COMPLEX CHRONIC DISEASES PROGRAM

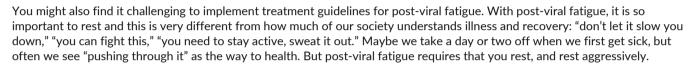
Cope: Coping & resiliency

Living with post-viral fatigue can bring up many complicated emotions: despair, grief, sadness, anger, overwhelm and frustration. It can also lead to a reordering of what is important, to new sources of community and support, to the joy that comes after pain. None of this is linear and you may experience many ups and downs.

Social impacts of post-viral fatigue

These might include:

- Stigma that comes along with your COVID-19 diagnosis
- Difficulty accessing care through the pandemic
- Difficulty getting a clear diagnosis of your symptoms
- Lack of understanding about your illness from family and friends





Of course life doesn't stop even in the face of illness. There are many things that might make you feel like you do not have the time to rest:

- Caregiving responsibilities
- Friends and family who want to see you
- Financial stress and staying on top of bills
- Daily chores like laundry, cleaning the house, and running errands

Not doing all the things you usually do in order to take rest might make you feel guilty, ashamed, angry, anxious, or sad. It's important to remember that resting doesn't mean that you are lazy; resting is the best thing that you can do to take care of your health right now. See our "Cope: Managing Relationships" handout for suggestions around how to get the practical help you need from loved ones as you focus on recovery. Review our handout "Engage: Disability Supports" that can help alleviate financial stress while you focus on your health.

How can you manage the emotional impacts of your illness? In the rest of this document, we have outlined some tools that may help.

Mindful self-compassion

We have adapted this section from Kristen Neff's work on mindful self-compassion. You can read more at self-compassion.org

Compassion is when we recognize the suffering of others' and we take steps to alleviate that suffering. Many of us treat our loved ones with kindness, compassion and care but treat ourselves harshly. We may speak to ourselves in ways that we would never use with a friend, or even acquaintance.

Self-compassion is giving ourselves the same love and care that we give to others. This support and care may be gentle, like offering ourselves the words we need to hear in a tender moment, or it can be fierce, like setting boundaries or standing up for ourselves in difficult situations.



Self-compassion can include things like:

- Telling yourself that it's ok to pace yourself and take rest when you need to
- Setting a boundary, so that you can take care of yourself
- Taking a deep breath, and saying something kind to yourself when strong emotions arise

There are three main components to mindful self-compassion:

- Mindfulness
- Common humanity
- Self-kindness

Mindfulness is paying attention to the present moment, on purpose, and without judgment. You can practice mindfulness by tuning into your surroundings, focusing on your breathing, feeling your feelings, or noticing your thoughts without judging them. Mindfulness can help you to practice self-compassion by allowing you to recognize moments of suffering or difficulty, and allowing you to be available to yourself in those moments.



We may get so used to the critical voice in our head that it becomes part of the way we see ourselves and the world. Mindfulness can help us take a step back and notice this voice for what it is: just a critic who may be right, or wrong, or really, really wrong. Oftentimes this inner critic places unreasonably high standards on us and makes us feel worse when we're already down. This noisy inner critic may have taken hold as a way to protect or motivate us at some point in time – but can become so toxic that it actually starts lead us further away from living the life we want to lead and cultivating a positive relationship with ourselves.

Common humanity means taking a moment to recognize our suffering as part of the human condition. It is not a personal failing if we make mistakes, experience pain, or feel anxious, sad, angry or jealous etc. at times. It allows us to embrace our imperfections and see struggles and pain as something that connects us with the rest of humanity. This normalizes our experience of suffering and inner conflict and reminds us we are not all alone in these difficulties, that others have also spent time in these places. This helps us to not see our struggles as individual faults, but rather a normal part of the human experience. Offering ourselves this understanding can help us cope in times of difficulty and can support you in coping with the highs and lows that come with illness.

Self-kindness is making the choice to offer ourselves unconditional love and support in the face of these difficulties. Once we have acknowledged that we are suffering and placed this experience within the context of the human condition, we are more equipped to respond to that suffering, in either small or big ways. Self-kindness may come in the form of some words we offer to ourself in a moment of pain, or a physical gesture such as putting our hand over our heart, or it may show up as an opportunity to take action on our feelings: express our needs, reach out for support, set a boundary, or make a change in our lives for the better.

Research shows that self-compassion is powerfully linked to well-being. It has been associated with lowered incidence of depression, anxiety and shame. Self-compassion can help improve coping with trauma, chronic illness, and chronic pain, as well as supports motivation and resiliency in the face of adversity. It has strong links to both physical and emotional regulation by helping calm the nervous system.

HOW TO PRACTICE SELF-COMPASSION

Treat yourself the same way you would treat a close friend.

How would you treat a friend is taken from Kristen Neff's website.

Take out a pen and paper. Then follow these steps:

1. Think about a time when a close friend felt badly about themselves. How would you respond to your friend in this situation? Write down what you would do, what you would say. Think about the tone of voice you would use when you talk to your friend.



- 2. Think about a time when you have felt badly, or when you have struggled. How did you treat yourself in these situations? Write down what you typically do and what you say. Think about the tone of voice you use when you talk to yourself.
- 3. Did you notice a difference between the way you would talk to a friend and the way you talk to yourself? If so, ask yourself why. What factors or fears affect the way that you treat yourself, and what allows you to treat the people you love differently?
- 4. Write down how you think things might change if you treated yourself the same way you treat your close friends if they are having a hard time.
- 5. The next time you notice that you're being hard on yourself, look back at this exercise, and try treating yourself the way you would treat a close friend.

Learn more about mindful self-compassion

<u>Kristen Neff's website</u> has lots of free guided meditations, exercises, and articles, as well as a self-compassion quiz to test your level of self-compassion.

The <u>Self-Compassion Break</u> is a helpful and brief tool for practicing self-compassion when we are feeling overwhelmed or distressed.

The Centre for Clinical Interventions has made a free info guide and workbook on self-compassion available for download.

Calming the nervous system

There are numerous benefits to learning skills for calming the nervous system. These techniques can help us to better manage stress and the demands of daily life in general, but for people with post-viral fatigue, they can play a significant role in illness management and recovery.

By becoming more skilled with calming the nervous system we can:

- Help support more restorative rest and recovery. For more information about pacing and the different types of
 energy we can expend (physical, cognitive, emotional/social) see the "Plan: How to pace" handout.
- Help regulate pain responses in the body and enhance pain management strategies. Engaging the parasympathetic nervous system regularly helps to reduce over sensitization of the nervous system, which can reduce the brain's reactivity to pain.

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Techniques such as mindfulness and meditation support greater self-awareness, enabling us to better attune to our physical needs in order to self-manage. This can help you recognize the need for rest, or warning signs of a pain flare or migraine, allowing for improved management.

Greater self-awareness also includes awareness of our emotional experience. This often means we begin to better identify what is happening for us emotionally, allowing us to identify our needs and perhaps see opportunities to take action, such as seeking outside support or practicing self-compassion.

Before we review some techniques for regulating the nervous system, let's first take a closer look at how the nervous system works.

Autonomic nervous system

The autonomic nervous system is divided into two branches: the sympathetic nervous system, which helps prepare the body for quick action, and the parasympathetic nervous system, which helps slow down the bodily processes and return it back to baseline. Both are important in the body's stress response and recovery, and together they work to keep the body in balance.



Sympathetic nervous system, or the "gas pedal"

The sympathetic nervous system (SNS) is often described as the "gas pedal" and is triggered when the brain perceives a threat or stressor and wants to mobilize the body quickly. The SNS leads to changes in physiology including increased heart rate, increased breath rate, and increased blood flow to the muscles, to name just a few.

This reaction is also known as the "fight or fight" response and evolved as a survival response. The body is shifting its energy resources towards defending, protecting, or fleeing from the threat. Once the stressor has resolved, the body is designed to return to its pre-emergency state. The sympathetic nervous system response is intended to be used for short periods of time, until the perceived danger has passed.

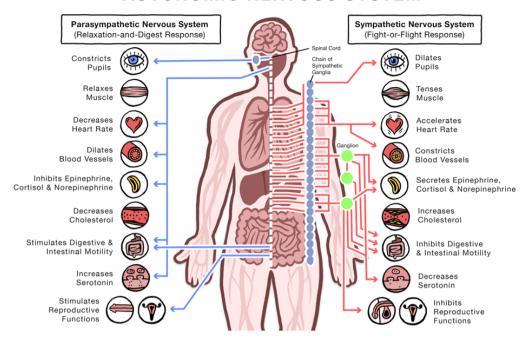
Parasympathetic nervous system, or the "brake pedal"

The parasympathetic nervous system (PNS) is the calming, restorative part of our nervous system. When activated, it helps our bodies rest, repair, digest, and relax. It is often described as the "brake," sending signals to your body to slow down and conserve energy. The PNS has the opposite effect as the SNS, and in this state, the heart rate decreases, breathing rate decreases and breaths lengthen, and intestinal activity increases.

The image below elaborates further on this process.

Review the below image to identify cues that your body is in sympathetic nervous system activation and when it has returned to parasympathetic system activation.

AUTONOMIC NERVOUS SYSTEM



An overactive nervous system

As described above, the PNS and SNS have different roles, but work in partnership to regulate our bodily functions. The purpose of the SNS is to enable people and other mammals to react quickly to life threatening situations, such as a sabre tooth tiger! However, today, our stressors or threats look much different and are much more frequent, such as traffic jams, work or financial stress, family difficulties, or illness, such as symptoms of post-viral fatigue; but they still trigger the same sympathetic nervous system responses.

Therefore, in experiencing symptoms of illness (e.g. fatigue, pain), the SNS remains activated because the body perceives these symptoms as a threat to normal functioning. However, health is best supported and maintained by the PNS.

Prolonged sympathetic nervous system activation means stress hormones, including cortisol and adrenaline, are being fired frequently, and this can start to negatively impact the body over time. This can result in an increased risk of:

- Headaches
- Muscle tension and pain
- Sleep disturbances
- High blood pressure and other cardiac issues
- Memory and concentration impairment
- Metabolic disorders (obesity, diabetes)
- Brain changes that may contribute to anxiety, depression, addition



Emotional changes

In addition to the physiological shifts in the body, emotional and behavioural changes can also occur with our nervous system responses. When the SNS is activated and the body is in fight or flight mode, it is common to experience feelings of anger (frustration, irritation, impatience, criticism) and fear (worry, anxiety, overwhelm). Often the fear will be experienced as racing thoughts and difficulty concentrating.

This is the body's attempt to be vigilant for threats and direct all resources to defense and protection. The executive functioning parts of the brain – the ability to concentrate, recall memories, access vocabulary - is not engaged when the SNS is activated. Alternatively, with the PNS activated, feelings of calm, connection, compassion, curiosity, and creativity may be more readily experienced. When experiencing symptoms leading to physiological and emotional or behavioural changes, it can be helpful to know these are normal adaptive responses of your body.

WAYS TO SUPPORT YOUR NERVOUS SYSTEM (PUTTING ON THE BRAKES)

As you become more aware of signs your SNS is activated, you can implement techniques and practices to shift into the PNS. One of the ways the PNS can be activated is by stimulating the vagus nerve. The vagus nerve is the longest nerve in the autonomic nervous system, extending to almost every major system in the body. It acts like a superhighway, sending information from the brain to the body, and from the body to the brain.

The vagus nerve can be stimulated with:

- Mindfulness and meditation
- · Deep, slow, abdominal breathing
- Singing, humming, chanting and gargling
- Voo breath
- Laughter
- Drumming

And much more.

Click the links below for guidance on specific exercises and techniques. The tools that follow can be especially helpful when we are experiencing a strong emotional reaction or feel overwhelmed. However, if we practice them when we are feeling calm, they will be easier and come more naturally in moments of stress.

Voo technique

Box breathing

5-4-3-2-1

Calm breathing (4-7-8)

5 finger breathing



EVERYDAY SELF-CARE

There are many other ways to calm the nervous system or promote a relaxation response as part of regular self-care, day to day, not only when you are already feeling stressed or anxious.

It's beneficial to dedicate time to doing activities that are soothing, rhythmic or repetitive including:

- Arts & crafts
- Spending time in nature
- Bonding with a pet
- Reading
- Journaling
- Listening to/playing music
- Singing or chanting
- Visualization
- Gentle mindful movement such as yoga, tai chi, or qi gong
- · Seeking opportunities to laugh, such as watching a funny video, listening to comedy, or spending time with friends
- Seeking out social support and connections
- Mindfulness and meditation

FURTHER MINDFULNESS AND MEDITATION RESOURCES

The Science of Meditation

Meditating with Beginner's Mind

UCSD Center for Mindfulness

<u>Guided audio files</u> for practicing Mindfulness-Based Stress Reduction (MBSR) from the UC San Diego Center for Mindfulness.

Kelty Mental Health Resource Centre

Collection of short, <u>free guided mindfulness meditations</u> and other resources from BC Children's Hospital Centre for Mindfulness.

Breathworks

Organization <u>founded by Vidymyala Burch</u> that specializes in mindfulness for pain, illness and stress. Many paid resources plus some <u>free recordings and talks</u> can be found on Soundcloud.

Mindfulness for Managing Long-COVID

Free, online, self-paced, <u>7-session program</u> developed by Breathworks, NHS, and University College London to help people manage their recovery from long-COVID.

UCLA Centre for Mindfulness

 $\underline{Free\ guided\ meditations}\ and\ mindfulness\ exercises\ in\ multiple\ languages.$

Palouse Mindfulness

Free, online, self-paced 8-week Mindfulness Based Stress Reduction (MBSR) course

Tara Brach podcast site

Interested in learning how to meditate? Here are some apps that can help:

- UCLA Mindful (free, straightforward app with short meditations. Great app for beginners)
- Insight Timer (app with extensive amount of free content, some paid features)
- **Breathr** (free app for youth and adults, developed by Kelty Mental Health & BC Children's Hospital Centre for Mindfulness)
- Healthy Minds (free app)
- Headspace (paid app with free trial)
- Calm (paid app with free trial)
- Balance (free for one year)

ADDITIONAL RESOURCES FOR ENHANCING COPING SKILLS

Centre for Mindfulness Studies

Online mindfulness-based training for individuals and professionals.

Positive Coping with Health Conditions, A Self-Care Workbook (Dan Bilsker, PhD, RPsych, Joti Samra, PhD, RPsych, Elliot Goldner, MD, FRC(P), MHSc) is a <u>self-care manual</u> authored by scientist-practitioners with expertise in issues relating to coping with health conditions. This manual is designed for individuals who deal with health conditions, including patients, physicians, psychologists, nurses, rehabilitation professionals and researchers.

Bounce Back BC

A <u>free skill-building program</u> designed to help adults and youth 15+ manage low mood, mild to moderate depression, anxiety, stress or worry. Delivered online or over the phone with a coach, you will get access to tools that will support you on your path to mental wellness.

• 1-(866)-639-0522

Anxiety Canada

Formerly Anxiety BC, this site has <u>lots of self-help resources</u>, including free worksheets and information on how to use CBT to help with worries, anxiety or panic. Creators of the MindShift App.

Get Self Help UK

• Website with <u>CBT self help resources</u>, including worksheets and information sheets, plus videos and self help mp3s. Most is free, although there are some ads on the site. Creators of the STOPP app.

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