

# Returning to work...

**Tips for people living with Long COVID on managing health care interactions and disability claims.**



**This document is intended to help people living with Long COVID navigate the complex world of disability and employment claims.**

Returning to work with a complex, episodic illness is difficult. This document is a collection of recommendations based on the lived experiences of persons living with Long COVID, and clinicians working with people living with Long COVID.

## **Tip #1: Don't Go it Alone**

Trying to attend appointments and meetings, while still having enough energy to manage your daily activities, can be very challenging. Try to find support systems to help you go through the process.

- **Peer support groups:** seek out (online) peer supports – you will need people who understand what you're going through and who might be able to offer advice from their own experiences.
- **Friends, family, neighbours:** ask for what you need as many people will want to help but won't know how to help. In addition, accept supports from others – which can be very hard to do if you are not used to it!
- **Formal support:** seek out formal supports for navigating systems, processing grief & stress - such as social workers, external advocates, and mental health practitioners.

## **Tip #2: Advocating for Support**

Many disability plans (such as long term disability and Workers' Compensation) will provide in-home support including snow removal, housekeeping, food preparation, transportation to and from appointments, mobility supports including stair lifts, electric scooters, wheelchairs, bidets, etc.

**For those without disability benefits, search for what supports might be available in your community.** Your doctor may be able to refer you to home care/home nursing for assistance. You may also consider seeking out home support services like Meals on Wheels, food delivery programs, home care, and house cleaning. Each community, municipality, and province have different resources available, so you may need to look for what is available in your area.



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### Tip #3: Navigating Health Appointments

Whenever possible, bring an advocate with you. This could be a family member, friend, or colleague. Ask them to take notes during the meeting/appointment as it is often difficult to understand all of what is said, and then remember it later.

**Keep a binder** with notes from your appointments, so that you can refer back to what was done or discussed at previous appointments with other health care practitioners. Ask for copies of tests or charts to have with you, in the event information is not being shared among different providers. Within that binder, you may also want to include information you have gathered on Long COVID, as there are still some health care providers who are not familiar with Long COVID or its symptoms, like Post Exertional Malaise (PEM)/Post Exertional Symptom Exacerbation (PESE). You may need to advocate for yourself, to avoid harmful recommendations (like graded exercise).

Using a **daily activity journal** to track your activities and response to activities (symptoms) can help health care providers better understand and monitor your health. Often in Long COVID, routine diagnostic tests are “normal,” and it is difficult for health care providers to report on health status. Reviewing your activity journal can help them help you.

Advocate for **virtual appointments** for energy conservation, where you can. In-person appointments may be necessary at times, but there are instances when virtual may be the better option. You may have to request this from your health care provider or case manager, as it may not be offered initially. However, most professionals can provide virtual appointments or meetings.

**Pace your appointments.** If possible, try not to have multiple appointments in one day, and give yourself some rest days with no appointments at all. If you find you are getting overwhelmed, then take a “medical break,” and give yourself 5-7 days of no appointments or meetings. Cancel and reschedule appointments if you are not well enough to attend.

### Tip #4: Navigating Conversations with Disability Claims Managers and Employers

As with health appointments, try to **have an advocate with you**, who can help record information discussed, especially if cognitive dysfunction (“brain fog”) is an issue. To help support cognitive pacing, ask for communications to occur in writing (such as email), or ask to record conversations.

**Ask for meetings to be over the phone or virtual**, rather than in-person, whenever possible. Cancel and reschedule appointments if you are not well enough.

If possible, **seek out any workplace benefits coordinator** (human resources) to help navigate the claims process for you and with you.

It is important to note that you are not obligated to provide medical information to an insurer from prior to the date of the illness you are claiming for. You only need to disclose the nature of the disability, limitations, restrictions, and prognosis for recovery, but not the diagnosis.

### Tip #5: Return to Work Accommodations

**Employers have a legal obligation to accommodate disability, so long as it does not cause undue hardship to the company.** However, it is important to note, that not everyone recovers enough to return to meaningful employment; many people need long term accommodations to remain employed, which may not be available.

If you are able to successfully return to employment, consider that your methods/abilities for completing work may differ from your pre-illness status -- seek out tools that work for you; memory aids, writing down/recording info; permanent change in hours, working from home etc. A slow, phased return to work (ie: starting with 3-4 hours per week) is recommended. Increasing hours should be based on personal response, as opposed to a preconceived timeline.

Given the episodic nature of Long COVID, there may be a need to leave work after attempting a phase of return to work. Consider if there are changes to your disability support if you return to work at a reduced level, but then require being on leave again (this may result in reduced benefits). **Flexibility of employers and benefits programs and policies will be important to ensure a supportive, timely, and safe return-to-work trajectory.**

**A new resource to help determine where you might need accommodations, as well as what kind of accommodations may work is available here:**  
<https://aced.iwh.on.ca/jdapt/worker-en/access>.



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