



## Recovering at home after a COVID-19 hospital stay

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\*Access the other sections of [this workbook](http://michmed.org/ng2Wl) by visiting: <http://michmed.org/ng2Wl>



## What can I expect while recovering?

*“He likes to be in control of everything. It was hard for him not to be in control. To be the caretaker--that’s normally his role. So, he just felt really depressed. Here I was, having to clean him and bathe him [...] that’s the way it was. It was a blow to him [...] I told him, ‘I’m going to help you.’ And he was like, ‘This is too much on you.’ And, you know, I was like, ‘Babe, I love you. We took vows for this. This is what our wedding vows meant--right now.’ So I just encouraged him and so he got himself together.”*

**- Spouse of a COVID-19 patient, November 2020**

While the worst of the virus may be over, recovering from COVID-19 can be a long, winding journey. You may experience a wide range of joys and challenges. Your relationships with your family, friends, and your own body and mind may be changing. You may find yourself needing to do everyday activities differently or needing help with things you never needed help with before. Be kind to yourself as you navigate the changes that come with this stage of the journey.

### If you are a patient:<sup>1</sup>

You may still feel the effects of your hospital stay both physically and emotionally. You may experience:

- Weakness and fatigue
- Shortness of breath
- Difficulty concentrating
- Depression or anxiety
- Difficulty completing tasks
- A sense of helplessness

### If you are a caregiver:<sup>2</sup>

You may be affected physically and emotionally during and after the patient’s hospital stay. You may experience:

- Inability to sleep
- Anxiety
- Depression
- A sense of loss
- Symptoms of post-traumatic stress
- Stress of caring for someone

Throughout it all, make sure you are taking care of yourself. Remember to:<sup>1</sup>

- Accept help from friends, family, and faith communities. For example, let people drop off meals and ask for encouraging text messages
- Get enough sleep and eat healthy foods
- Avoid or significantly limit alcohol and drug use
- Ask your care team questions regarding self-care
- Consider seeing a therapist or counselor, or join a support group
- See a doctor regarding any ongoing health issues you may have

<sup>1</sup>Adapted from: de Bear, Kevin, and Evan Haezebrouck. Functional Recovery after a COVID-19 Hospital Stay. <http://www.med.umich.edu/1libr/InternalMedicine/FunctionalRecoveryCOVID-19.pdf>. Published June 23, 2020. Accessed December 12, 2020.

<sup>2</sup>Adapted from: University of Michigan Post ICU Longitudinal Survivor Experience (PULSE) Clinic. Staying on the Road to Feeling Better. <http://www.med.umich.edu/1libr/ICU/AfterAnICUStay.pdf>. Published August, 2019. Accessed December 12, 2020.



## What are common health issues following a hospital stay?<sup>3</sup>

As a patient, you may face:

- **Low appetite and restricted diet.** If you are taking medications, there may be certain foods that you need to avoid. You may also find that you do not have an appetite for the same foods that you typically do.
- **Boredom.** You may need things to do and contact with other people to prevent feeling bored. Television, music and calling others on the phone are great ways to stay entertained and connected. It is also a good idea to get some fresh air outside daily.
- **Circulatory issues.** Less movement than you are used to can create circulatory issues. The best prevention is getting out of bed daily, by yourself if able or with assistance. Ask your doctor if there is any equipment or supplies they recommend to prevent circulatory issues.
- **Breathing troubles.** COVID-19 is a disease that can seriously impact your ability to breathe. It is possible that your doctor may give you a device to help exercise your lungs and muscles involved in breathing.
- **Bed sores.** Prevent bed sores by repositioning during the day and at night. Shift your body position and use pillows to reduce pressure to your heels, tailbone, hips and shoulders. Use pressure-relieving mattresses and cushions if available.
- **Weakness.** Often, you may feel weaker following a hospital stay and have trouble doing tasks that were simple before. This may include getting dressed, bathing, preparing meals, or even standing up and walking. Take your time and plan to rest a bit between tasks. It's okay to use assistive devices like canes, walkers, and shower chairs for support and safety. These devices are often covered by insurance with a prescription from your doctor.
- **Fatigue.** You may feel more tired than normal upon returning home. Daily activities may lead to becoming tired more quickly or feeling the need for a nap during the day. You may also have difficulty sleeping after being in the hospital. Reestablishing a nap and bedtime routine can be helpful, including limiting caffeine and long naps after 3 pm and reducing screen time from phones, televisions, and other devices 2 hours before bed.
- **Difficulty with memory or concentration.** You might have trouble remembering details or events after being ill with COVID-19. You may also have a harder time concentrating while reading or watching television.
- **Feeling depressed or anxious.** Recovery from a hospital stay does not usually happen over night and can take longer than expected, which can be stressful. Performing daily activities and being with family can also be tiring. You may also experience sadness, worrying, and restlessness.

<sup>3</sup>Adapted from: de Bear, Kevin, and Evan Haezebrouck. Functional Recovery after a COVID-19 Hospital Stay. <http://www.med.umich.edu/1libr/InternalMedicine/FunctionalRecoveryCOVID-19.pdf>. Published June 23, 2020. Accessed December 12, 2020.



## What is post-COVID syndrome?<sup>4</sup>

The common health issues listed above should improve as you recover. However, some health issues that come from a difficult hospital stay may be persistent. Ongoing symptoms following a hospital stay are referred to as **post-COVID syndrome** or **post-ICU syndrome (PICS)**.

PICS is a group of health problems that continue to affect your quality of life after you have survived a life-threatening illness, such as COVID-19. People who develop PICS can experience a combination of physical, emotional, and cognitive symptoms. These symptoms may be entirely new problems, or they may be the worsening of problems that were present even before the critical illness.

There are many aspects of PICS that are common to a lot of people following a hospital stay. If you experience any of the symptoms listed below, know that you are **not alone** in feeling this way. **These symptoms are common** and you may experience these symptoms at any point throughout your recovery journey.

### Physical symptoms:

- **Weakness**, including muscle weakness or difficulty doing things you were able to do before being hospitalized
- **Being tired**, including emotional and physical exhaustion, having little or no energy, or like you are unable to get anything done
- **Difficulty sleeping**, including not being able to fall asleep, waking up frequently, nightmares, or pain
- **Shortness of breath**, including breathing problems or difficulty when walking, standing, bathing, or housekeeping

### If I'm experiencing these physical symptoms, what should I do?

- ✓ Consider using supporting devices at home (canes, walkers, shower chairs, etc.)
- ✓ Do physical and occupational therapy
- ✓ Exercise according to your doctor's instructions
- ✓ Ask a dietitian about healthy food

<sup>4</sup>Adapted from: University of Michigan Post ICU Longitudinal Survivor Experience (PULSE) Clinic. Staying on the Road to Feeling Better. <http://www.med.umich.edu/1libr/ICU/AfterAnICUStay.pdf>. Published August, 2019. Accessed December 12, 2020.



## What is post-COVID syndrome?<sup>5</sup>

### Thinking, memory, and concentration symptoms:

- **Signs of short-term memory problems**, including asking the same question over and over again, difficulty remembering words, or forgetting why you went into another room
- **Difficulty concentrating**, including difficulty concentrating when reading, having trouble following a conversation, or struggling to follow the plot in a television show
- **Difficulty making decisions**, including being unable to process all the details needed to make a decision or becoming frustrated or overwhelmed when asked to make a choice or decision
- **Difficulty getting things done**, including having trouble following a recipe or doing something that you have done many times before, difficulty following instructions, or difficulty paying bills and managing finances

### If I'm experiencing these symptoms, what should I do?

- ✓ Be alert to changes in thinking
- ✓ Use calendars, notebooks, and apps on your phone to help you keep track of things
- ✓ Ask your doctor to be screened if you are concerned about problems with thinking, memory, or concentration

<sup>5</sup>Adapted from: University of Michigan Post ICU Longitudinal Survivor Experience (PULSE) Clinic. Staying on the Road to Feeling Better. <http://www.med.umich.edu/1libr/ICU/AfterAnICUStay.pdf>. Published August, 2019. Accessed December 12, 2020.



## What is post-COVID syndrome?<sup>6</sup>

### Mental health symptoms:

- **Signs of Anxiety**, including:
  - Worrying a lot
  - Irritability
  - Being very tired
  - Feelings of panic or restlessness
- **Signs of depression**, including:
  - Loss of pleasure or joy in activities
  - Feelings of extreme sadness
  - Feelings of worthlessness, hopelessness, or helplessness
  - Being tired all the time, inability to sleep, or sleeping all the time
  - Irritability
- **Signs of post-traumatic stress**, including:
  - Nightmares
  - Unwanted thoughts of ICU experiences, such as flashbacks
  - Feeling on edge or thinking something bad is going to happen without any reason
  - Fear or anxiety about being in places or situations that remind you of your ICU stay
  - Unexplained sense of horror, anger, or guilt
  - Numbness or difficulty connecting with others

### If I'm experiencing mental health symptoms, what should I do?

- ✓ Consider seeing a therapist or counselor
- ✓ Schedule an appointment for a thorough check-up with a doctor
- ✓ Talk to your doctor about anti-depressant and anti-anxiety medications. These medications are often helpful, even for short periods of time and particularly when combined with counseling.
- ✓ Refer to the “Mental Health Tracker” and resources available later on in this section

<sup>6</sup>Adapted from: University of Michigan Post ICU Longitudinal Survivor Experience (PULSE) Clinic. Staying on the Road to Feeling Better. <http://www.med.umich.edu/1libr/ICU/AfterAnICUStay.pdf>. Published August, 2019. Accessed December 12, 2020.



## What is post-COVID syndrome?<sup>6</sup>

*“I want to get back to the normalcy that we had, but [...] we’ve talked about it. When we came [home] from the hospital, we looked each other in the face, and I said ‘Sweetie, I have a feeling we’re both going to need some psychotherapy.’ I said, ‘I think we both have PTSD,’ and we talked openly about it. He goes, ‘I believe I do.’ We told the nurses that called. We told the doctors that called. We openly spoke about it. I mean, constantly. We still do. And I think that’s helped.”*

**- Spouse of a COVID-19 patient who was also a COVID-19 patient, July 2020**

### Be on the lookout for...

#### **Post-ICU Syndrome (PICS) for Caregivers**

If you are caring for someone who was in the ICU with COVID-19, you may also experience post-ICU syndrome (PICS). Critical illness can be difficult for everyone, even after the loved one is home from the hospital. You may also find yourself experiencing some of the mental health symptoms included above, such as depression, anxiety, or post-traumatic stress disorder. It is important that you set aside time to take care of yourself, ask for support when you need help, and work with your own healthcare providers to manage any symptoms you may have.

#### **Strategies that can help:**

- Because PICS looks different for each person, seeking help depends on your symptoms. Treatment may include medication, physical therapy, occupational therapy, and psychotherapy.
- You may find it helpful to share stories with other caregivers—both to get advice and for the benefits of being able to help others. See the appendix section “[Building Your Support Network](#)”: <https://michmed.org/wO9gD>



## What are the long-lasting symptoms of COVID-19?<sup>7</sup>

People who have had COVID-19 may have symptoms that are **persistent**: lasting for weeks, months, or more. Sometimes, the people experiencing these long-lasting symptoms identify themselves as **long-haulers**.

The most commonly reported long-term symptoms include:

- Fatigue
- Shortness of breath
- Cough
- Joint pain
- Chest pain
- Headache

Other reported long-term symptoms include:

- Difficulty with thinking, memory and concentration
- Depression, anxiety, and changes in mood
- Muscle pain
- Headache
- Off-and-on fever
- Fast-beating or pounding heart
- Skin rashes and hair loss
- Problems with smell and taste
- Sleep challenges

More serious long-term symptoms affecting the heart, lungs, and kidneys are less common, but have been reported. The long-term importance of these effects is not yet known. However, the CDC is actively working to understand how common these symptoms are, who is most likely to get them, and whether these symptoms will eventually resolve.

### Did you know?

Survivor Corps keeps an updated list of care centers for patients with long-lasting COVID-19 symptoms, or post-COVID care centers. To find a [post-COVID care center in Michigan](#), visit: <http://michmed.org/xo095>

<sup>7</sup>Adapted from: Centers for Disease Control and Prevention. Long-Term Effects of COVID-19. <https://www.cdc.gov/coronavirus/2019-ncov/long-term-effects.html#:~:text=Dermatologic%3A%20rash%2C%20hair%20loss,depression%2C%20anxiety%2C%20changes%20in%20mood>. Updated November 13, 2020. Accessed December 12, 2020.





## As a patient, how can I improve my symptoms and strength at home?<sup>8,9</sup>

Try the following recommendations to improve symptoms and strength at home:

- **Improve your sleep**
  - Aim for 8 hours of sleep per night
  - Try to go to sleep and wake up at similar times each day
  - Turn off your cell phone, television, or computer screens 2 hours before bedtime
  - Avoid caffeine and limit long naps (more than 30 minutes) after 3pm
  - Do something relaxing before bed
- **Exercise**
  - Try to get 30 minutes of activity or exercise per day. This can be broken up throughout the day and includes housework, walking, or structured exercise
  - Work with your occupational and physical therapist to create a home exercise program
  - Check that you have helpful equipment in place at home, such as canes, walkers, or shower chairs
  - Break-up tasks into smaller portions so that they are more manageable
  - Allow for rest breaks so that you can finish activities without getting too tired
  - Slowly increase your daily activity over time
- **Set a routine**
  - Establish a daily routine. Routines are important for maintaining your activity level and may improve memory and thinking changes
  - Do your daily tasks and chores, such as showering, getting dressed, or eating meals, at similar times each day
  - Resume activities you enjoy as much as possible, even if you need to do them differently than before. For example, try cooking while you sit
- **Ask for help**
  - Schedule an appointment for an in-depth check-up with your doctor. Ask to be screened for problems with thinking, memory, and concentration; ask a pharmacist to review your medications and a dietician to review your meals
  - Consider seeing a therapist or counselor. You can also talk to your doctor for help with anxiety, depression, or any other concerns you have about your mental health or mental health changes
  - Contact your doctor to see whether other physical therapy, occupational therapy, speech, and language help would be useful

<sup>8</sup>Adapted from: de Bear, Kevin, and Evan Haezebrouck. Functional Recovery after a COVID-19 Hospital Stay. <http://www.med.umich.edu/ilibr/InternalMedicine/FunctionalRecoveryCOVID-19.pdf>. Published June 23, 2020. Accessed December 12, 2020.

<sup>9</sup>Adapted from: University of Michigan Post ICU Longitudinal Survivor Experience (PULSE) Clinic. Staying on the Road to Feeling Better. <http://www.med.umich.edu/ilibr/ICU/AfterAnICUStay.pdf>. Published August, 2019. Accessed December 12, 2020.



## As a caregiver, how can I help the patient improve their symptoms and strength at home?<sup>10</sup>

Try the following recommendations:

- **Make sure the person is comfortable.** Their bedroom should be clean and neat. Put supplies and equipment in a section of the room so they can have the rest of the room for personal belongings and furniture. A person who is recovering from illness may not want to look at reminders of the illness throughout the room.
- **Encourage getting out of bed.** It is a myth that bed rest is good for a person recuperating from an illness. Sitting or lying in bed can cause many problems for the body such as bedsores, chest infections, reflexes becoming inactive, and blood pressure increasing. Try encouraging the patient to get 30 minutes of activity or exercise per day.
- **Keep a routine.** The patient should try to go to sleep and wake up at similar times each day. You can try and prevent boredom by encouraging activities they enjoy. Additionally, mealtime routines are especially important. Be flexible if the person wants to eat smaller portions more frequently. This sometimes works better than three regular meals a day.
- **Be encouraging about progress.** While everyone would like a smooth recovery with few set-backs, this is not always possible. As a new problem arises, step back and develop a new plan. If you are feeling overwhelmed, consider seeking help. See the end of this section for resources.
- **Ask for help.** If you have questions about medicines or need information about how to manage the patient's care at home, call a doctor. Additionally, remember that providing care can affect your own health, work, and relationships. Consider seeing a therapist or counselor. You can also talk to your doctor for help with any concerns you have about your health and well-being.

For detailed instructions on how to make a bed with a person in it, toileting, and bathing, visit the “Setting Up a Room for Administering Care” tab of [Health In Aging’s “Caregiver Guide: Helping With Recovery From Illness”](http://michmed.org/axgG1): <http://michmed.org/axgG1>

**Call the patient’s doctor immediately if there are any new troubling symptoms.** New symptoms can mean a change in the person’s condition and should be reported to their doctor. Report any symptom that suddenly becomes more severe or difficult to manage. Know the answers to the following questions before calling the doctor:

- What is the symptom, including its severity?
- What is happening when the symptom is better? What is happening when the symptom is worse?
- What medicines is the person taking?

<sup>10</sup>Adapted from: Health In Aging. Caregiver Guide: Helping With Recovery From Illness. <https://www.healthinaging.org/tools-and-tips/caregiver-guide-helping-recovery-illness>. Published 2020. Accessed December 12, 2020.



## How do I find the motivation to reach my goals?

*“He’d been wanting to buy a new car, so ‘Go online and look for a new car.’ We’re gonna live. You live. Let’s live. Go buy that new car. So I gave him a laptop and he got a little excited about that. And I said, ‘But you got to be able to walk to the garage if you gonna get it, you know?’ So ‘Yeah, I’m going to go practice walking to the garage.’ You know, he did that. He was game then. He had a goal. And I let him pick his goal. And I think that’s what you have to do with anyone that you’re a caretaker of. Let them be a part of that. And I had to learn that: let him be a part of where he wanted to be. Cause he could have fell into that self-pity mode, but you also have to have a caregiver that’s not gonna allow you to do that, too.”*

**- Spouse of a COVID-19 patient, November 2020**

Caregivers and patients, together, have an important role to play in setting and reaching recovery goals. Some caregivers take on a coaching role to help the patient reach their desired goals. Practical advice for setting goals:

- **Create clear recovery goals.** Work together to set clear, realistic goals to accomplish throughout recovery. Focus on something you care about or look forward to and incorporate this into your planning. Start with specific goals that accomplish certain tasks, such as being able to walk to the garage.
- **Create structure.** Creating a plan on how to achieve these goals through smaller steps can increase the likelihood of success. To reach your bigger goals, it can be helpful to break them into smaller goals, such as first being able to walk to the front door, then to the garden path, and then to the garage. Include in this structure regular times to eat, sleep, and exercise. Also include small activities that make you happy such as listening to music. Structure helps to create purpose in your day.
- **Keep a recovery journal.** Over time, it can be easy to forget how much progress you have made. You may experience what you see as setbacks, which is normal. Keeping a journal can help you see your progress and help keep track of strategies that work for you. You could write the journal in a book or record videos.
- **Treat yourself with kindness.** Stay focused on positive progress and be realistic about the possibility that it may take longer than you would like to recover. Talk to your doctor and other healthcare providers about your expectations and how you can get to where you would like to be.
- **Celebrate small wins.** Celebrate the victories, even if they’re small. Enthusiasm is a great motivator. Acknowledging progress can inspire more results and improve motivation to continue achieving goals. Celebrating victories and progress can also build confidence in what you can do.



## My recovery planning guide

**My goals for recovery are:**

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**Specific, small steps I can take to reach my goals:**

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**People who can help me reach my goals:**

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**Create a daily structure:**

Use a daily planner to schedule out your day. Include important activities such as:

- Activities that make you happy
- Wake-up and bedtime routines
- Meals
- Medications
- Exercises
- In-home care
- Appointments



## My recovery planning guide (cont'd)

An example daily planner is below. See the next page for a template you can fill out.

Time	General Daily Schedule ( <b>Example</b> )
5:00am	
6:00am	
7:00am	Wake-up routine
8:00am	Breakfast, take medications
9:00am	PT exercises, breathing exercises and get some fresh air
10:00am	
11:00am	Breathing exercises while watching TV
12:00pm	Lunch, take medications
1:00pm	Breathing exercises
2:00pm	Home visit from nurse
3:00pm	PT exercises, breathing exercises
4:00pm	
5:00pm	Dinner, take medications
6:00pm	Video call with family
7:00pm	
8:00pm	Bedtime routine, take medications
9:00pm	
10:00pm	



## My recovery planning guide (cont'd)

Fill in your general daily schedule below. Include your important activities such as:

- Activities that make you happy
- Wake-up and bedtime routines
- Meals
- Medications
- Exercises
- In-home care
- Appointments

Time	Generally Daily Schedule
5:00am	
6:00am	
7:00am	
8:00am	
9:00am	
10:00am	
11:00am	
12:00pm	
1:00pm	
2:00pm	
3:00pm	
4:00pm	
5:00pm	
6:00pm	
7:00pm	
8:00pm	
9:00pm	
10:00pm	



## What are some feelings and emotions I may have?

*“We had some battles. There were times when I would go in the bathroom and cry because he gets frustrated with me [...] I’d call my brother-in-law crying a couple of times about it, saying, you know, ‘maybe I should have let him go.’ And he’s like, ‘no, you’re doing the best thing.’ And I was like, ‘I know I am.’*

*But [my husband] tells everybody today that if it wasn’t for me, you don’t know where he would be. [...] And I’m like, OK, that’s good to hear now. But, back in March and April, you didn’t like me too much.*

*Well, and what you’re doing [as a caregiver] is important. I just had to know that that really wasn’t him, but it was the disease that was attacking me. And that’s where I really had to put my focus on that. That’s not my husband saying that. [...] And once I came to that, I was good.”*

**- Spouse of a COVID-19 patient, November 2020**

Caring for someone who has had COVID-19, or recovering from COVID-19 yourself, can lead to mixed emotions and can challenge your relationships. Sometimes, it can be difficult to process our feelings because we don’t have the words to describe what we are feeling. The next few pages contain word lists that may help you identify the feelings you may be having. You may also have feelings that are not on these lists. Your response to what you are going through could look completely different, and that is okay.

As you read, circle or make note of the feelings you have below. You can also track your feelings each day or week by writing down the feelings you identify with and rating them on a scale from 1 to 10.

**Remember, you are allowed to feel grateful, even though you may also wish that some things had happened differently.**



## What are some feelings and emotions I may have?

If you are a patient, you may feel:<sup>11</sup>

- **Afraid:** You may be afraid that you will never be able to do the same things you used to do or that you will never get through your ongoing symptoms. You may also be afraid that you will get COVID-19 again.
- **Angry:** You may feel angry from having limited access to support you need, from certain things that have happened to you while you were in the hospital, or from the way your workplace or someone else has responded.
- **Bored:** It is easy to become bored when you are not able to do the things you want to do. You may also feel impatient. Try coming up with new ways of doing the things you enjoy, such as sitting while you cook.
- **Embarrassed:** The need for assistance may put you in situations that are otherwise embarrassing to be in. You may feel ashamed of these or not want to talk about them.
- **Euphoric:** You may feel extremely happy, or euphoric, that you are out of the hospital or care facility and back home in a place that's familiar to you.
- **Frustrated:** The recovery process is slow and takes more energy than desired. You may feel frustrated towards the changes you are experiencing and wonder why this has happened to you. You may be frustrated with the pace at which you are recovering.
- **Grateful:** You may feel extremely grateful for the healthcare workers who helped you in the hospital, for your family, friends, and community, and for living through the disease.
- **Guilty:** You may feel guilty that you are still alive after having COVID-19, when others have lost ones they love. Additionally, you may have a hard time asking for help from your family members because you feel as if you have become a burden in their life.
- **Helpless:** You may feel helpless because you can no longer do things you used to be able to do. Because of this, you might feel like a burden to your friends and family as they care for you. Remember that you are doing all that you can in order to get better, and they understand that.
- **Lonely:** You may feel lonely if you have lost relationships that you had before getting sick, or if your family and friends are not allowed, able, or willing to visit you. Remember that they may have new boundaries or restrictions because of COVID-19.
- **Love:** You may feel immense love towards your family, friends, and community who are supporting you and caring for you.
- **Relieved:** You may feel relieved that you are through the worst of COVID-19 and can focus your energy on getting better.
- **Tired:** You could experience an overwhelming tiredness. You have just gone through an intense and draining experience, both physically and emotionally.
- **Uncomfortable:** You may have experienced things in the hospital that you do not want to discuss. You may feel uncomfortable if someone asks you to talk about them. You may also feel physical discomfort from ongoing symptoms.

<sup>11</sup>Adapted from: Schempp, Donna. Family Caregiver Alliance. Emotional Side of Caregiving. <https://www.caregiver.org/emotional-side-caregiving>. Published 2014. Accessed December 12, 2020.





## What are some feelings and emotions I may have?

### Be on the lookout for...

**Often, patients report experiencing stigma after having COVID-19.** Even after you are not contagious, people may respond to you differently or cautiously. Because of this reaction, you may feel angry from having limited access to the support you need or from the way your doctor's office, workplace, or someone else has responded. You may also feel lonely or isolated if this causes you to lose relationships that you had before getting sick, or if your family and friends are not willing to visit you.

*"But my doctor was doing AIDS care in the 80s so he's used to working with people with viruses. [...] So when I called him and I was like, 'Hey, I'm sick with COVID,' they're like, 'Come right in,' but every other doctor that I called was like, 'Woah, we'll do telehealth.' And I was like I need to be touched or seen in person. [...] So I think that's the difficult part. You go from constant care to a leper within like three hours of leaving the hospital."*

**- COVID-19 patient, August 2020**

*"[The lab I usually go to] had a different protocol because of COVID [...] your temp and all that. And I said, 'Well, I've had COVID.' And the girl who was checking me in reacted like she'd seen a zombie [...] I just freaked her out. I felt bad. [...] I guess that it was a challenge learning [...] how other people would react to it. I'm thinking I'm a world beater because it's behind me and I'm feeling like the top of the world. [...] But yeah, I guess that was the biggest eye-opening experience. [...] And while I usually don't care about people, how people react to me, I really don't want to freak 'em out."*

**-COVID-19 patient, July 2020**

Consider seeing a therapist or counselor to talk about this experience, and continue reading for resources that can help you.



## What are some feelings and emotions I may have?

If you are a caregiver, you may feel:<sup>12</sup>

- **Afraid:** You have a lot of responsibility for the day-to-day care of the patient. You may feel afraid that you or the patient are doing too much or not enough. You may also be afraid that they will get COVID-19 again.
- **Ambivalent:** You may have mixed feelings about both wanting to do something and not wanting to do it at the same time.
- **Anxious:** You may feel worried, or anxious, about finances, the number of things you have to do, whether or not the patient is getting better, and whether their symptoms are what you should be expecting. You may also feel anxious about your own health and relationships.
- **Bored:** It is easy to become bored when you are stuck at home taking care of someone else and not doing the things that fulfill your own wants and needs. By the end of the day, you may also feel too tired to pursue something of interest to you.
- **Euphoric:** You may feel extremely happy, or euphoric, that the patient is out of the hospital or care facility and back home in a place that's familiar to them.
- **Frustrated:** Caring for another person is time consuming and often pushes you both physically and emotionally. You may feel frustrated by not being able to control your circumstances.
- **Guilty:** You may feel guilty when you take time for yourself. You may feel like you are not doing enough. You might also feel guilty for being the healthy one while your family member or friend is still recovering.
- **Grateful:** You may feel extremely grateful for the healthcare workers who helped the patient in the hospital, for your family, friends, and community, and for the fact that the patient lived through the disease.
- **Love:** You may feel immense love towards your family, friends, and community who are supporting you and caring for you.
- **Neglected:** You may feel neglected if it's difficult to find resources or make connections with resources for your health after your hospital stay.

<sup>12</sup>Adapted from: Schempp, Donna. Family Caregiver Alliance. Emotional Side of Caregiving. <https://www.caregiver.org/emotional-side-caregiving>. Published 2014. Accessed December 12, 2020.



## What are some feelings and emotions I may have?

If you are a caregiver, you may feel (continued):<sup>13</sup>

- **Overwhelmed:** You may feel overwhelmed by the amount of things you need to do. You may feel fully responsible for the patient's recovery and well-being. Know that it is a team effort, and you can ask for help.
- **Relieved:** You may feel relieved that the patient is through the worst of COVID-19 and is alive. You may also feel relieved from resources, assistance, or help that you receive.
- **Resentful:** Likely, becoming a caregiver has changed your own life. You may not be able to do your work fully, or your own relationships and health may be negatively affected. Because of this, you may feel resentful towards the patient or your caregiver duties. It is okay to have this feeling: feeling resentful does not mean you do not love the patient or are unhappy that they are with you and alive.
- **Unappreciated:** You may feel unappreciated if the patient pushes away your attempts to be helpful and caring, or if they do not thank you or see how much you are giving up in order to care for them. Remember that most of us do not want to be dependent on someone else, and that learning to accept help is hard. You may also feel unappreciated if no one else ever offers to help. Have a conversation with your family and friends about the support you need. See if you can identify tangible things they can do to help and make you feel appreciated.
- **Uncertain:** You may feel uncertain in your ability to provide care. Try and seek training that can help you feel more confident and comfortable when helping the patient.
- **Wary:** You may feel the need to sanitize everything constantly and may feel overly cautious so that no one in your family has to experience COVID-19 firsthand again.

<sup>13</sup>Adapted from: Schempp, Donna. Family Caregiver Alliance. Emotional Side of Caregiving. <https://www.caregiver.org/emotional-side-caregiving>. Published 2014. Accessed December 12, 2020.



## Who can I turn to for support during recovery?

Whether you are a patient or a caregiver, there are many resources available to assist you.

### U-M PULSE Clinic

The University of Michigan Post ICU Longitudinal Survivor Experience Clinic (U-M PULSE) is designed to help patients and their families manage this challenging time following discharge from the intensive care unit (ICU). The U-M PULSE team partners with you and your family to provide medical care and expert guidance after critical illness. The U-M PULSE team works to:

- Identify the changes that are most disruptive to your life.
- Identify your strengths and supports.
- Develop a comprehensive care plan that addresses your goals.
- Help you access additional services and support.

For more information about the [U-M PULSE Clinic](http://uofmhealth.org/um-pulse), visit: <http://uofmhealth.org/um-pulse>

### Guest Assistance Program (GAP)

At Michigan Medicine, a social worker may also help you through the Guest Assistance Program. The **Guest Assistance Program** can connect you with several types of resources (all based on eligibility) for social needs related to medical care at Michigan Medicine:

- Communication with government and community organizations
- Pharmacy assistance for prescriptions
- Durable medical equipment/supplies
- Costs for medication, supplies and equipment
- Lodging assistance
- Meal assistance and Food insecurity
- Transportation and parking

For more information about the [Guest Assistance Program](http://michmed.org/q4kRz):

- Phone 800-888-9825 (Monday-Friday from 9:00am - 5:00pm)
- Visit <http://michmed.org/q4kRz>



## Who can I turn to for support during recovery?

### COVID-19 Peer Mentor Program

Michigan Medicine and the Office of Patient Experience are partnering to create a volunteer program for COVID-19 patients and the people caring for them. As a participant, you will be linked to a **peer** — someone who has experienced similar challenges and situations — to provide you with additional support and guidance along your journey. In the Peer Mentor Program you will:

- Get connected to COVID-19 resources
- Gain support across your COVID-19 journey
- Have an outlet for socialization and friendship
- Learn from others who understand the challenges you face

Mentoring makes a trusting and accommodating connection between two individuals. Mentors provide personalized guidance to their mentees, help to navigate daily stressors, and are a hand for those who need assistance.

If you are interested in becoming a Peer Mentor, complete the [COVID-19 Peer Mentor form](http://myumi.ch/E3wAp) (<http://myumi.ch/E3wAp>) or email [UMHS-PFCC@umich.edu](mailto:UMHS-PFCC@umich.edu).

### Support Groups

Support groups have become quite popular over the past few months as a means of sharing information about common experiences. Many of the current COVID-19 support groups are designed for patients who had COVID-19 themselves. However, if you are caring for someone who is recovering from COVID-19, whether or not you had it yourself, you may also find the groups useful and are welcome to join them.

To learn more about caregiving and COVID-19 supports including support groups and mutual aid groups, see Appendix A: [Building your Support Network](https://michmed.org/wO9gD): <https://michmed.org/wO9gD>

### Michigan COVID-19 Pandemic Resource Guide

Michigan Poverty Solutions has created a Michigan COVID-19 Pandemic Resource Guide. This guide provides information on programs that can support Michiganders during the COVID-19 pandemic. The programs in this guide are supported by the state and federal government, private companies, and nonprofits. There are special sections at the end of this guide for programs serving Detroit residents and local resources for other areas of the state.

To access Michigan Poverty Solutions' [Michigan COVID-19 Pandemic Resource Guide](http://michmed.org/1A7Xw), visit: <http://michmed.org/1A7Xw>



## Who can I turn to for support during recovery?

### If you need help with:

- Employment
  - **State of Michigan Benefits for Workers:** Visit <http://michmed.org/axJ1Y> for information about accessing employee benefits during COVID-19.
  - **State of Michigan Employee Guidance:** Visit <http://michmed.org/dlYoX> for general guidance about workplace safety, refusal to work, and unemployment assistance.
  - Continue reading under [“What if I cannot work because of my COVID-19 symptoms?” \(page 114\)](#) and [“As a caregiver, how do I balance work and caring for someone?” \(page 115\)](#)
- Housing, Food, Finances, or Healthcare
  - **Michigan 2-1-1:** Visit <https://www.mi211.org/> or dial 2-1-1 to connect with resources in your local community, like housing and financial assistance.
  - **MI Bridges:** Visit <https://www.michigan.gov/mibridges> to apply for benefits, such as food assistance and health care coverage, and learn about resources in your community.
- Mental Health
  - **Michigan Stay Well Counseling:** Call 1-888-535- 6136 and press “8” to talk with a Michigan Stay Well counselor or visit [Michigan.gov/StayWell](https://Michigan.gov/StayWell) for more information. Counseling is free, confidential, and available 24/7.
  - Continue reading under [“Where can I find mental health resources?” \(page 116\)](#)

For other resources that can help you during quarantine and isolation, visit [Michigan.gov](https://Michigan.gov): <http://michmed.org/YlbyZ>



## What if I cannot work because of COVID-19?

### Social Security Disability Insurance and Supplemental Security Income

Social Security has two disability benefits programs with very similar names:

- **Social Security Disability Insurance (SSDI)** gives cash benefits to people with disabilities who qualify because they used to work or have a parent who worked.
- **Supplemental Security Income (SSI)** gives cash benefits to people with disabilities who have low income and low resources. You do not need to have worked in the past to get SSI.

Some people qualify for both programs at the same time. For more information about [Social Security Disability Insurance and Supplemental Security Income](#), visit:

<http://michmed.org/xo061>

### Workers' Compensation

Workers' compensation laws protect employees who get hurt on the job or sick from it. COVID-19 infection can be covered by workers' compensation if you were infected at work. The laws establish workers' compensation, a form of insurance that employers pay for. These laws vary from state to state and for federal employees.

For [general information about workers' compensation](#), visit: <https://www.usa.gov/unemployment#item-34867>. For more information about [workers' compensation in the State of Michigan](#), visit: <http://michmed.org/9alG6>

### Pandemic Unemployment Assistance *(available as of December 2020)*

Individuals are eligible for **Pandemic Unemployment Assistance (PUA)** if they do not qualify for regular unemployment benefits (including self-employed workers and independent contractors) and cannot work because of the COVID-19 pandemic. Individuals are not eligible for PUA if they can telework or are receiving paid sick leave or other paid leave benefits (regardless of meeting a category listed above).

For eligibility information about [Pandemic Unemployment Assistance in the State of Michigan](#), visit: <http://michmed.org/Wn2bm>

### Pandemic Emergency Unemployment Compensation *(available as of December 2020)*

The Coronavirus Aid, Relief, and Economic Security (CARES) Act creates a new temporary federal program called **Pandemic Emergency Unemployment Compensation (PEUC)**. PEUC provides up to 13 weeks of additional unemployment benefits to individuals who previously collected state or federal unemployment compensation (UC) but exhausted those benefits.

For eligibility information about [Pandemic Emergency Unemployment Compensation](#), visit: <http://michmed.org/R1YkW>



## As a caregiver, how do I balance work and caring for someone?

The many responsibilities of caring for someone often leads to job conflicts for the caregiver. Work is a financial necessity and a major source of personal satisfaction, but for many caregivers, it is often difficult to balance the twin responsibilities of caregiving and working. Each caregiver's working conditions are different. Talk to your supervisor and look in the employee handbook or other human resources publications to learn about your company's policy on caregivers.

### Family and Medical Leave Act (FMLA) for Caregivers

In order to care for your loved one, it may become necessary for you to take leave from work. There are laws in place to help protect caregivers in these types of situations. Ask your employer whether you qualify for the Family and Medical Leave Act (FMLA).

### Community Caregiving

If you are struggling, ask family and friends for help. Whether it is looking after your loved one for a couple hours or bringing groceries to you, small acts of service can make a big difference on your task list. You can try a caregiving coordination service such as [Lotsa Helping Hands](https://lotsahelpinghands.com/) (<https://lotsahelpinghands.com/>), a free website where you can post tasks you need assistance with on a private group calendar. Family, friends, and community members can visit the site and sign up for a task and will be reminded when it needs to be done.

Note: Michigan Medicine has no connection to these resources and has not reviewed their services. This list is intended for informational purposes only, not as an endorsement of these services.

### Be on the lookout for...

#### Feelings of resentment

Likely, becoming a caregiver has changed your own life. You may not be able to do your work fully, or your own relationships and health may be negatively affected. Because of this, you may feel resentful towards the patient or your caregiver duties. These thoughts may be followed by feelings of guilt. It is okay to have these feelings: feeling resentful does not mean you do not love the patient or are unhappy that they are with you and alive. Caregiving is a difficult job, and these emotions are common feelings.





## Where can I find mental health resources?

From help with reducing stress to crisis counseling, a wide range of mental health resources are available to you. Several major organizations are highlighted below, but many more resources can be found at these websites:

- [Michigan Medicine Psychiatry Resources for COVID-19](http://michmed.org/Bvj9l): Visit <http://michmed.org/Bvj9l>
- [State of Michigan Coronavirus Mental Health Resources](http://michmed.org/R1Ywo): Visit <http://michmed.org/R1Ywo>

**If you or someone you know are thinking of taking your life, get help immediately.**

- **[National Suicide Prevention Lifeline](https://www.suicidepreventionlifeline.org) (available 24/7):**
  - Call: 1-800-273-8255
  - Text: TALK to 741741
  - Visit: [suicidepreventionlifeline.org](https://www.suicidepreventionlifeline.org)
  - Deaf and Hard of Hearing (TTY) users: Use your preferred relay service or dial 711 then 1-800-273-8255
- **Crisis Text Hotline (available 24/7):**
  - Text: HOME to 741741
- **U-M Psychiatric Emergency Services (available 24/7):**
  - Call: 734-936-5900

### **[Michigan Stay Well Counseling](#)**

If you're feeling emotional distress due to the COVID-19 pandemic, help is available. Confidential and free counselors are available 24/7 through the Michigan Stay Well program.

- Call: 1-888-535-6136 and press "8" to talk to a Michigan Stay Well counselor
- Visit: <http://michmed.org/R1Ywo>

### **[Mental Health America Warmlines](#)**

Mental Health America is the nation's leading community-based nonprofit dedicated to promoting the overall mental health of all Americans. A warmline exists to give you support when you just need to talk to someone. These calls are typically free and confidential.

- In Michigan, call: (586) 307-9100
- Visit: <http://michmed.org/48mY4>

Note: Michigan Medicine has no connection to these resources and has not reviewed their services. This list is intended for informational purposes only, not as an endorsement of these services. Continued on next page.



## Where can I find mental health resources?

### **Psychology Today’s “Find a Therapist” Tool**

Consider finding a counselor or therapist in your area. To make access easier, many counselors and therapists are offering telehealth sessions during the pandemic. Ask your doctor for a recommendation or use the “Find a Therapist” tool through *Psychology Today*. Using the tool, you can filter therapists based on location, speciality, and the type of insurance they accept.

- Visit: <https://www.psychologytoday.com/us/therapists>

### **Headspace App**

If you would like to try managing your stress and anxiety through meditation, sleep, and exercise, Headspace is now free to all Michigan residents.

- Visit: [headspace.com/mi](https://www.headspace.com/mi)

### **BetterHelp Online Counseling**

BetterHelp is an online counseling service. They provide a network of licensed, accredited, and experienced counselors who can help you with a range of issues including depression, anxiety, relationships, trauma, grief, and more. Visit their website to learn more.

- Visit: <https://www.betterhelp.com/>

### **Talkspace Online Counseling**

Talkspace is an online counseling service. They offer comprehensive online mental health treatment options to meet all your needs. Visit their website to learn more.

- Visit: <https://www.talkspace.com/>

### **Michigan 211**

Michigan 2-1-1 is a free referral and information helpline that connects people to a wide range of health and human services in their area, 24/7.

- Dial: 2-1-1 from any phone
- Visit: <https://www.mi211.org/>

### **National Disaster Distress Helpline**

If you are experiencing emotional distress due to the COVID-19 crisis, you can reach out to the National Disaster Distress Helpline to get help, 24/7.

- Call: 1-800-985-5950
- Text: TALKWITHUS to 66746

Note: Michigan Medicine has no connection to these resources and has not reviewed their services. This list is intended for informational purposes only, not as an endorsement of these services.





### Help improve these materials

Please help make these materials better for other patients and caregivers.

[Share your feedback here \(http://michmed.org/8R4wZ\)](http://michmed.org/8R4wZ), or scan the QR code.

This Quality Assurance/Quality Improvement effort was reviewed under IRB-Med #HUM00190878 and determined not to require IRB approval (Not Regulated - non-research).

Disclaimer: This document contains information and/or instructional materials developed by Michigan Medicine for the typical patient with your condition. It may include links to online content that was not created by Michigan Medicine and for which Michigan Medicine does not assume responsibility. It does not replace medical advice from your health care provider because your experience may differ from that of the typical patient. Talk to your health care provider if you have any questions about this document, your condition or your treatment plan.

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