

Cope: Self-advocacy rights

Self-advocacy is when you have a clear understanding of your needs, and then set boundaries and communicate with others to make sure that your needs are met. This can help you to feel more in control of your health management. It can also help you to get your needs met and access the help that you need when facing challenges or barriers in interpersonal, community, institutional, employment, or academic settings.

Self-advocacy can include:

- Voicing your needs
- Expressing how you are feeling about a particular situation
- Setting boundaries and giving yourself time to consider requests made of you
- Gathering information and asking questions
- Educating the people around you about your symptoms and experiences
- Making the decision not to explain your symptoms and experiences when others ask
- Saying “no” when you aren’t able to meet a demand
- Asking for help from friends, family members, or healthcare providers/professionals who can support you with the emotional or practical aspects of managing your health condition



You may need to self-advocate to access medical care or access government supports and services.

A BILL OF RIGHTS FOR PEOPLE LIVING WITH POST-VIRAL FATIGUE

Living with a complex illness like post-viral fatigue can feel scary. You might be facing a lot of uncertainty about your health condition and have a lot of unanswered questions about what is happening and why. This may leave you feeling vulnerable. You might find yourself saying “yes” to every treatment or recommendation that you hear about, in hopes that it will make you feel better. On the flip side, it might also be hard to trust new people with your personal health information and experiences, and you may find yourself being more protective than usual. These are both normal responses when you’re dealing with new health issues that have disrupted your sense of stability, safety, and wellbeing.

It can be helpful and reassuring to know what you deserve and what can reasonably be expected as you navigate the healthcare system and beyond.

Remember that you have the right to:

- 1) Be treated like a whole person and not be defined by your illness/diagnosis
- 2) Seek any course of treatment, remedy, or protocol as guided by your intuition
- 3) Not accept your diagnoses (or lack of diagnosis) as an identity
- 4) Choose nondiscriminatory providers (physicians, clinics, therapists, etc.) and reserve the right to revoke permission at any point in time
- 5) Be treated with kindness and compassion in the face of illness, pain, and any deviation from the “normal” definition of health
- 6) Choose alternative services and practitioners to help alleviate pain and suffering
- 7) Be transparent and honest about your reality rather than hide it and carry the burden in secret
- 8) Have a spectrum of emotions about your illness, diagnoses, the care you receive, the care you don’t receive, and all that accompanies your health journey
- 9) Reject the notion that you are responsible for the onset of your illness

- 10) Speak publicly about your struggles without fear of punishment, ridicule, or receiving an onslaught of recommendations and suggestions from others on how to fix, cure, or improve your condition
- 11) Decide who can access your health information
- 12) Not have your lived experience minimized
- 13) Be extraordinarily kind, compassionate, and gentle with yourself
- 14) Make informed decisions in all aspects of your health journey
- 15) Change your mind and change course at any time and for any reason
- 16) Ask for help and allow others to SEE your experience
- 17) Experience an abundance of joy and pleasure
- 18) Voice your concerns and demand change in policy making, government regulations, and systemic issues like racism, sexism, classism, ableism, ageism, heterosexism, and transphobia.
- 19) Not wait for your illness to be resolved in order to live a full life.



Adapted from Nicotra, S.H. (2020). *Chronically ill bill of rights*. www.likeavitaminforyoursoul.com [website inactive]

RESOURCES

The resources listed below may help you to advocate for yourself in different settings. They also show you where to go if you are being discriminated against or have reason to make a formal complaint.

Your Rights as a Patient in BC.

The **Health Care Consent and Care Facility Admission Act** outlines the following rights for patients:

- To receive appropriate and timely care
- To be treated with dignity and respect
- To receive health services without discrimination
- To have access to their personal health information unless, in the opinion of a relevant health professional, the disclosure could result in immediate and grave harm to the patient's health or safety
- To refuse consent to any proposed treatment. For example, choosing not to take medications to manage symptoms
- To be fully informed of all treatment options:
 - To have a doctor explain all treatment options available and support patients to make their own decisions around their care with the best available information
- Health care providers must follow directions around a patient's care given by a legally appointed person; patients have a right to have their Representative or Substitute Decision Maker recognized

- The recognition of patients' Advance Directive: Respecting choices patients have made around their care in advance, should they be incapacitated or unable to make their own decisions due to progression or status of a medical condition
- To a second opinion: The right to consult more than one doctor or specialist about a diagnosis, prognosis, treatment, etc
- The right to receive support and information around management of pain and symptoms
- To information and support around assisted death



Learn more about [BC's Health Care Consent and Care Facility Admission Act](#).

Information on Advance Care Planning. Learn more about [making future health care decisions](#).

Information on Medical Assistance in Dying (MAID) in BC, including [current legislation and where to get support](#) around decision making.

If you have an issue with a doctor:

You have different options depending on the issue that you have with your doctor. The resource below helps you examine what steps you can take, including reporting/complaint options if you are unable to resolve the issue by talking with the doctor. The [ClickLaw Wikibooks resource](#) also provides an overview of the complaint process and possible outcomes.

Complaints to the College of Physicians and Surgeons of British Columbia

You have the right to make a complaint about a physician's professional or clinical competence. Physicians are bound by practice standards, Professional guidelines, and must adhere to their professions code of ethics. You can make complaints regarding inadequate care or treatment of a medical condition, inappropriate or unprofessional conduct, or concerns of an intimate or sexual nature.

- You can make a complaint to the College of Physicians and Surgeons British Columbia [through their website](#).

PRIMARY CARE PROVISION IN WALK-IN AND URGENT CARE CLINICS

The College of Physicians and Surgeons BC has a practice standard stating that when an individual does not have a primary care provider "but attends the same clinic repeatedly and consistently, then the registrants (physicians) and medical director are collectively responsible for offering these patients longitudinal medical care, including the provision of appropriate periodic health examinations."

We know it can be very difficult to find a family doctor in BC. This legislation is meant to ensure that even those who do not have a family doctor, can access necessary medical care in their community. As long as you are attending the same walk-in clinic consistently, these rules apply and the clinic is responsible for providing primary care services, including prescribing and renewing prescriptions, referring to specialists, and arranging for necessary tests.

Read more about [patient rights for walk-in clinics](#).

DISCLOSING ILLNESS OR DISABILITY TO YOUR EMPLOYER

The **Disability Alliance of BC** has created a [Disclosure Guide](#) with guidance around disclosing illness or disability to your employer. Many individuals living with a disability or facing health issues find themselves unsure of what they should, or need to, tell their employer about their limitations and needs. You may need certain accommodations to perform your job duties, but are unsure what you can ask for. It's also very common for people to worry what the consequences will be if they tell their employer about their disability. This guide provides important information about your rights as an employee, and helps you make decisions about what to tell your employer.

HUMAN RIGHTS COMPLAINTS

Provincial complaints

If you believe you have experienced discrimination or harassment you may be able to file a complaint with **BC's Human Rights Tribunal** or the **Canadian Human Rights Commission**. You will need to determine which one to make the complaint to. Under Canadian and International laws there are protections for all people against discrimination based on things like race, nationality, religion, family status, sex, gender, gender expression, age, genetic characteristics and ability. Human Rights complaints can be filed against public institutions as well as private ones.

Here you will find information about complaints made under BC's Human Rights Code which only applies to certain areas, including:

- Employment (work at a job)
- Employment advertisements (job ads)
- Tenancy (renting an apartment or space)
- Services like stores and schools
- Buying a house or other land
- Being a member of a union
- Publications
- [Learn more](#) through BC's Office of the Human Rights Commissioner.

Federal complaints

Here you will find information on grounds for discrimination complaints under the Canadian Human Rights Act. The Canadian Human Rights Act applies to federally regulated institutions such as federal departments, Crown corporations and agencies, First Nations governments, and private companies that are regulated by the federal government such as banks, airlines, trucking companies, broadcasters and telecommunications companies. This website also helps you decide which government office to make a human rights complaint to.

- [Learn more](#) through the Canadian Human Rights Commission.