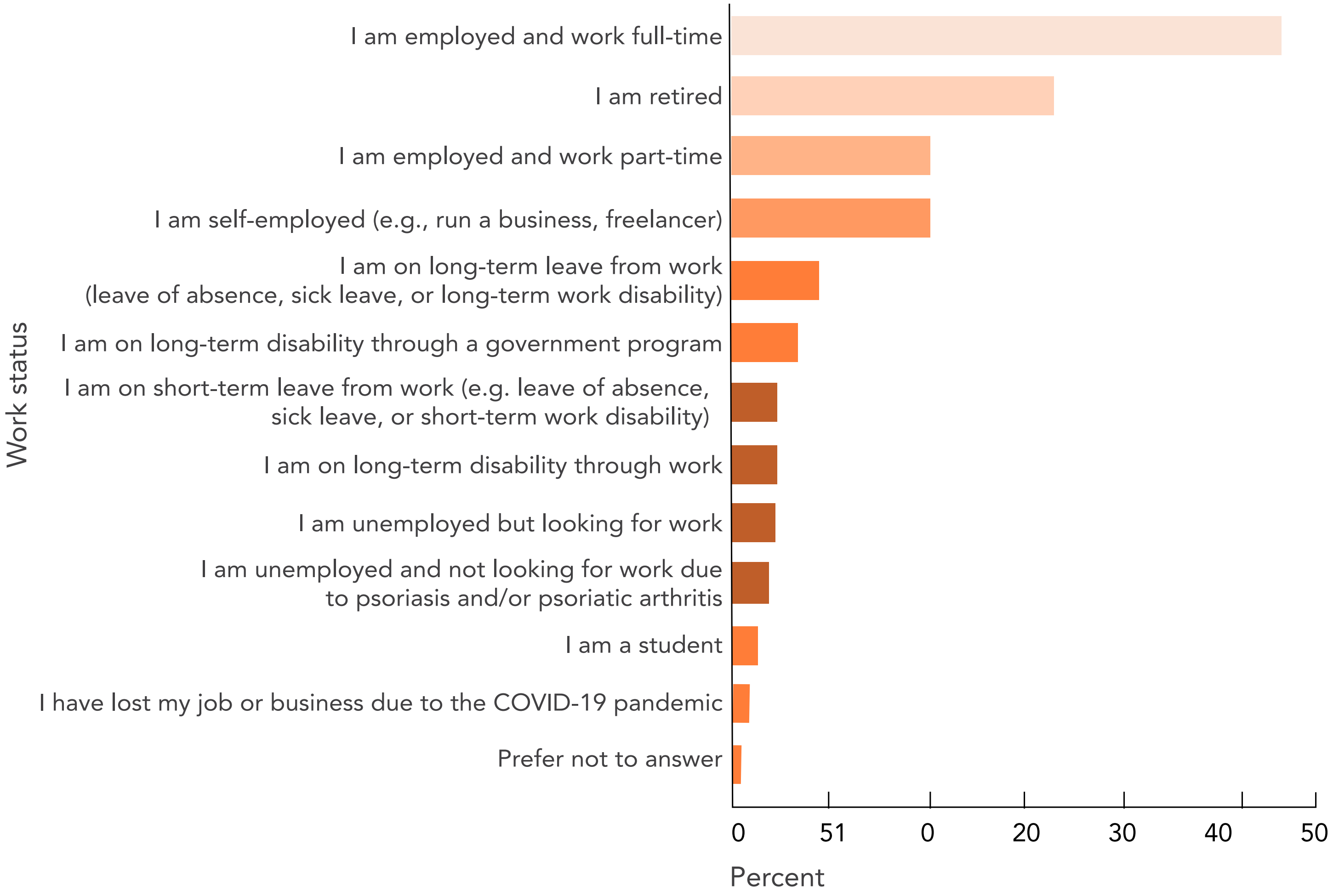
5. Ethnicity

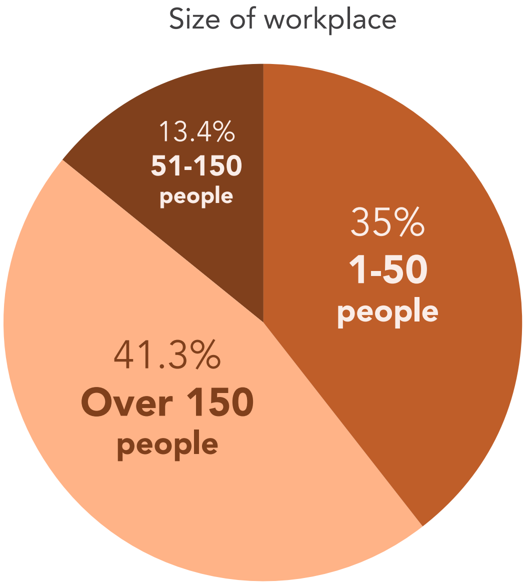


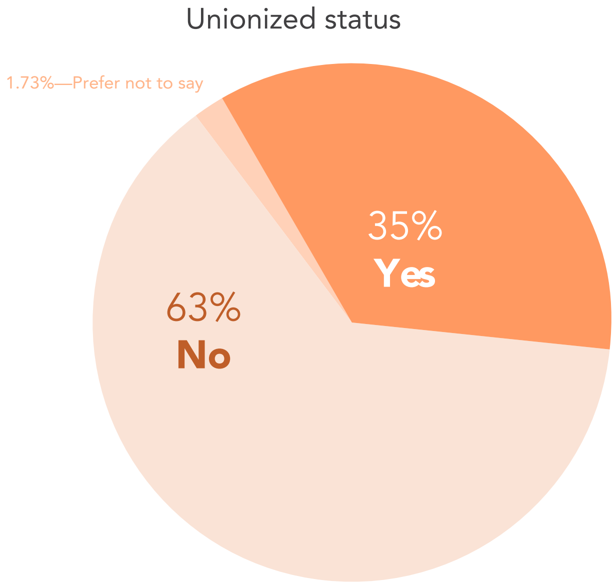


From top to bottom:

5. Types of Pso/PsA
6. Other health conditions

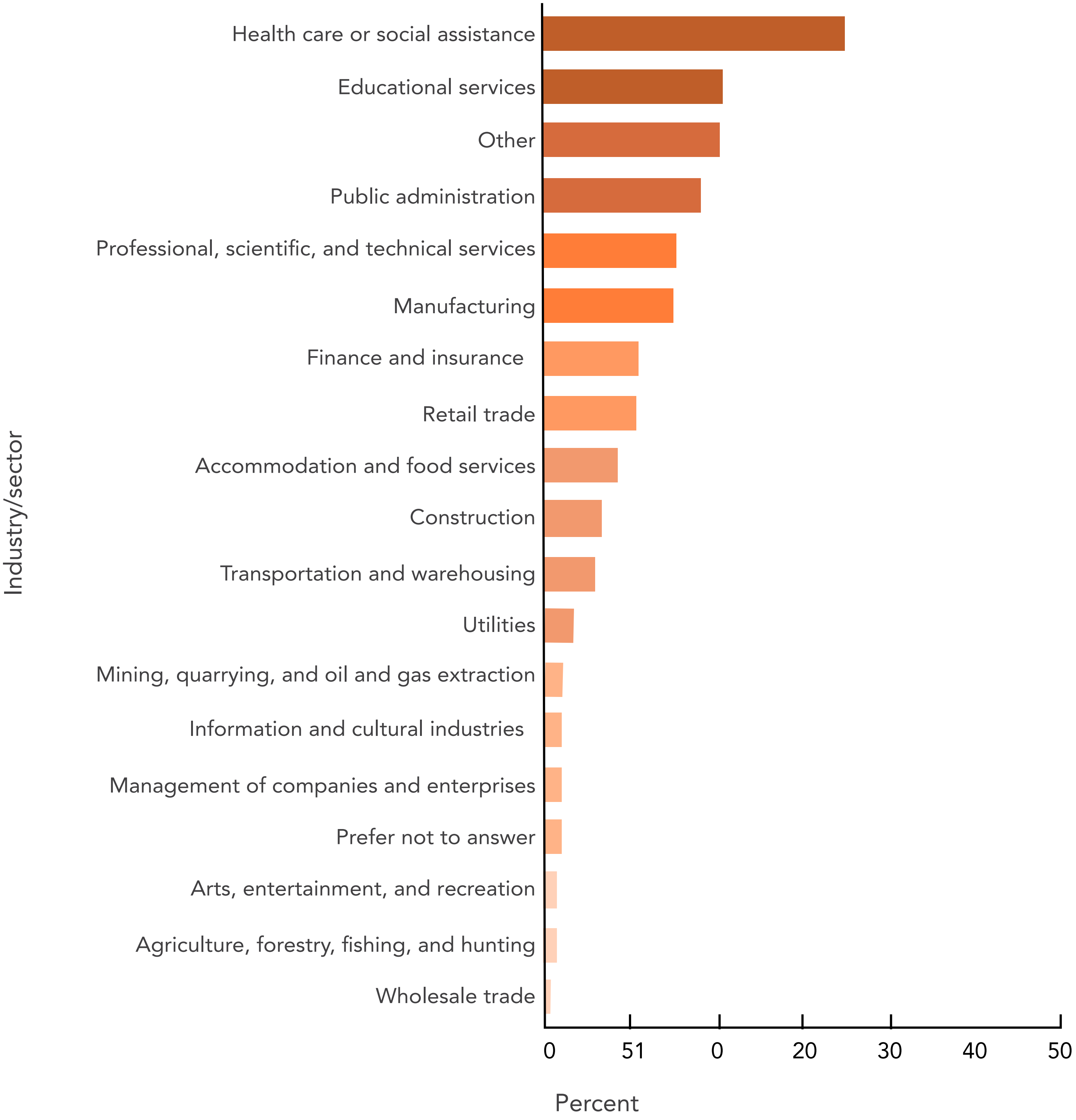






From top to bottom:

7. Work status
8. Size of workplace
9. Unionized status



10. Industry sector

Demystifying Workplace Accommodation

A guide for people with psoriasis and psoriatic arthritis (PsA)

Canadian Psoriasis Network
Réseau canadien du psoriasis

CAPP ACPP
Canadian Association of Psoriasis Patients
Association canadienne des patients atteints de psoriasis

Unmasking PSORIASIS

Demystifying Workplace Accommodation

Have you experienced difficulties at work because of psoriasis or psoriatic arthritis (PsA)? Do you understand your rights and responsibilities in accessing workplace support? This guide will help you learn about getting workplace support and navigating workplace accommodation to bring your best to work. We crowdsourced much of this information directly from people living with psoriasis or PsA—close to 200 people shared their experiences through a recent survey.

What are typical work challenges for people with psoriasis or PsA?

People living with psoriasis and PsA can experience challenges at work. Over 50% of survey participants said that psoriasis and PsA had a negative impact at work. When it comes to performing job tasks, they identified these challenges:

1. Reporting to work at the scheduled time due to fatigue.
2. Concentration was affected by itching.
3. Staying focused due to pain.
4. Staying focused due to stress.
5. Staying focused due to fatigue.
6. Difficulties performing physical tasks, like standing.
7. Location of psoriasis plaques affected work, e.g., hands or feet.

Mental health continues to be a critical challenge for people with psoriasis or PsA. Over 50% of survey participants worried that psoriasis or PsA will affect their current and future employment and felt upset or angry about how the condition affects them at work. Research suggests that self-esteem, shame, and anger can negatively affect work productivity (Pearce, 2013) so it's important to recognize that mental health is just as important to manage as other symptoms.

Some people with psoriasis or PsA said they felt they were treated differently (20%) by their supervisor, clients, or coworkers. Other issues were focused on supervisors; some people (20%) felt their supervisors didn't understand and support their health needs. This can change depending on the job, supervisor, and colleagues. Close to 30% of survey participants said that someone at work made inconsiderate remarks about their psoriasis or PsA.

It can also be difficult to manage the ups and downs of psoriasis and PsA flares. This brings added challenges to adapt workplace support. Some supervisors, clients, and coworkers understand and support needs relating to psoriasis and/or PsA, while others do not (33% of survey participants).

Useful resources:

Arthritis in the Workplace: Resources for Patients, by Patients

Working with a rheumatic disease:
an interactive tool for youth and young adults

How can workplace challenges be addressed?

Workplace challenges can be addressed by changing or adapting the work environment or working conditions to better support you. These adaptations or changes are called ***workplace accommodations.*** In Canada, there are laws that require employers to offer reasonable workplace accommodations for people with disabilities in the workplace. Accessing these needed supports can help you stay productive and healthy (Gignac, 2015).

Employers in Canada are required to follow human rights legislation that outlines the ***duty to accommodate.*** It often applies to people with disabilities (like psoriasis or PsA) but also applies in other circumstances, such as age, family status, race, gender identity, etc. These laws require employers to remove barriers that have a negative impact on employees protected under these laws to the point where it causes ***undue hardship,*** like costs, health, and safety. When considering requests for accommodation, a number of factors are considered under human rights law. For example, significant financial costs, the size and resources of the employer, disruption of operations, morale problems of other employees that could result from using the accommodation, and substantial interference with the rights of other employees.

Employers are required to implement reasonable workplace accommodations to allow employees to do their jobs to the best of their ability. Many workplace accommodations are simple and affordable. However, if there are costs to implementing workplace accommodation, employers are responsible for paying for these costs. For example, a workplace accommodation includes providing a flexible start time for work or working from home a portion of the time. However, an employer can decide to not accommodate if the job requirement is considered a bona fide occupational requirement. This means that the requirement is essential for the job, put in place with good intentions, and connected to the job. However, an employer cannot decide to not accommodate because it is not convenient.

Useful resources:

ARCH Disability Law—My Rights at Work: Limits to the duty to accommodate in Ontario

ARCH Disability Law Fact Sheet—My Rights at Work: Requests for disability-related accommodation in Ontario

L’accommodement raisonnable (Commission des droits de la personne et des droits de la jeunesse)

When can workplace accommodations be used?

Workplace accommodations can be put in place at any time and can be permanent or temporary. For example, if you are flaring, you may need different workplace accommodations, however the type of support needed may change when you are feeling well again. You may also wish to speak with your supervisor before a flare occurs to plan ahead and determine what accommodations are needed during periods when your psoriasis or PsA is stable and what is needed when these conditions are flaring. If you have been away from work due to illness, it is important to communicate the need for accommodation to your supervisor or employer. Typically, a gradual return to work is used to ensure adjustments can be made based on how well you are feeling.

What is the process for accessing workplace accommodation?

The process for accessing workplace accommodation will be different depending on the processes used by your employer. It could be as simple as having a conversation with your supervisor who can implement the changes immediately, or it might involve multiple discussions, documentation from your medical specialist, and completing several forms. In general, there are ***five main steps*** to prepare and request workplace accommodation and these steps are explained in the following section.

Step 1: Research human resources policies and processes

To start off, it's important to become informed about human resources policies (if you work for a large organization), to review applicable laws, and to see if your organization has a process for workplace accommodation requests. Start by looking at the internal website for human resources policies and forms that might be used (typical for large organizations) or there might also be bulletin boards in the workplace that have some of this information. If you are a union member, you may wish to speak privately with the local union steward to learn about workplace processes and practices. Human resources staff might also be helpful but please be aware that they are representatives of the employer or management.

Step 2: Prepare for a discussion with a supervisor or employer representative

It is important to plan for a discussion with your supervisor, or employer representative, and to be prepared to advocate for your needs. Think about your limitations and restrictions at work, and ask yourself:

- Are the symptoms of psoriasis or PsA having an impact on completing job tasks?
- Are there any work tasks that are difficult to do because of psoriasis or PsA? For example, standing, concentrating due to fatigue, or reporting to work at a certain time.
- Are there aspects of the job where you aren't performing to an acceptable standard due to psoriasis or PsA? If so, what should change?

If you could change two or three things about work, what would they be?

For example, you may have difficulties with grasping or fine motor coordination, difficulty standing for long periods of time, or difficulties concentrating due to stress and anxiety. Your dermatologist, rheumatologist, occupational therapist or other health care professional can also assist in identifying limitations and restrictions and the impact they have on the job.

Step 3: Identify workplace accommodations

Now that you have a clear sense of workplace challenges, you can research what changes are needed at work. Based on our survey, people with psoriasis and PsA identified the following effective workplace accommodations (presented in order of helpfulness):

1. Paid time to attend medical appointments.
2. Flexible hours of work (e.g., report to work later).
3. Breaks to give their body/joints time to recover.
4. Working from home one or more days a week.
5. Reduced work hours.
6. Better physical layout (e.g., stools, desks, workspaces).
7. Using heating and ventilation equipment (e.g., space heaters or coolers, vent covers).
8. Modifying work tasks.
9. Equipment (e.g., voice to text software).

Research also suggests that the accommodations mentioned above can be helpful as well as other accommodations like job-sharing, modified schedules, and special equipment and adaptations (Gignac, 2014, Jetha, 2018).

Useful resources:

Job Accommodation Network—information on skin condition*

Job Accommodation Network—information on arthritis*

Job Accommodation Network—information on mental health conditions*

* These resources were developed by a U.S. based organization and information concerning law and policy may differ from those in Canada.

Step 4: Decide what to share or disclose with a supervisor or employer representative

Deciding what information to share and when to share it is a personal decision that only you can make. Remember that you don't need to disclose your health condition(s) to access workplace accommodations. Employers can only ask for information about functional limitations and restrictions that affect you at work due to your disability. You don't need to share everything about living with these conditions. However, here are a few additional factors to consider:

- What is the work environment like? Are relationships positive, or sometimes difficult? What effect might this have on your request?
- Does your employer have a formal policy for supporting people with disabilities? Look for policies on employment equity, diversity or inclusion and see what they say.
- Has your employer ever made changes to the workplace for people with disabilities? If so, how well were these changes made?
- What are you ***personally*** comfortable sharing? What is comfortable for one person may not be what is comfortable to another.

Also, disclosing information is not a one-time event. You may be more comfortable sharing small bits of information to assess the reaction of your supervisor or employer representative.

This disclosure tool can help guide you through the process.

Step 5: Speak with your supervisor or employer representative

To request workplace accommodations, you will need to discuss the request with your supervisor or employer representative. Remember that this will be an ongoing dialogue and there may be several conversations to discuss your needs and possible workplace accommodations. It's important to come prepared for a discussion with your supervisor, for example:

- Clearly communicate the need for workplace accommodation, e.g., "I am having some health issues and feel changes are needed at work to help me better manage my health and be effective at work."
- Communicate the top two or three workplace limitations or restrictions.
- Suggest the most helpful accommodations that will work for you.
- Consider the costs of the workplace accommodations and how it fits with work activities.
- Share what you are comfortable disclosing about your health status and limitations.
- Suggest an accommodation plan be developed, preferably in writing.
- Monitor the accommodation process to ensure it meets your needs.
- Have regular discussions with your supervisor or employer representative about workplace needs.

The supervisor or employer has final decision-making authority in deciding what accommodations are implemented but they need to involve you in the discussion. You can play an important role by shaping the discussion and communicating your needs as clearly as possible.

What are my responsibilities in the accommodation process?

As an employee, your main responsibilities start with identifying and communicating the need for accommodations. You also need to:

- Answer questions or provide information about restrictions and limitations. This might mean you need to get documentation about restrictions and limitations from your health care professional(s), however it depends on the process used by your employer
- Actively contribute to discussions about accommodation solutions
- Work with your supervisor to implement the accommodations and monitor the accommodation process to ensure it meets your needs
- Inform your supervisor of any changes to accommodation needs, for example, a flare may change the kind of workplace supports needed

The employer may offer an accommodation that is different from what is requested. The laws in Canada say that ***reasonable*** accommodations must be provided, and this will be different from one employer to another, or the specifics of the situation. If you are not satisfied with the accommodation offered, you can ask for an explanation and communicate why the accommodations offered will not address your concerns, and how the accommodations you suggested will address them. If you are a union member, you can seek the assistance of your union representative to assist with this process. For non-union members, concerns should be made in writing to the employer's human resources department or designate. If your employer refuses to provide the accommodation requested, they must still work with you to find a reasonable alternative. If a solution is still not reached, employees may have grounds to file a human hights complaint or, in union settings, a grievance against the employer.

What are the employer's responsibilities?

Your employer is required to provide reasonable workplace accommodations based on the grounds noted in human rights laws, including disability, age, and family status. This begins when the employer is made aware of your need for accommodation, or there are circumstances where they should have known that an employee's performance has been impacted by an underlying medical issue. For example, the duty to inquire requires that employers take proactive steps to ascertain whether an employee is struggling with mental health issues. The duty to inquire requires employers to take note of any significant behaviour changes, increased absences, increased frustration, or decrease in work performance. The employer must also keep accommodation requests private and confidential and monitor that accommodation needs are being met on an ongoing basis.

This resource was developed by Laurie Proulx, human resource consultant and patient advocate.

Legal Rights and Obligations for Employees and Employers Around Workplace Accommodation for Psoriasis and Psoriatic Arthritis

Canadian Psoriasis Network
Réseau canadien du psoriasis

CAPP ACPP
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Unmasking PSORIASIS

Legal Rights and Obligations for Employees Around Workplace Accommodation for Psoriasis and Psoriatic Arthritis

One of the key challenges for patients with psoriasis and psoriatic arthritis is how to navigate these unique medical conditions within the workplace. Psoriasis can be visible within the work setting and some employees are excluded from certain types of work because of their visual symptoms. Misconceptions about psoriasis lesions create additional challenges given that the condition can be either dismissed as a rash (when in fact it is itchy and uncomfortable) or, on the other end of the spectrum, improperly thought to be contagious. In addition to visible symptoms, there are non-visible symptoms associated with both psoriasis and psoriatic arthritis such as underlying inflammation, joint pain, stiffness, and impacts on mental health. When an employee is absent from work for medical reasons or requires modifications within the workplace to accommodate a medical condition it is up to the employee to communicate these needs to the employer. Many employees are nervous about approaching these topics, as they wish to keep this information private. The legal landscape for employment in Canada, however, specifies that employers have a legal obligation to accommodate an employee who requires medical accommodation within the workplace. Similarly, employers cannot discriminate against, discipline, or terminate an employee because of a medical condition.

Workplace absence

With respect to workplace absences, an employee is required to report the reason for absence to the employer in a timely manner. If requested by the employer, or if it is a requirement under a workplace policy, employees must also provide medical notes to support absences from scheduled work. In the event of an extended absence, a medical note must be provided to the employer so that the employer can make any necessary arrangements to temporarily address the employee's absence.

Asking for accommodations at work

If an employee is returning to work after a medical absence, or in instances where an employee can still work, but only under modified circumstances, an employee must take steps to seek accommodation from the employer. As mentioned above, it is up to the employee to communicate his, her or their limitations, based on the medical recommendations of his, her or their physician. What type of accommodations are required and whether the request for accommodation is reasonable will depend on the specifics of the situation, the type and size of employer, and the type of work the employee is responsible for. Employers are legally required to provide any reasonable accommodations up to "the point of undue hardship". Whether something creates an undue hardship varies according to the employer's size, availability of resources, type of work, and other factors specific to the employer. Any accommodation requests should be made in writing, to the human resources department or the company's management team.

Once an employee has notified the employer that their situation requires accommodation, it is important for the employee to understand that they must continue to work with the employer to reach a resolution. The case law in this area makes clear that the accommodation process is a "two-way street" requiring ongoing dialogue between the employee and the employer to come up with an accommodation plan that is appropriate in the circumstances. An employee should provide information on whether the medical condition is permanent or episodic, what physical restrictions or limitations the employee has, and whether treatment, including medication, will impact the employee's ability to complete their job duties.

While in most cases, employees and employers are able to successfully work together to implement an accommodation plan, not all employers understand their obligations to accommodate an employee. If an employee is unsuccessful in obtaining a workplace accommodation, it is recommended that they keep records and a timeline of their attempts to discuss the request with management and the human resources department (e.g., note down discussions in a diary or by emailing themselves updates).

In some cases, an employer's refusal to accommodate or an employer's mismanagement of an employee's medical leave may be grounds for an employee to file a claim against the employer on the basis of constructive dismissal or wrongful dismissal. An employee may also be required to file a human rights complaint against the employer to seek a resolution in the event that the employer refuses to comply with the employee's reasonable requests for accommodation. It is strongly recommended that an employee first attempt to mediate the situation with the employer and to seek guidance from an employment lawyer prior to taking legal action.

Examples of Accommodations that may be required for Employees with Psoriasis and Psoriatic Arthritis

- Granting unpaid time off for the employee to attend medical appointments
- Providing the employee with additional protective equipment for handling chemicals or materials that may cause a flare or worsen their disease
- Reducing an employee's hours of work during a flare
- Allowing the employee to utilize a UV light source within the workplace
- Increasing the frequency of breaks for an employee
- Permitting the employee to use a humidifier within the workplace
- Allowing the employee to have time off from work for recovery
- Exempting an employee from having to perform specific workplace tasks
- Allowing the employee to work remotely during a flare
- Allowing the employee to work part-time in the office and part-time remotely

Legal Rights and Obligations for Employers in the Context of Workplace Accommodation for Employees with Psoriasis and Psoriatic Arthritis

An employer has several duties and obligations to its employees that arise when an employee makes a request for medical accommodation within the workplace. Accommodation means granting exceptions to, or making changes to, certain rules or policies within the workplace so that an employee is not negatively impacted by the rules because of their medical condition. The obligation for the employer to accommodate the employee arises from federal and provincial human rights legislation which mandate that workplace rules, standards, cultures, and physical environments do not negatively impact an employee based on an employee's physical or mental medical condition (or other protected grounds such as age, religion, or ethnicity).

Within the context of an employee who has been diagnosed with psoriasis and / or psoriatic arthritis, which can have both physical and mental impacts, an employer has the obligation to work with the employee to make reasonable changes or exceptions to enable the employee to perform his or her work duties without having to endure detrimental consequences or conditions, because of his, her or their physical or mental medical condition. The employee themselves, through the guidance of their medical physician, is best positioned to know which workplace accommodations are most appropriate to address the limitations of the employee's medical condition. When an employee becomes aware of the need for accommodation or experiences an adverse impact resulting from a medical condition, the employee should notify the employer and begin a confidential discussion about their limitations and how they can be addressed.

The employer should make employees aware of any processes or procedures that are in place within the workplace for an employee to submit requests for accommodation and time off requests due to physical and mental health related to medical conditions. If your employer does not have policies and procedures in place for this, it is recommended that you submit requests in writing, via e-mail or text message, to management and to maintain records of the request as well as the employer's response to the request. Keeping proper documentation is important for both the employer as well as the employee. Employers should keep this information on the employee's personnel file and should ensure that the information is only accessed by the human resources representative assigned to the file, management, and the employee. Accommodation requests and requirements should not be shared with other employees, unless the employee provides permission to do so.

Accommodation matters and medical leaves are typically within the scope of the human resources representative to address. If your employer does not have a designated human resources contact person, this information should be brought to the attention of a manager or a person with decision-making authority. In some circumstances, such as situations requiring modified work hours or requests for time off, an employee should consult with his, her or their physician to obtain a medical note before approaching the employer, as most employers require medical notes to justify an employee's absence from the workplace during scheduled hours of work.

Summary of the employer's obligations, rights, and limitations relating to workplace accommodations:

- The employer has the duty to cooperate in the accommodation process and to work with the employee and his or her medical physician to establish what is needed for accommodation.
- The employer has the obligation to keep the employee's personal medical information confidential.
- The employer has the right to obtain medical information that is necessary to understand the employee's limitations and to provide the necessary accommodations.
- The employer is not permitted to contact the employee's doctor via phone, unless the employee provides consent.
- The employer must take steps so that the information is not shared with other employees.
- The employer is not permitted to request medical information that is not employment-related.
- The employer does not have a right to know the employee's diagnosis, except in very limited circumstances.
- The employer is not allowed to terminate the employee (e.g., fire the employee) on the basis of a medical condition.
- The employer is required to ensure that other employees do not harass, demean, or otherwise act disrespectfully towards an employee due to his or her medical condition.
- The employer has an obligation to communicate relevant information related to the medical benefit plan to the employee.

It is in the best interest for both the employer and the employee to work together to ensure that adequate accommodations are provided within the workplace. If an employer ignores or disregards an employee's reasonable request for accommodation, they could be liable under human rights law or civil common law[1]. An employer's failure to accommodate an employee could also make them a target of negative treatment in the media and social media sources, which could be damaging to the employer's reputation, revenues, and public image.

Privacy Considerations for Workplace Accommodation

Within the work setting, the federal and provincial governments put limits on employers regarding the type of information that an employer is permitted to collect from its employees. Information such as the employee's address, phone number, and social insurance number are within the employer's right to request as this information is necessary for the employer to properly fulfill its duties to administer payroll, pay taxes, maintain personnel files, communicate with the employee, and other tasks that are incidental to workplace operations. However, employers do not have a broad scope of access to an employee's personal information – the information that they are permitted to collect from an employee is limited.

The provinces of British Columbia, Alberta, and Quebec each have comprehensive legislation that provide specifics on information that can be collected within the private sector[2]. Other provinces and territories, including Ontario, Manitoba, and Saskatchewan, are governed by the federal *Personal Information Protection and Electronic Documents Act* (PIPEDA), which outlines the rules for the collection of information in commercial activities, or "for profit" activities, that most employers must abide by. In addition to PIPEDA, Ontario and the Atlantic provinces each have health-specific privacy laws that apply to accessing and sharing an individual's medical information.

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[1] In Canada, there is provincial and federal human rights legislation. The *Canadian Human Rights Act* applies to employees who work within a federally regulated industry (for example, banking, airports, etc.). Provincial human rights legislation applies to employees who work in non-federally regulated workplaces (for example, hospitals, schools, etc.).

[2] British Columbia and Alberta each have legislation called the *Personal Information Protection Act.* In Quebec, it is the *Quebec Private Sector Act.*

Suffice it to say, privacy laws in Canada are confusing—which specific rules apply to an employee depends on where the employee resides, whether the employee's personal information crosses provincial or national boundaries, and the type of information collected.

There are, however, some common rules regarding personal information and an individual's right to privacy within the workplace which are summarized below:

- Only certain types of information can be collected from an employee by the employer.
- Generally, an employer can only collect an employee's personal information that is necessary for completing its duties (for example, information necessary to administer payroll).
- An employer should tell the employee the reason and purpose of collecting his, her or their personal information and must get consent from the employee to release that information to anyone else (unless they are required by law to share it).
- The personal information collected by an employer, including medical information disclosed by an employee, must be kept confidential and safe.
- In very limited circumstances, an employer may be entitled to an employee's personal medical information if it relates to the discharge of its duties. For instance, to comply with its duties under health and safety legislation, the employer may require an employee to disclose his, her, or their vaccination status to minimize the risk of virus transmission in the workplace.
- An employer's right to an employee's medical information is very limited (for example, collecting vaccination status in order to implement a Health and Safety plan).
- Employers do not have a right to request information about an employee's medical diagnosis, except in very limited circumstances (for example, if an employee is ill with COVID-19 and attended work while ill).
- An employer has an obligation to keep an employee's medical diagnosis confidential, if it is disclosed by the employee to the employer.
- Employers do not have the right to access or request an employee's medical record.
- An employer is required to provide information (description of duties, pay rate, number of hours worked per week, and length of employment) to the worker's compensation board and disability benefits insurers to support an employee's claims for compensation.

This resource was developed by Kimberley Holland, Employment Law Associate at Bow River Law LLP.

Employee Tool for Requesting Doctors to Prepare Medical Notes, Accommodation Forms, and Disability Benefits Application Forms

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Useful Tips for Doctors in Preparing Medical Notes in Support of Work Absence

- The purpose of a medical note is to communicate to the employer that the employee will be absent for a specific period of time.
- Medical notes should be brief and concise.
- Medical notes should outline that the patient has been assessed and that they are unable to work due to medical conditions.
- Unless the patient asks to include one, the medical note should not contain a specific diagnosis.
- The start and end date of the period that an employee is unable to work should be clearly outlined.

Useful Tips for Doctors in Preparing Accommodation Forms

- The purpose of an accommodation form is to communicate to the employer what, if any, limitations or restrictions the employee has within the workplace arising from the employee's medical condition.
- An accommodation form should not disclose the employee's medical diagnosis or treatment plan.
- The accommodation should focus on medical recommendations such as:
  - The number of hours worked each day.
  - The number of days worked each week.
  - The requirement of periodic breaks (specify duration and frequency).
  - The percentage of time spent on certain equipment (computer usage, screen-time, driving, etc.).
  - Limitations on time spent standing.
  - The requirement of a specific device/instrument within the workplace (for example, a humidifier).
  - Any requirements to make certain changes to the workplace environment.

Useful Tips for Doctors in Preparing Disability Benefit Applications

- The purpose of the disability benefit application form is to prove that the individual is not able to work due to medical reasons.
- Detailed information should be provided.
- Prognosis should be outlined and should include an estimated timeline for required treatment/recovery and length of work absence.
- The doctor's opinion should clearly state that the individual is unable to work in any capacity (if they are able to work in a limited capacity, then the medical accommodation form should be used instead).
- Detailed symptoms should be documented, such as:
  - Physical symptoms: itch, rash, joint pain, debilitating fatigue, low energy, stiffness, difficulty moving joints, etc.
  - Mental symptoms: trouble sleeping, difficulty concentrating, blurred vision, loss of memory, forgetfulness, etc.

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About the Canadian Psoriasis Network (CPN)

CPN is a national not-for-profit organization with a mission to enhance the quality of life of people with psoriasis and psoriatic arthritis. We do this in part by providing current information on research and treatment options and by working with others to build awareness and advocacy about the complexity of these conditions.

www.canadianpsoriasisnetwork.com

About the Canadian Association of Psoriasis Patients (CAPP)

CAPP is a national not-for-profit organization that was formed to better serve the needs of people living with psoriasis and psoriatic arthritis in Canada. We raise awareness about the burden of psoriatic disease, provide education, support research into psoriatic disease and advocate on behalf of our community.

www.canadianpsoriasis.ca

About Unmasking Psoriasis

Unmasking Psoriasis is a Saskatchewan-based awareness group looking to educate employers and the public. We support patients with psoriasis through education and changing the way we think of psoriasis.

www.unmaskingpsoriasis.org

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