



## **COVID-19 PSYCHOLOGICAL WELLNESS GUIDE:**

### **LONG-HAULERS**

**Version 1, 12/27/2020**

The short-term effects of COVID-19 are well known: cough, fever, chills, loss of the sense of smell, and fatigue, among others. What scientists and patients are discovering is a growing list of long-term side effects of the virus too. The term “long-haulers” has been created to refer to individuals who experience lasting effects of the virus. Although there’s no official definition of a long-hauler, it has been used by online support groups and medical and psychological providers to describe people with ongoing symptoms after being infected with COVID-19. There can be a range of symptoms, commonly including fatigue, shortness of breath, body aches, difficulty concentrating, headaches, difficulty sleeping, palpitations, dizziness, brain fog (troubles thinking and concentrating) and others. These symptoms can last weeks to months. Interestingly, many long-haulers only had mild or moderate symptoms to begin with and right now there is no way to predict who will develop lasting symptoms.

The science and medical communities are still learning about the long-term effects of COVID-19. In the meantime, here are some tips and resources to help you cope with the challenges that come with being a COVID-19 long-hauler. We’ve also included advice to share with your loved ones or healthcare providers to help them support you the best they can.

### **Address Your Emotional and Psychological Needs**

- Be gentle and compassionate with yourself
  - Take care of yourself and don’t blame yourself for the things you are unable to do right now
    - Recognize your symptoms may prevent you from helping in the ways you usually do at work, at home, in social settings, or in your education
  - Do not be discouraged or put yourself down for having long-term side effects of a “mild” or “moderate” case of COVID-19 (or even if you had the classic symptoms of COVID-19 but never tested positive)
    - Remember, extended symptoms can be found in people with any range of early symptoms of COVID-19 and having a mild case does not mean your symptoms now aren’t very real
  - Avoid the temptation to focus on what you “should be doing by now”
    - Accept what your current reality is each day
    - Avoid thinking “should”



- Try not to get discouraged by people who don't believe you or try to minimize your experience with your long-term symptoms
  - Know your symptoms are real and there is still so much to be learned about the symptoms you're experiencing
  - Ignore, address, or challenge the quick and incorrect assumptions other people make that make it harder for you to cope
- Pay attention to triggers for your emotional and psychological symptoms
  - Identify things that make these symptoms worse
  - Avoid these triggers to the best of your ability
- Manage brain fog
  - Create a system that helps you organize your thoughts – this can help you adapt to the situation and doesn't mean you are failing
    - Create to-do lists
    - Write ideas on paper where you can find them later if you have trouble with your memory
  - Limit or avoid the activities that make your brain fog worse - this can include participating in long phone calls or virtual meetings, eating large meals, getting dehydrated, or not getting enough rest or sleep
- Stay in the present
  - Focus on and experience positive moments in the present
  - Be aware that your mental health can worsen if you focus too much on the past or the future given all the unknowns surrounding long-term symptoms
- Find purpose and meaning in each day
  - Ask yourself “what are some core parts of my identify?” (e.g., relationships with family or friends) and do small things in keeping with what is core to who you are
  - Do something that matters to you and that gives your life meaning
    - Modify these actions to be consistent with how you are feeling (e.g., 15-minute chat versus an hour walk with a family member or friend)
    - Lean on your spiritual beliefs if this is relevant to you
  - Determine new or old hobbies you can look forward to without wearing yourself out
    - Embrace these new activities as ways to give you a sense of purpose
  - Celebrate each victory you have related to finding purpose, even if the steps you take are small (e.g., prepare your own meal, write a note to mail to a friend)



- Discuss your ongoing emotional and psychological concerns with a healthcare provider
  - Solicit their ideas about what else you can do to more effectively manage your emotional and psychological symptoms
  - Talk to a counselor if these symptoms are distressing or concerning
  - Find out if there are medications to help with your symptoms, such as anti-depressants
    - Take these medications as prescribed

### **Focus on your Physical Needs**

- Listen to your body
  - Let your body tell you when you have used too much energy or when it's not ready for certain activities
  - Pace yourself - once you know how much your body can handle, do that amount but don't go past that level - sometimes that will mean doing half a task (like washing dishes or doing laundry) and then coming back to finish it after you've rested
  - Use what your body tells you to validate your emotional experience
- Take care of your physical self
  - Recognize physical signs and determine the triggers of your physical symptoms
    - Avoid or minimize these triggers as much as possible
  - Keep as regular of a sleep schedule as possible
    - Do not take naps in the late afternoon or evening, even if you're unable to sleep at night
    - Remember, being tired will help you fall asleep when nighttime comes
  - Drink plenty of water throughout the day
  - Eat a well-rounded diet and make sure you are getting enough to eat, especially if you've lost your sense of taste or smell – your body needs fuel even if your appetite is less than normal or you're not getting enjoyment from the flavors in your food
  - Exercise, but start slowly and then build up your exercise
    - Start with exercise that is easier on your body
      - Try restorative yoga
      - Try exercises you can do laying down (e.g., rowing machine, some forms of pilates that you can do in bed, recumbent bike)



- Wait to perform more challenging exercise, such as running or weightlifting, until you feel confident your body is ready
- Discuss an appropriate exercise plan with your healthcare provider
- Switch up your environment
  - Switch chairs or rooms to prevent feeling confined in one space, even if you only have the energy to sit or lay down all day
  - Make your bed a place for sleeping and sex only, not working or relaxing
- Find something cozy and comforting to keep with you so you get the physical comfort you want and need
  - Consider having a soft blanket, stuffed animal or fuzzy pet who can offer you physical comfort – especially important if you have fevers that continue and you can't have human touch, even if it's what you want and need the most
- Be realistic about your physical limitations
  - Set accurate expectations to help prevent you from being disappointed or surprised when you're unable to complete your goals or plans for the
  - Start small with your expectations and build as you learn what your body is able to handle
  - Be patient with your physical limitations - this might be the first time you've come face-to-face with a chronic health condition and that can be very challenging physically and psychologically
    - Allow yourself time to adapt to the new expectations you need to have for your body and mind

### **Connect with Other People and Reach out for Support**

- Stay connected with people
- Adapt the activities you love to do with your family or friends in a way that is comfortable for you – will help bring a sense of normalcy to you and your family/friends
  - Simplify or change activities so it is easier for you to participate
    - Shorten activities
    - Use walkie-talkies and send your children on a scavenger hunt while you're able to sit in the comfort of your bed or couch
    - Watch movies you all love even if you have to watch them earlier in the evening to accommodate for feeling tired later at night



- Ask other people for help
  - Reach out broadly to family, friends, coworkers, neighbors, religious leaders, etc.
    - Turn to different people for different types of help
  - Let people know what you need so you get the help you need
    - Request practical assistance like with daily activities, or childcare, or work responsibilities
    - Ask for emotional support and understanding
    - Ask for financial help when you need it - you might have a large change in finances if your symptoms prevent you from working normal hours - this is not something to be ashamed of
      - Ask people close to you for financial help if they have resource
      - Reach out to community organizations that have been put in place specifically to help with financial troubles
- Say yes when others offer to help you
  - Let others help with basic daily tasks, which may give you more energy to do the things you enjoy throughout the day
    - Save energy for doing the things that will bring purpose to your life
  - Take advantage of help when it is available to you (often early in the process) - you will appreciate it both now and later.
- Connect with a healthcare provider or team you really trust
  - and who believes you when you discuss your symptoms. It's important to have a good relationship with your healthcare providers as you figure out how to manage your condition.
- Find and participate in support groups for people who have long-term COVID symptoms
  - Check out online platforms in which you can share your experiences with others and get advice from people living with similar symptoms
    - See below for information about some of these support groups
  - Use information from other related types of support groups since there isn't a lot of information about long-haulers yet
    - Check out groups and information related to chronic fatigue syndrome or dysautonomia
    - Look to these sources to find ways that might help you cope and manage your symptoms while the medical and scientific communities learn more about long-hauler



## Share this Advice with your Caregivers and Healthcare Providers

- Validate your loved one or patient's experiences
  - Be mindful that there is a lot left to be discovered about being a long-hauler and it helps if the individual feels validated by those around them as they learn how to live and cope with their symptoms
  - Understand this might be the first time your loved one or patient has had to manage a chronic health condition and they need time to adjust and learn how to cope with these new challenges
  - Be patient with them
- Be aware of and address the myths surrounding long-haulers
  - Do not accuse people who have long-term symptoms of making these symptoms up, which can be very difficult for your loved one or patient's mental health
  - Provide the person support if others' have challenged the truth of their symptoms
- Help fight the stigma surrounding long-hauler symptoms
  - Avoid making assumptions about their symptoms or the ways it affects them
    - Ask and learn from them about what they're experiencing instead of making assumptions.
    - Recognize that long-term symptoms can have a large impact on a person's financial situation, and this can cause additional challenges for the person
  - Reflect on ways in which you might spread stigma about long-haulers
  - Speak up when you hear misinformation being spread
- Help your loved one or patient find purpose in each day
  - Use this as a bonding experience and create a strong team while improving the long-hauler's mental health
- Offer your assistance
  - Make it easier on the person who is a long-hauler and offer help or simply assist
  - Offer different kinds of help
    - Help with things they have the most difficult time doing
    - Assist with things you imagine would be the most tiring
    - Provide emotional and/or financial support, not just practical and physical support, if possible
  - Organize teams to help the person manage their lives



- Get the support YOU need
  - Take care of yourselves as well
  - Reach out to people that can help you in the ways you need
  - Try not to place your emotional burden on the loved one you're caring for and instead find others around you that can help relieve some of your burden

### Helpful Resources

- Body Politic COVID-19 Support Group: <https://www.wearebodypolitic.com/covid19>
- Website with a great list of resources: <https://www.wsha.org/post-covid-recovery-resources/>
- Dysautonomia International: <http://www.dysautonomiainternational.org/>
- The Dysautonomia Project: <https://thedysautonomiaproject.org/>
- American Myalgic Encephalomyelitis and Chronic Fatigue Syndrome Society: <https://ammes.org/>
- The ME Association: <https://meassociation.org.uk/>
- CDC website for late-sequelae of COVID-19: <https://www.cdc.gov/coronavirus/2019-ncov/hcp/clinical-care/late-sequelae.html>
- Doctors/Post-COVID Treatment Centers (as of 12/2020) – these will continue to be created, so it may help to do your own search in the area surrounding you as well:
  - University of Alabama-Birmingham Post COVID Treatment Program: <https://uabmedicine.org/web/guest/patient-care/conditions/coronavirus>
  - Cleveland Clinic: <https://consultqd.clevelandclinic.org/life-after-covid-19-post-icu-recovery-clinic-is-an-option-for-some-survivors/>
  - Mount Sinai: <https://www.mountsinai.org/about/covid19/center-post-covid-care>
  - Penn Medicine: <https://www.pennmedicine.org/for-health-care-professionals/for-physicians/physician-education-and-resources/clinical-briefings/2020/september/post-covid-assessment-and-recovery-clinical-briefing>
  - University of California Davis: <https://health.ucdavis.edu/health-news/contenthub/new-post-covid-19-clinic-helps-long-suffering-long-haul-patients/2020/10>
  - University of California San Francisco: <https://www.ucsfhealth.org/clinics/pulmonary-practice-at-pannassus>
  - University of Colorado Health: <https://www.uchealth.org/today/covid-19->



- long-haulers-get-help-at-special-icu-clinic/
- Vanderbilt: <https://opensched2.app.vumc.org/web/#/landing> (ask about the ICU Recovery Center)
- Westchester Medical Center: <https://www.westchestermedicalcenter.org/wmchealthpostcovid19recoveryprogram>