

# Working it Out: Better workplace supports for people with psoriatic disease

White Paper on Income Support and  
Employment Policy in Canada

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Canadian  
Psoriasis  
Network



Réseau  
canadien  
du psoriasis





# Summary

Financial security and employment are important to people living with psoriatic disease in Canada. Our [Working it Out](#) report was our first step to understand the workplace experiences of people living with psoriatic disease, where more than half of survey participants indicated that psoriatic disease impacted them at work. Our next step was the Environmental Scan of Income Support and Employment Policy in Canada in order to understand the current state of financial security measures and workforce support available for our community and find inspiration from international jurisdictions. Building on the Environmental Scan, this White Paper will outline key policy and administrative changes to meet the needs of our community and will focus on the following areas:

1. provide financial security through income support programs, sickness benefits, and employment insurance programs
2. reimburse additional costs such as prescription drugs and equipment
3. support workforce participation such as job search, workplace accommodation, and retraining
4. support employers in hiring and employment

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

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# Context

Psoriasis is a chronic inflammatory condition of the skin, causing itchiness, pain, and discomfort among other symptoms. Approximately 30% of people with psoriasis live with psoriatic arthritis (PsA), a chronic, autoimmune form of arthritis that causes joint inflammation, pain, and stiffness in the joints and irreversible joint damage. People often live with comorbidities, including depression, anxiety, diabetes, cardiovascular and metabolic disease, causing further stigma and discrimination. These conditions are increasingly being known as psoriatic disease – recognizing the impact of these conditions on the whole body.

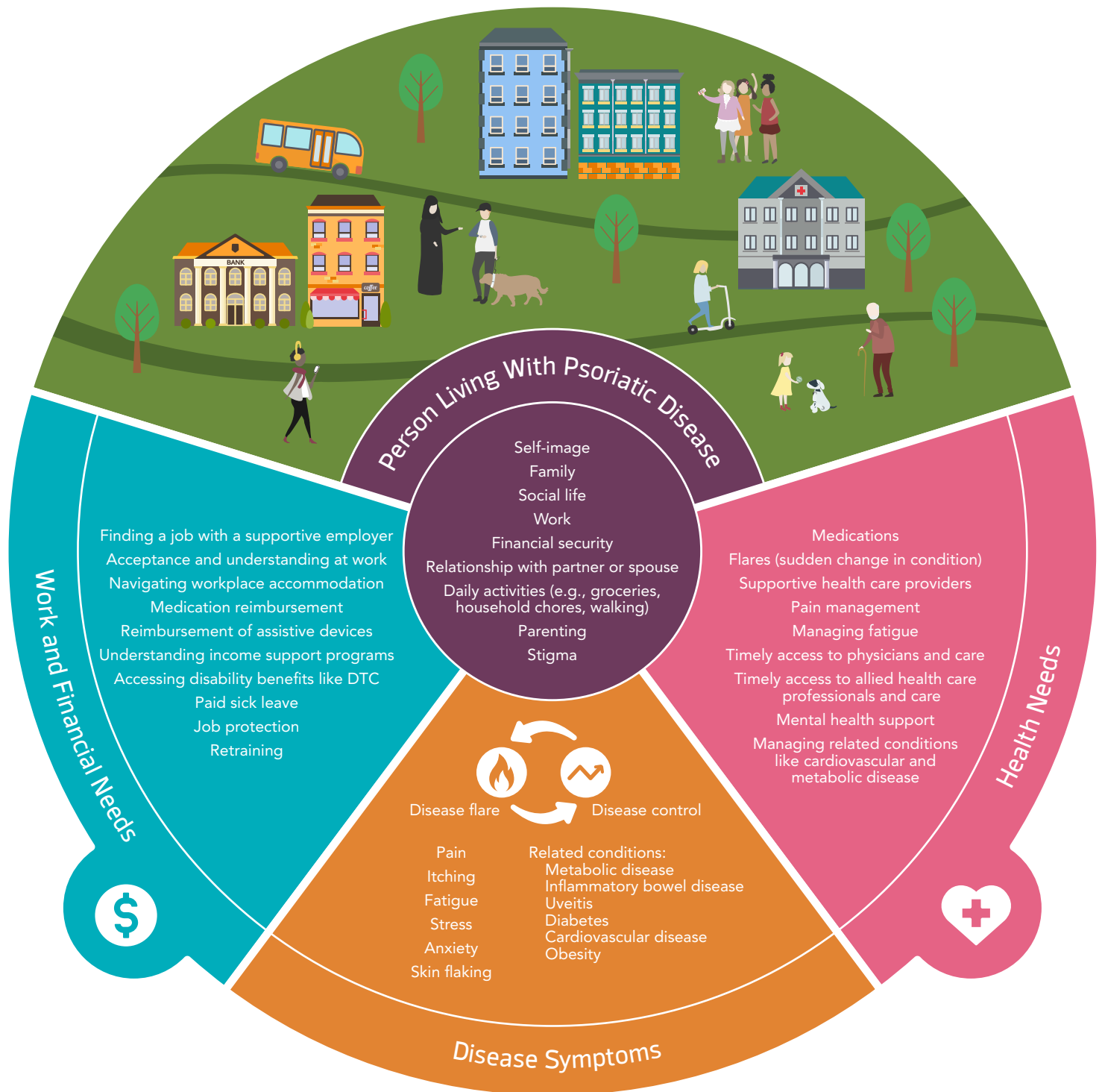
People with psoriatic disease experience a range of challenges that cause disability and prevent them from participating fully in social and economic life, like the workplace. Our [Working it Out report](#) and survey found that many people with psoriatic disease worry about how condition will affect their ability to stay employed. The pandemic further strained financial security where one in four people indicated that they worried about their finances due to the COVID-19 pandemic and keeping their job or their business operating.

During the COVID-19 pandemic, the federal government introduced income support measures to Canadians whose employment was impacted by public health measures and closures. The [Canada Emergency Response Benefit \(CERB\)](#) provided support to employed and self-employed Canadians affected by COVID-19. The benefit provided \$2000 for a 4-week period. In contrast, the [maximum benefit](#) provided to Canada Pension Plan (CPP) Disability Benefits (DB) recipients is \$1464.83 per month. Many [observed](#) this decision as further evidence of the lack of consideration and value placed on the lives of people with disabilities who are at [higher risk](#) of poverty and accessing the basic necessities of life.

*“It was so stressful when I was off work on disability benefits because the future was so uncertain. I was not paid anything for six months and had to use my savings.”*

*Person living with psoriatic disease*

# Needs Of People With Psoriatic Disease





# Principles

There are many important principles governing [the United Nations Convention on the Rights of Persons with Disabilities](#) including “respect for inherent dignity and individual autonomy including the freedom to make one’s own choices, accessibility, and equality of opportunity.” Beyond these fundamental principles of inclusion, we have identified additional principles to guide the policy and administrative changes needed to support people living with psoriatic disease in Canada from an income and employment policy perspective:

- engage directly with people with lived experience of psoriatic disease and disability in decision making
- create a seamless service experience
- use a whole-of-government policy and administration approach
- create and nurture partnerships and relationships
- act with transparency and accountability, and
- recognize the specific needs of people with episodic disability, like psoriatic disease



# Key Areas

A range of essential changes must be made to income support and employment policy and administration to provide financial security to people living with psoriatic disease and to enable them to fully participate in the labour market and workplace. These key changes are described in the following sections.

## **1. Change the criteria for the Canada Pension-Plan Disability Benefit (CPP DB) and Disability Tax Credit (DTC) to recognize episodic disability and ensure it is defined in a way that relates to the challenges, seriousness, and impacts of living with psoriatic disease**

The current criteria for CPP DB and DTC make it difficult for people with psoriatic disease to identify how their restrictions and limitations relate to program eligibility criteria. These programs only recognize a permanent disability, not an episodic disability that may fluctuate and include periods of health followed by significant periods of disability.

For example, to access CPP DB one must show the disability is **severe and prolonged**. Severe is where is a “mental or physical disability that regularly stops you from doing any type of substantially gainful work” and prolonged is where “disability is long-term and indefinite duration”. This definition is incompatible with the fluctuating, intermittent periods of episodic disability where people may experience periods of wellness followed by periods of severe disability.

*“It seemed I had to have a stable or permanent disability to apply for disability benefits. Knowing that I have flares and possible periods of remission, I wasn’t sure if I would qualify.”*

### *Person living with psoriatic disease*

There are similar difficulties in relating the symptoms of psoriatic disease to the DTC criteria,

namely the cumulative effect of significant restrictions criteria. Although we recognize the recent changes to DTC criteria, people with psoriatic disease still cannot relate restrictions in vision, walking, feeding, dressing, and mental functions necessary for daily care since these limitations can occur with psoriatic disease. However, symptoms fluctuate with the episodic nature of the illness and people feel their disability is not severe enough to meet the current DTC criteria and don’t apply for the program. Often, health care providers reinforce these sentiments and indicate that they don’t qualify for CPP DB and DTC programs. To improve access to the DTC, we recommend that the experiences and needs of people living with psoriatic disease and other episodic disabilities be at the centre of any policy and administrative changes using a human-centred design or design thinking approach.

*“Every time psoriatic disease gets more severe for me, I think of looking up programs for financial support. I go back and find the information and when I look at the criteria, it doesn’t seem to fit for my circumstances. The criteria make it sound it has to be life threatening in order to qualify.”*

### *Person living with psoriatic disease*

The goal of these changes is to provide financial security to people with psoriatic disease, so we expect to see the following key outcomes or indicators of success:

- increase in access to these disability programs
- increase in financial savings, and
- increase in income/earnings



## 2. Provide a minimum disability benefit that reflects the costs of living and that address the cost of prescription drugs

A new disability benefit can provide direct financial support instead of the current suite of specialized tax credits and deductions, which [evidence](#) suggests provide less benefit to people with low incomes. It is imperative that a minimum disability benefit not be clawed back through provincial or territorial disability support programs to provide financial security and stability for recipients. Any integration with provincial or territorial programs needs to ensure that people receive more financial benefits as opposed to less.

The current benefits provided by CPP DB need to increase as they are not sufficient to address the costs of living for people with psoriatic disease. The current maximum monthly benefit is approximately \$1500/month or \$18,000/year. Canada's Official Poverty Line (as measured through the [Market Basket Measure \(MBM\)](#)) sits at approximately \$40,000 and represents the basic income needed to pay for food, health care, shelter, transportation, and other costs. The benefits must be adjusted to reflect the costs of living in urban centres and address additional costs like assistive devices, medical equipment, prescription medications and costs associated with applying to disability programs (e.g., physician fees).

*“When I was trying to find a treatment plan that worked for me, no one asked if I had good benefits. At one point, I received a bill for \$35,000.”*

*Person living with psoriatic disease*

A new *Canada Pharmacare Act*, promised by the federal government, must specifically address the needs of people living with psoriatic disease and reimburse directly for medication costs. A crucial

design feature of a national drug formulary for people with psoriatic disease is that it provides a range of treatment options as people with psoriatic disease often try numerous medications before finding medications that address their health. There is evidence ([Iragorri](#), 2018, [Beroukhim](#), 2016, [Reich](#), 2020) that medications keep people with psoriatic disease in the workforce. Medications may fail to work after a period of time, or the person may be unable to tolerate a medication or formulation and need to change treatments. People often live with the fear that their options will run out making the situation difficult and emotional. It can take years – sometimes longer than 10 years – for a person to feel that psoriatic disease has [stabilized](#).

The goal of these changes is to provide financial security to people with psoriatic disease, so we expect to see the following key outcomes or indicators of success:

- increase in income/earnings
- increase in financial savings
- reduction in poverty levels of people with psoriatic disease, and
- minimal or zero out of pocket costs for prescription medications and other disability-related costs



### 3. Establish national standards for sick leave and job protection

Psoriatic disease is episodic in nature and characterized by periods of wellness followed by intermittent or episodic flares when the condition's symptoms increase. During flares, support is often needed from health care providers who adjust treatment plans and medical interventions. This means that people with psoriatic disease may need time to stabilize their health and can often return to work, with workplace accommodations, once their health situation has stabilized.

Employment supports like paid sick leave are beneficial for people with psoriatic disease to have the time and support to address their health situation. Although we recognize [improvements](#) have been made to the *Canada Labour Code* to provide for three days of sick leave and up to ten days of sick leave available in a year, each province has their own provincial employment standards and the sick leave provisions often fall short of what is provided under the *Canada Labour Code*. We recommend that a national employment framework and funding agreements be put in place to guarantee a minimum standard for paid sick leave across Canada, including job protection during periods of short-term illness.

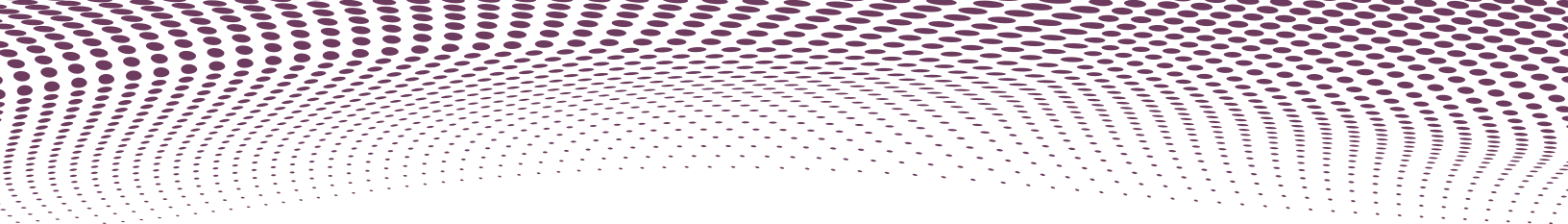
*"I worked one week but by the following Monday, I could barely walk. I felt bad calling in sick, but I had used all of my sick leave. When I called in to work, I got this curt message that said, "if you are not well enough by Monday then we will have to put you on short-term disability."*

*Person living with psoriatic disease*

The goal of these changes is to provide employment security to people with psoriatic disease, so we expect to see the following key outcomes or indicators of success:

- increase in employment rates, and
- greater confidence and ability to manage transitions from periods of health to disability





#### 4. Create a single, streamlined application process for income support and other disability support programs

There are a wide variety of programs available to people with psoriatic disease and disabilities, however it can be challenging to navigate and apply to these programs. Many people must look up these programs, reflect on their individual circumstances and determine whether it is beneficial to apply for each of these programs. Many people with psoriatic disease and disabilities are unaware of these programs and lack support in navigating these programs once they are aware of them.

*I found it challenging to find out what I was eligible for and what I was not eligible for. I was overwhelmed – where do I fit in? What do I qualify for?”*

*Person living with psoriatic disease*

We ask that the federal government simplify and integrate the application processes for CPP DB, and DTC using principles of human centred and universal design. Recent changes focus exclusively on improving the application process for medical practitioners, not the person with a disability. Once developed, other programs can be added to the application process, such as provincial income support programs and other disability programs.

*“I found nothing about programs available to me and I’m pretty good with searching. It takes a lot of time to manage this disease, like getting to and from phototherapy appointments is a 2-hour drive.”*

*Person living with psoriatic disease*

The goal of these changes is to provide financial security to people with psoriatic disease, so we expect to see the following key outcomes or indicators of success:

- increase in awareness of disability related programs
- applicant satisfaction with the application process, and
- increase in applications and recipients of CPP DB and DTC programs

## 5. Provide early and direct support to keep people with psoriatic disease and disabilities at work

The current income support and employment policy approach in Canada responds primarily to situations where work incapacity is significant and permanent. Once provided, people worry about losing the minimal amount of financial security offered by the program particularly with an onerous and lengthy application process for CPP DB and other programs. We propose to shift the paradigm to focus on early support and intervention to keep people with psoriatic disease and disabilities at work. Current [evidence](#) suggests that “successful long-term employment outcomes are even more remote for recipients who get established on disability benefits.” A new disability benefit can support poverty reduction; however, better support is needed to keep people at work, such as:

- increase the amount of [work and earnings](#) allowed when receiving CPP DB to enable a partial or full return to work
- create a disability gateway website that provides information on income support programs, DTC, and other disability programs
- connect people with psoriatic disease to supported employment specialists that act as a connector between the job seeker, support person (if applicable) and employer, not for profit organizations, and other support services to provide individualized support and gather resources to support return to work
- develop a centre of expertise for people with psoriatic disease and disabilities to directly access independent human resources advice to navigate workplace accommodation

- provide funding for not-for-profit organizations to train and orient employers to remove implicit and explicit biases with the goal of improving employment opportunities and working conditions for people with psoriatic disease

*“Everything is very hard to navigate when you can’t do your job anymore. I learned that it was OK to be in mourning for my job. It’s OK to be grieving.”*

### *Person living with psoriatic disease*

The goal of these changes is to provide employment support to people with psoriatic disease, so we expect to see the following key outcomes or indicators of success:

- increase in employment rates and labour force participation
- satisfaction, confidence, and support in finding and keeping employment, and
- increase in job satisfaction for people with psoriatic disease and other disabilities.

## 6. Provide direct support to businesses to support their efforts to recruit and retain people with psoriatic disease and disabilities

There are a range of excellent resources to support businesses and employers in recruiting and retaining people with psoriatic disease and disabilities, such as the [Working it Out Accommodation Tools](#), [Canadian Association of Supported Employment](#) and [Hire for Talent](#). However, it can be challenging for employers to find this information when needed and the following actions are recommended:

- create a disability gateway website for employers that consolidates resources from various not for profit organizations and supported employment agencies
- develop a centre of expertise for employers to directly access independent human resources advice to support the recruitment and retention of people with psoriatic disease and disabilities
- refining existing grant programs, like the [Enabling Accessibility Fund \(EAF\)](#), to make it easier for employers to apply for funding that improve accessibility and address systemic barriers in employment

*“I heard from a colleague that they were replacing me permanently at my job (I’m on short-term disability). I really would have liked to hear firsthand from my boss. There is no role for me now.”*

*Person living with psoriatic disease*

The goal of these changes is to provide increased support to employers and businesses, so we expect to see the following key outcomes or indicators of success:

- increase in hiring of people with psoriatic disease and other disabilities
- increase in the retention rate of people with psoriatic disease and other disabilities, and
- employer satisfaction with accessing employment support

## 7. Build relationships and outreach capacity to repair the distrust in income support systems

The COVID-19 pandemic has left many people living with disabilities feeling like they have been [left behind](#). This sentiment builds on existing [distrust](#) in both federal and provincial income support programs and the [negative impact of retroactively ceasing benefits](#). For any policy changes to be successful, it is crucial to rebuild relationships with the psoriatic disease and disability communities by acknowledging existing sentiments, listening, and actively working to sustain these relationships over the short and long-term.

## 8. Transparent processes and accountability to people with psoriatic disease and disabilities

Currently, there is a lack of clarity about how CPP DB and DTC applications are considered and how the programs are managed. It is crucial to establish governance mechanisms by a central and independent organization to track progress against the results noted throughout this White Paper. Regular meetings and outreach should be undertaken with disability groups, including the Canadian Psoriasis Network and Canadian Association of Psoriasis Patients, to engage people with disabilities in decision making and in the day-to-day operation of federal disability programs.

## *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](http://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](http://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](http://www.unmaskingpsoriasis.org)

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