

Covid-19 Survivor's Tools

Welcome to rehabilitation - we are glad you are here. The following packet is designed to help you understand:

- what happened to you medically
- what symptoms you might expect to have now
- how to move forward from here

What happened?

According to the CDC, COVID-19 is a new disease that is caused by a type of virus called a coronavirus. COVID-19 is short for “coronavirus disease 2019”. It is called this because it was first identified in 2019.

COVID-19 causes respiratory illness, and can also cause fever, cough, difficulty breathing, and in some cases diarrhea, vomiting, and loss of smell or taste.

Your doctors determined that you were infected with COVID-19 through a test that identifies the virus in your body.

Although some people with COVID-19 are able to recover at home, because your symptoms were serious, you were admitted to the hospital for additional care.

While in the hospital, you may have had the following treatments.

- Medications to fight the virus and to keep your blood pressure in the right range
- Oxygen through the nose to help keep the oxygen in your blood high enough
- Placed on a ventilator to help support your lungs while they could not do all the work themselves

What can I expect now?

People who have been cleared by their doctors to start rehabilitation can begin the process of getting back to normal life.

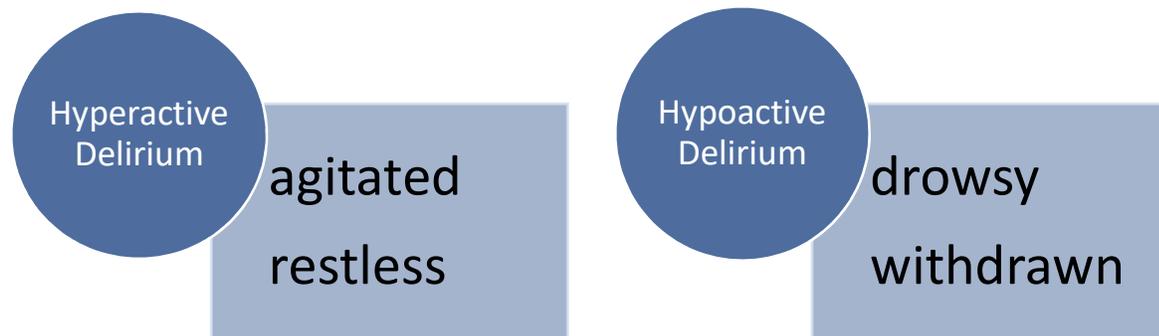
Many people with COVID-19 develop a serious lung condition called Acute Respiratory Distress Syndrome, or ARDS. ARDS, and the treatments to fight it, can cause a variety of symptoms.

- Post-Intensive Care Syndrome happens when someone has ARDS or another condition that requires extensive care in the intensive care unit (ICU). Post-Intensive Care Syndrome can cause:
 - Delirium and cognitive changes
 - Weakness
 - Mental health concerns

REHAB TIP: USE THE NOTES PAGE AT THE END TO REFLECT ON WHAT HAS CHANGED FOR YOU SINCE BEING IN THE HOSPITAL.

Delirium and Cognitive Changes

Delirium is a worsening of person's mental state that happens quickly (over hours or days). Delirium symptoms usually improve when whatever is causing it is treated or gets better on its own. Delirium is broken down into two types:



Other symptoms of delirium include:

- Being less aware of your surroundings
- Being unable to speak or follow a conversation
- Being confused
- Having dreams that may be frightening, and may keep going when you're awake
- Seeing or hearing things that aren't real
- Believing things are happening that aren't, which can be frightening
- Thinking people are trying to harm you
- Having a change in personality

REHAB TIP: IF YOU EXPERIENCED DELIRIUM DURING YOUR HOSPITALIZATION, HAVE A TRUSTED SOURCE TELL YOU WHAT THE MAJOR MILESTONES OF YOUR CARE WERE. THIS WILL HELP YOU "PUT YOUR STORY TOGETHER."

Other Cognitive Changes

Even if you didn't have the above symptoms of delirium, you may notice a change in your thinking. About 30-80% of patients leaving the ICU develop some kind of problem related to thinking, paying attention, solving problems, and organizing thoughts. This can affect whether you can immediately return to work, balance a checkbook, or perform other daily tasks.

Weakness

ICU-acquired weakness is muscle weakness that develops while you are in the hospital. Up to 50% of people who stay in the ICU for a week or more develop this weakness. This weakness can make it difficult to immediately return to your daily activities like grooming, dressing, feeding, bathing, and walking.

Mental Health Concerns

People who have been critically ill commonly experience the following symptoms after they leave the ICU:

- Difficulty falling or staying asleep
- Nightmares or unwanted memories

REHAB TIP: TALK TO YOUR PSYCHOLOGIST ABOUT SYMPTOMS. THERE ARE EFFECTIVE TREATMENTS THEY CAN PROVIDE TO SHORTEN THE TIME THESE SYMPTOMS AFFECT YOU.

- Feeling upset by reminders of your illness or hospital experience
- Depression
- Anxiety
- Feeling hyperalert or “on edge”

How to Move Forward

At Johns Hopkins, we are committed to helping you set goals that make sense for your life, and working with you to recover independence after your experience with COVID-19.

You will work with the following team members:

- Physical Medicine and Rehabilitation Physicians (also known as Physiatrists)
- Rehabilitation-credentialed nurses
- Patient Care Technicians
- Licensed Clinical Rehabilitation Psychologists
- Occupational Therapists
- Physical Therapists
- Speech-Language Pathologists
- Dieticians
- Care Managers
- Chaplains

Your team will help you handle recovery from COVID-19 Post-Intensive Care Syndrome through the following treatments:

Delirium and Cognitive Changes

- You will be assigned a Rehabilitation Psychologist and possibly a Speech-Language Pathologist who will work together to assess and treat changes in your thinking
- Your doctors and nurses will evaluate for changes in medications that can help you feel more clear-headed
- You can work with your psychologist and/or chaplain to work on strategies to improve your brain health, like getting good sleep

Weakness

- Your doctors and nurses will help manage your medications and health concerns so that you can regain strength as much as possible
- Occupational Therapists will work with you on strengthening and on being able to do your daily tasks like grooming, bathing, and feeding yourself
- Physical Therapists will work with you on strengthening and on walking, moving around your home, and coming up with ways you can get around your community

Mental Health Concerns

- Your psychologist will evaluate any symptoms and work with you to find ways to combat those symptoms
- If spirituality or religion is important to you, a chaplain will also be available to you for support
- For many people simple education and basic care in the hospital are sufficient to make mental health concerns better
- You will be encouraged to complete a follow-up visit with a psychologist so that any symptoms you may have do not bother you long-term

Other things you should know

Some people may be able to go home directly from rehabilitation, and others will need to go to another facility to continue to recover. Talk to your team about which plan will work best for you and your family.

Many people who go home still need therapy as an outpatient even after they leave inpatient rehabilitation to continue to work on getting stronger. Think of your recovery from COVID-19 as a marathon, not a sprint. Leaving the hospital is a major milestone and should be celebrated – but it is likely not where your recovery journey ends.

You're a survivor, and you are in charge of your recovery

What you do now that you're in rehabilitation makes a big difference in how quickly you recover. Things you can do to make the most of your time in rehabilitation and get better as quickly as possible include:

- Talk to your family or friends about your experiences and feelings while you were hospitalized and your experiences during rehabilitation over the phone or via video chat. Remember, getting support from loved ones is one of the most important ways to heal.
- Take care of yourself by eating well.
- Get plenty of rest overnight.
- Try to encourage your body to relax by meditating, praying, or doing other relaxing activities in your free time like reading, coloring, doing puzzles, etc.
- Do your best during therapy sessions.

Resources

Department of Physical Medicine and Rehabilitation
(Rehabilitation Psychology and Neuropsychology)
443-997-5476

Society of Critical Care Medicine Thrive
<https://www.sccm.org/MyICUCare/Home>

American Thoracic Society
<https://www.thoracic.org/patients/patient-resources/>

