



COVID-19 Patient & Caregiver Collaborative Care Workbook

Table of Contents

- 03** [Acknowledgements](#)
- 08** [Introduction](#)
- 11** [Features of this workbook](#)
- 13** [COVID-19 facts, symptoms, and prevention](#)
- 21** [Navigating COVID-19 exposure, testing, and quarantine](#)
- 38** [Preparing to go to the emergency department for COVID-19](#)
- 51** [Communicating with your care team while in the hospital for COVID-19](#)
- 64** [Helping patients and caregivers stay connected during COVID-19](#)
- 73** [Preparing to go home after a COVID-19 hospital stay](#)
- 92** [Recovering at home after a COVID-19 hospital stay](#)
- 120** [Appendix A: Building your support network](#)



Acknowledgements

This workbook would not have been possible without the support and creativity of many people. Below is a list of faculty, researchers, editors, designers, and others who offered their time and advice to this project. But most of all,

Thank you to the COVID-19 patients and their families for sharing your stories and wisdom. Your perseverance is our inspiration.

Faculty Advisory Committee:

- Richard Gonzalez, PhD, *Director of U-M ISR Research Center for Group Dynamics, Amos N. Tversky Collegiate Professor, Department of Psychology and Statistics, University of Michigan*
- Theodore J. Iwashyna, MD, PhD, *Professor of Internal Medicine, Division of Pulmonary and Critical Care Medicine, Michigan Medicine*
- Amanda Leggett, PhD, MS, *Research Assistant Professor, Department of Psychiatry, Michigan Medicine*
- Louis Penner, PhD, MA, *Professor, Department of Oncology, Wayne State University*
- Hallie Prescott, MD, MS, *Associate Professor of Internal Medicine, Division of Pulmonary and Critical Care Medicine, Michigan Medicine*
- Sheria G. Robinson-Lane, PhD, RN, *Assistant Professor, School of Nursing, University of Michigan*
- Natalie Leonard, MS, *Research Area Specialist, BioSocial Methods Collaborative, Institute for Social Research, University of Michigan*
- Grace Oxford, BS, *Research Technician, BioSocial Methods Collaborative, Institute for Social Research, University of Michigan*
- Sophia Li, BSN, *Research Assistant, BioSocial Methods Collaborative, Institute for Social Research, University of Michigan*
- Andrew Lemmen, *Research Assistant, BioSocial Methods Collaborative, Institute for Social Research, University of Michigan*
- Tanbirul Miah, *Research Assistant, BioSocial Methods Collaborative, Institute for Social Research, University of Michigan*
- Sadia Rahman, *Research Assistant, BioSocial Methods Collaborative, Institute for Social Research, University of Michigan*

Authors:

- Jeannette Jackson, MBA, *Managing Director, BioSocial Methods Collaborative, Institute for Social Research, University of Michigan*
- Alicia Carmichael, MS, *Research Process Director, BioSocial Methods Collaborative, Institute for Social Research, University of Michigan*

U-M HEART Study (HUM00158390)

Research Team:

- Lee A. Kamphuis, MPH, *Project Manager, Center for Clinical Management Research, VA Ann Arbor Health Services Research & Development*



Acknowledgements

U-M HEART Study (HUM00158390) Research Team (cont'd):

- Jillian Peacock, MSI, *Research Data Analyst, BioSocial Methods Collaborative, Institute for Social Research, University of Michigan*
- Sarah Seelye, PhD, *Data Scientist, Center for Clinical Management Research, VA Ann Arbor Health Services Research & Development*
- Donna Walter, BA, *Participant Coordinator, BioSocial Methods Collaborative, Institute for Social Research, University of Michigan*
- Nicklas Helton, BS, *Research Assistant, BioSocial Methods Collaborative, Institute for Social Research, University of Michigan*
- Florence Johnson, RN, *PhD Student, School of Nursing, University of Michigan*
- Tannaz Sabetfakhri, MA, *Research Area Specialist, Institute for Social Research, University of Michigan*
- Maren Wisniewski, BS, *Research Assistant, BioSocial Methods Collaborative, Institute for Social Research, University of Michigan*
- Elaina Baker, *Research Assistant, Department of Psychiatry, Michigan Medicine*
- Janeann Paratore, *Research Assistant, BioSocial Methods Collaborative, Institute for Social Research, University of Michigan*
- Samuel Uribe-Botero, *Research Assistant, BioSocial Methods Collaborative, Institute for Social Research, University of Michigan*

- Abigail Williams, *Research Assistant, BioSocial Methods Collaborative, Institute for Social Research, University of Michigan*
- JJ Wright, *Research Assistant, BioSocial Methods Collaborative, Institute for Social Research, University of Michigan*

Michigan Institute for Clinical & Health Research (MICHR) Team:

- Lisa Connally, BS, *Participant Recruitment Program Lead, Recruitment, MICHR*
- Aalap Doshi, MS, *Program Director, Translational Innovation Program, MICHR*
- Linde Huang, BS, *Human-Centered Designer, Translational Innovation Program, MICHR*
- Tricia Piechowski-Whitney, MSW, MPH, MA, *Program Director, Community Engagement*
- Abbey Skrzypek, BA, *Clinical Research Communications Coordinator, Recruitment, MICHR*
- Meghan Spiroff, MHA, *Community Network Research Specialist, Community Engagement*

Graphic Designer:

- Casey Frushour, BFA, *Freelance Graphic Designer, Casey's Head*



Acknowledgements

Patient Education and Health Literacy (PEHL) Team:

- Ruti Volk, MSI, AHIP, *Program Lead, PEHL, Office of Patient Experience, Michigan Medicine*
- Karelyn Munro, BA, *Resources Coordinator and Plain Language Writer, PEHL, Office of Patient Experience, Michigan Medicine*

Proofreader:

- Donna Walter, BA, *Participant Coordinator, BioSocial Methods Collaborative, Institute for Social Research, University of Michigan*

University of Michigan Advisors:

- Bryana Bayly, *Medical Student, MedConnect, Michigan Medicine*
- Sue Anne Bell, PhD, FNP-BC, *Assistant Professor, School of Nursing, University of Michigan*
- Leila Cherara, DNP, MSPSL, RN, CHSE, CNE, *School of Nursing, University of Michigan*
- Toni Coe, PhD, PharmD, *Assistant Professor of Clinical Pharmacy, University of Michigan*
- Amy Cohn, PhD, *Arthur F. Thurnau Professor, Department of Industrial & Operations Engineering, University of Michigan*
- Molly Dwyer-White, MPH, *Administrative Director, Office of Patient Experience, Michigan Medicine*

- Kara Gavin, MS, *Research and Policy Media Relations Manager, Institute for Healthcare Policy and Innovation, University of Michigan*
- Evan Haezebrouck, PT, DPT, CCS, *Michigan Medicine*
- Diana Kenney, MSW, *ICU Clinical Social Worker, Department of Care Management, Michigan Medicine*
- Kellie Kippes, PharmD, *Adjunct Clinical Assistant Professor, College of Pharmacy, Michigan Medicine*
- Diane Lehman Wilson, MPP, JD, MA, *Regulatory Specialist, Medical School Office of Regulatory Affairs, University of Michigan*
- Kelly Malcom, BA, *Lead Research Communicator, Michigan Medicine*
- Jakob McSparron, MD, *Post ICU Longitudinal Survivor Experience Clinic, Michigan Medicine*
- Deborah Metcalf, MDiv, *Chaplain Resident, Michigan Medicine*
- William Meurer, MD, *Associate Professor, Emergency Medicine, Michigan Medicine*
- Rima Mohammad, PharmD, *Clinical Associate Professor of Pharmacy and Clinical Pharmacist, Michigan Medicine*
- Mari Pitcher, MSW, *Post ICU Longitudinal Survivor Experience Clinic, Michigan Medicine*
- Rabbi Sara O'Donnell Adler, MA, BCC, *Staff Chaplain, Michigan Medicine*
- Jeremy Sussman, MD, MS, *Center for Clinical Management Research, VA Ann Arbor Health Services*



Acknowledgements

University of Michigan Advisors

(cont'd):

- Nikhil Theyyanni, MD, *Assistant Professor, Emergency Medicine, Michigan Medicine*
- Pat Ward, *Director, Regulatory Affairs, Michigan Medicine*
- Xiaoling Xiang, PhD, MPhil, MSW, *Assistant Professor, School of Social Work, University of Michigan*

Community Advisors:

- Angelica Giordimaina, DPT
- Kristen Hayden, *Organizer, Washtenaw County Mutual Aid*
- Misa A. Ito, MS, *Material Science TPT, Procter & Gamble*
- Laveeta Joseph, PhD, MBA, *Director, Open Innovation & Strategic External Partnerships, Procter & Gamble*
- Pastor Kiamba Knowlin, *Church of God in Christ Inc., Flint, Michigan*
- Yawen Ning, MSW, *Behavioral Health Social Worker, Henry Ford Allegiance Health*
- Tom O'Neil, MD, *Director, Arbor Hospice*
- Kate Porter, *Administrator, C-19 Recovery Awareness and Long-Haul COVID Fighters*
- Amy Watson, *Founder, C-19 Recovery Awareness and Long-Haul COVID Fighters*

Support Groups:

- CoRecovered, <https://www.corecovered.org/>
- C-19 Recovery Awareness, <https://www.c19recoveryawareness.com/>
- Survivor Corps, <https://www.survivorcorps.com/>



Workbook information

Citation

The full reference to this workbook should be:

BioSocial Methods Collaborative and HEART Research Project Team. *COVID-19 Patient & Caregiver Collaborative Care Workbook*. Ann Arbor: Michigan Medicine; 2020.

doi:[10.3998/2027.42/163715](https://doi.org/10.3998/2027.42/163715)

The reference to a section of this workbook should be, for example:

BioSocial Methods Collaborative and HEART Research Project Team. [Section Title]. In: *COVID-19 Patient & Caregiver Collaborative Care Workbook*. Ann Arbor: Michigan Medicine; 2020:[Page Numbers]. doi:[10.3998/2027.42/163715](https://doi.org/10.3998/2027.42/163715)

Sharing feedback

Help improve this workbook. [To provide feedback](#) on the content or submit corrections, visit <http://michmed.org/48z44> or scan the QR code.

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



**Share feedback
on this workbook**

<http://michmed.org/48z44>

Customization to other health systems

This workbook is free for anyone to use and for any hospital or health system to adapt to their needs. To access an editable version of this workbook (Adobe InDesign file format), contact covid-caregiving@umich.edu.

Patient Education by [Michigan Medicine](#) is licensed under a [Creative Commons AttributionNonCommercial-ShareAlike 4.0 International Public License](#). Last Revised 12/2020 Version 1.0.0

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.

Funding statement

Support for the creation of these materials provided by: the University of Michigan Institute for Social Research, Michigan Medicine, and the Procter & Gamble Company.



Introduction

What is the COVID-19 Collaborative Care Workbook about?

This workbook provides information about navigating a COVID-19-related hospital stay (before, during, and after) at Michigan Medicine.

We co-created this workbook with the help of COVID-19 patients, their family caregivers, healthcare professionals, and other community members who are engaged in providing support during the pandemic. Throughout the workbook, information is cited from reputable sources and combined with practical tips and wisdom from the people and families whose lives have been directly affected by COVID-19.

“I just became like a robot. I work full time. So I was home working remotely. I have two boys that were home. I knew what needed to get done, even though my feelings were still there. As long as I was busy doing something, I could get through the day. The phone was my lifeline. That’s how I learned updates on him. I couldn’t see him. I was at the mercy of the doctors that were treating him. It’s not like, ‘Oh, he has this disease. I’m going to call the best doctor to treat him.’ It’s just ‘this is what you’re getting’ and you pray he’s in good hands. And thankfully, they were able to fight for him and he survived.

It was hard to navigate when he came home, to figure out what he would need. It’s a lot on the caregiver because everything falls on that person. Especially today when people can’t be together. [My family was] there on the phone, but it’s not the same.

So you’re alone through all of this in so many ways. That’s probably the hardest part. Just trying to navigate and do everything on your own. It’s hard. It’s a lonely, frustrating feeling--a lot of running around and a lot of phone calls, a lot of trying to get the right answers and trying to get pointed in the right direction, no matter what it is--communication, insurance. It’s just always a lot of getting to really where you need to be. I have given everything to groom him and care for him. I became a caregiver.”

- Spouse of a COVID-19 patient, December 2020



Introduction

Who is this workbook for?

This workbook is for patients with COVID-19 and for anyone assisting in their care. Some of the information in this workbook is tailored to residents of the State of Michigan or, more specifically, to patients of Michigan Medicine at the University of Michigan in Ann Arbor. However, this workbook is free for anyone to use and for any hospital or health system to adapt to their needs. See Creative Commons Licensing (CC BY-NC-SA 4.0) for details, or contact covid-caregiving@umich.edu for editable templates.

Am I a caregiver?¹

This document refers to anyone who is providing care to someone during or after a hospital stay as a “caregiver.” This may be the first time you find yourself in a caregiving role, or you may have been a caregiver to this person (or others) for a long time.

If you are consistently caring for someone with a serious illness, or who is recovering from a serious illness, you are a caregiver. This can look like assisting someone with their daily needs, such as cooking, bathing, dressing, and other life affairs. Caregiving can also take other forms, such as providing emotional support or helping someone through the “mental fog” of COVID-19 recovery. If you are providing regular assistance, you are a caregiver.

Caregivers don’t have to be family members of the patient. They can also be friends, neighbors, and community members who want to help when and how they can. You may not think of yourself as a “caregiver” in a formal way, but what you are doing is very important. Caregiving can be physically and emotionally draining. Know that there are resources to help you, many of which are included in this workbook.

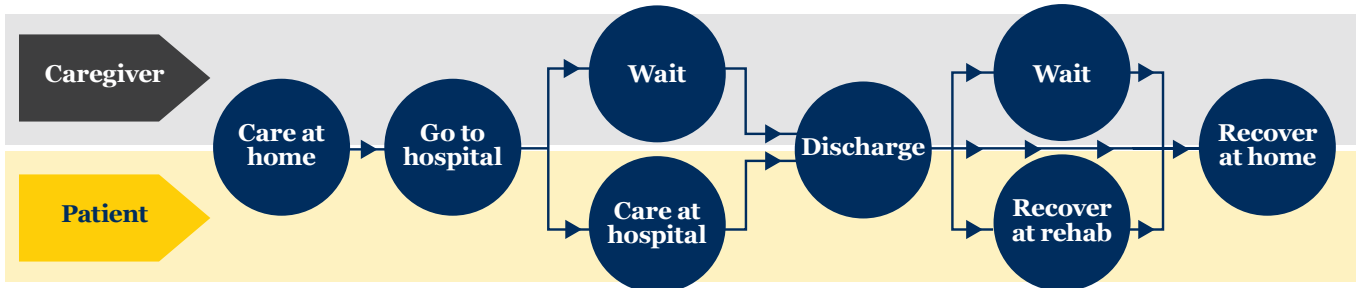
¹ Adapted from: Leukemia & Lymphoma Society. Caregiver Support. <https://www.lls.org/support/caregiver-support>. Published 2019. Accessed December 8, 2020.



Introduction

Organization of this workbook

This workbook is organized around a common “journey” that emerged from interviews with COVID-19 patients and their family caregivers. Each section in this workbook touches on a different point in this journey: before, during, and after a COVID-19-related hospital stay.



Above: A diagram of a common “journey” that patients and caregivers might experience before, during, and after a COVID-19-related hospital stay.

We know that COVID-19 impacts everyone differently. This workbook is not trying to say what your journey “should” or “should not” be. While parts of your experience may follow a straight path, other times it can feel like a winding road. Regardless of where you are along your COVID-19 journey, we hope this workbook can be helpful to you.



Features of this workbook

The individual sections of this workbook are available as PDFs. These PDFs are designed to be read online or printed for your convenience. Tips for using these PDFs are below.

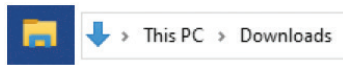
Downloading and printing

Printing and downloading instructions may vary depending on the Internet browser you use. Below are example instructions.

1. On your computer, click on the link to the workbook section you wish to print. This will open the document as a tab in your web browser.
2. Hover your mouse over the document. These icons will appear in the top right corner:



3. Click on the middle icon (the underlined arrow). This will download the document as a PDF onto your computer.
4. Open your file explorer, then navigate to your “Downloads” folder:



5. Double-click on the document name. This will open the PDF in a PDF viewer, such as Adobe Acrobat.
6. In the top-left corner of the PDF viewer, select “File,” then “Print.” You can also print by pressing the “P” key while holding down Ctrl (on a PC) or ⌘ Command (on a Mac). Before printing, make sure you have selected the printer you want to use.

Zooming on a PDF

On your computer, tablet, or phone, you can zoom in or zoom out to make text and images larger or smaller.. To Zoom:



Zoom Buttons: Depending on your browser or PDF viewer, there may be buttons to zoom in and out. Press or click the plus (+) button to zoom in.



Pinch to Zoom: On a smartphone or tablet, touch the PDF with your finger, then zoom by pinching two fingers in or out.



Zoom Shortcut Keys: Zoom in by pressing the + key while holding down Ctrl (on a PC) or ⌘ Command (on a Mac). Zoom out by pressing the - key while holding down Ctrl (on a PC) or ⌘ Command (on a Mac).

Using hyperlinks

This workbook contains hyperlinks. On your computer, tablet, or phone, you can click on a hyperlink to take you to a specific website or online resource. A hyperlink can look like text: [Centers for Disease Control](#), or like a web address: <https://www.cdc.gov/>.



Features of this workbook

Using QR codes

In addition to hyperlinks, this workbook contains **QR codes**: a type of “square barcode” that takes you to an online resource. It is sometimes easier to scan a QR code than it is to use a hyperlink or type out a web address yourself.

Most phones now have built-in QR code readers or are compatible with free apps that can read QR codes. To use a QR code:

1. Open your camera app on your smartphone.
2. Hold your smartphone camera over the QR code.
3. Your camera app should show a link on your screen. Click on this link, and it will take you to the online resource.



Interactive sections

The workbook was designed to be as interactive. To accomplish this, we have a few different key things that are present for you to customize to your own experience.

- **Table of Contents:** At the beginning of each section is a box that explains what questions the section answers. The questions are also hyperlinks. If you click on one of these hyperlinked questions, you can jump right to that section of the workbook.
- **Question Boxes:** Some sections include suggested questions to help you have meaningful conversations with healthcare providers. You may also want to write down answers you receive.
- **Checklists:** Some sections contain checklists to help you organize or plan. These are not things that you have to do, just things that might be helpful to consider.
- **Targeted Notes:** Throughout some sections, we provide space for you to write your own targeted notes. For example, you may want to write down hospital room numbers, medications, or questions for your doctor.
- **General Notes:** At the end of each section, we provide space for you to write your own general notes. You may also find it helpful to keep a notebook or journal for you to write down your thoughts or information.



COVID-19 facts, symptoms, and prevention

This section* will answer the following questions:

- [How is COVID-19 spread? \(page 14\)](#)
- [How can I protect myself and others from COVID-19? \(page 15\)](#)
- [Where can I learn about COVID-19 vaccines? \(page 15\)](#)
- [What are COVID-19 symptoms I should watch for? \(page 16\)](#)
- [Am I at higher risk for being hospitalized with COVID-19? \(page 17\)](#)
- [When should I seek emergency care? \(page 18\)](#)

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

For the latest, most reliable information about COVID-19, visit:

- [CDC's COVID-19 page: https://www.cdc.gov/coronavirus/2019-nCoV/index.html](https://www.cdc.gov/coronavirus/2019-nCoV/index.html)
- [State of Michigan's COVID-19 page: https://www.michigan.gov/coronavirus](https://www.michigan.gov/coronavirus)
- [Michigan Medicine's COVID-19 page: https://www.uofmhealth.org/covid-19-update](https://www.uofmhealth.org/covid-19-update)



Fast facts about COVID-19¹

What is COVID-19?

COVID-19 is an illness caused by a virus that can spread from person to person. The virus is a spread when a person with COVID-19 coughs, sneezes, or talks releasing respiratory droplets. These droplets can land in the mouths or noses of nearby people. COVID-19 symptoms can range from mild (or no symptoms) to severe illness.² Symptoms may appear 2-14 days after exposure to the virus. COVID-19 can be spread by people who are not showing symptoms.

What are symptoms I should watch for?

The most common symptoms of COVID-19 include:

- Fever
- Cough
- Headaches
- Fatigue
- Muscle or body aches
- Loss of taste or smell
- Sore throat
- Nausea
- Diarrhea

If you have trouble breathing, chest pain or pressure, new confusion, bluish lips or face, or difficulty staying awake, [get medical care immediately.](#)

Who can get COVID-19?

Anyone can get COVID-19. People who are older or have certain pre-existing health conditions (such as diabetes and asthma) are at higher risk of getting very sick from COVID-19.

How can I protect myself and others from COVID-19?

The three most important ways to help protect yourself and others from COVID-19 are:

1. Wear a mask over your nose and mouth
2. Stay at least 6 feet apart from others.
3. Wash your hands with soap and water for 20 seconds or use hand sanitizer with at least 60% alcohol

When should I get tested for COVID-19?

Consider getting tested if you feel sick, if someone close to you is sick or has symptoms, or if you work outside the home. Find a [testing location in Michigan](#):

- Visit <http://michmed.org/5L4z6>
- Call the COVID-19 Hotline for the State of Michigan (888-535-6136) or Michigan Medicine (734-763-6336)

¹Adapted from: Centers for Disease Control and Prevention. Things to Know about the COVID-19 Pandemic. <https://www.cdc.gov/coronavirus/2019-ncov/your-health/need-to-know.html>. Published 2020. Accessed November 19, 2020.

Center for Disease Control and Prevention. What You Should Know about COVID-19 to Protect Yourself and Others. Atlanta; 2020. <https://www.cdc.gov/coronavirus/2019-ncov/downloads/2019-ncov-factsheet.pdf>.

²Centers for Disease Control and Prevention. Symptoms of Coronavirus. <https://www.cdc.gov/coronavirus/2019-ncov/symptoms-testing/symptoms.html>. Published 2020. Accessed November 24, 2020.



How can I protect myself and others from COVID-19?

In the United States, **over 12 million total cases of COVID-19** have been confirmed and **over 250,000 people have died of COVID-19** as of November 24, 2020.³ To prevent the spread of COVID-19, everyone should:⁴

Wash your hands often

(see how: <https://youtu.be/bt2lothdWqs>)

- Use soap and water for at least 20 seconds especially after you have been in a public place, or after blowing your nose, coughing, or sneezing.
- If soap and water are not readily available, use a hand sanitizer that contains at least 60% alcohol. Cover all surfaces of your hands and rub them together until they feel dry.
- Avoid touching your eyes, nose, and mouth with unwashed hands.

Avoid close contact

- Stay at least 6 feet (about 2 arms' length) from other people.
- Remember that some people without symptoms may be able to spread the virus.

Cover your mouth and nose with a mask when around others

(see how: <https://youtu.be/VMlrfTvcnAI>)

- The mask is meant to protect other people in case you are infected.
- You could spread COVID-19 to others even if you do not feel sick.
- Continue to keep about 6 feet between yourself and others. The mask is not a substitute for social distancing.

Cover coughs and sneezes

- Always cover your mouth and nose with a tissue when you cough or sneeze or use the inside of your elbow and do not spit.
- Immediately wash your hands after covering a cough or sneeze.

Clean and disinfect

- Clean and disinfect frequently touched surfaces daily. This includes tables, doorknobs, light switches, countertops, handles, desks, phones, keyboards, toilets, faucets, and sinks.
- Use detergent or soap and water to clean and then use a household disinfectant.

Monitor your health daily

- Be alert for symptoms of COVID-19.
- Take your temperature if symptoms develop.

Where can I learn about COVID-19 vaccines?

Information about vaccines is rapidly developing. For the latest, most reliable information about COVID-19 vaccines, visit:

- [CDC's Facts about COVID-19 Vaccines page: http://michmed.org/9arx6](http://michmed.org/9arx6)
- [State of Michigan's COVID-19 Vaccine page: http://michmed.org/Wnd1m](http://michmed.org/Wnd1m)

For information about [Michigan Medicine vaccine trials](https://www.uofmhealth.org/covid19-vaccine), visit: <https://www.uofmhealth.org/covid19-vaccine>

³Centers for Disease Control and Prevention. CDC COVID Data Tracker: Maps, charts, and data provided by the CDC. <https://covid.cdc.gov/covid-data-tracker/>. Published 2020. Accessed November 24, 2020.

⁴Centers for Disease Control and Prevention. How to Protect Yourself & Others. <https://www.cdc.gov/coronavirus/2019-ncov/prevent-getting-sick/prevention.html>. Published 2020. Accessed November 24, 2020.



COVID-19 symptoms

What are COVID-19 symptoms I should watch for?

This chart shows common symptoms of allergies, colds, the flu, and COVID-19 to help you tell the difference between them. A checkmark means that a symptom is common. For example, not everyone with COVID-19 loses their sense of smell or taste.

It is important to note:

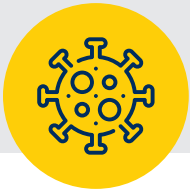
- **You do not need to have every symptom listed below to have that illness**
- Symptoms can be different from person to person
- Someone with COVID-19 may have no symptoms or very mild symptoms
- It is possible to have more than one of these illnesses at the same time

Symptoms/Signs	Allergies	Cold	Flu	COVID-19
Body aches		sometimes	✓	✓
Chills			✓	✓
Dry cough	✓	✓	✓	✓
Fatigue	sometimes	sometimes	✓	✓
Fever		rare	✓	✓
Headache		rare	✓	✓
Itchy eyes	✓			
New loss of taste/smell				✓
Nasal congestion/stuffy nose	✓	✓	sometimes	✓
Nausea/vomiting/diarrhea		sometimes	sometimes	✓
Runny nose	✓	✓	sometimes	✓
Sneezing	✓	✓	sometimes	
Sore throat	sometimes	✓	✓	✓
Shortness of breath	rare		sometimes	✓

Above: A chart comparing the symptoms of COVID-19 to other common illnesses.⁵ This chart is not a list of all the symptoms of COVID-19. Please call your healthcare provider for any other symptoms that are severe or concerning to you.

If you have trouble breathing, chest pain or pressure, new confusion, bluish lips or face, or difficulty staying awake, **get medical care immediately.**

⁵Adapted from: Washtenaw County Health Department. Is It Allergies, a Cold, the Flu, or COVID-19? 2020. <https://www.washtenaw.org/DocumentCenter/View/18663/Is-it-allergies-a-cold-the-flu-or-COVID-19-flyer-English?bidId=>. Accessed November 24, 2020.



COVID-19 risk factors

Am I at higher risk for being hospitalized with COVID-19?

Anyone can get COVID-19. However, the following groups of people may be at higher risk of getting very sick from COVID-19:

- Are aged 65 years and older
- Live in a nursing home or long-term care facility
- Have chronic lung disease or moderate to severe asthma
- Have serious heart conditions
- Have a weakened immune system. Many conditions can weaken the immune system, including:
 - Cancer treatment
 - Smoking
 - Bone marrow or organ transplantation
 - Immune deficiencies
 - Poorly controlled HIV or AIDS
 - Some medications
- With severe obesity (body mass index of 40 or higher)
- Have diabetes
- Are undergoing dialysis due to chronic kidney disease
- Have liver disease

Everyone should use basic infection prevention guidelines, including hand washing frequently, avoiding touching your face, staying away from people who are sick, and cleaning and disinfecting frequently touched surfaces.

For additional [guidance for patients with specific medical conditions](#), visit: <http://michmed.org/L1YKb>



COVID-19 emergency care and research

When should I seek emergency medical care?⁶

If you have an emergency warning sign (including trouble breathing), get emergency medical care immediately. Call 911 or call ahead to your local emergency facility:

- Tell the operator: I have or may have COVID-19.
- Put on masks before emergency personnel arrive or before going to the hospital.

Emergency warning signs* for COVID-19

If someone is showing any of these signs, seek emergency medical care immediately:

- Trouble breathing
- Persistent pain or pressure in the chest
- New confusion
- Inability to wake or stay awake
- Bluish lips or face

*This list does not include all of the possible symptoms of COVID-19. Please call your medical provider for any other symptoms that are severe or concerning to you.

If you were in close contact with someone who has COVID-19 or think you might have symptoms, read workbook section “Navigating COVID-19 Symptoms and Exposure.”

Participate in COVID-19 research at Michigan Medicine

Michigan Medicine researchers are studying about how to prevent, diagnose and treat COVID-19.

- To learn more about [Michigan Medicine COVID-19 vaccine trials](https://www.uofmhealth.org/covid19-vaccine), visit:
<https://www.uofmhealth.org/covid19-vaccine>
- For other coronavirus-related studies at Michigan Medicine, visit:
 - [Michigan Medicine's Other Coronavirus Research Studies page](http://michmed.org/R16ZW):
<http://michmed.org/R16ZW>
 - [U-M Health Research's list of coronavirus studies](http://michmed.org/axJnJ):
<http://michmed.org/axJnJ>

⁶Adapted from: Centers for Disease Control and Prevention. Symptoms of Coronavirus. <https://www.cdc.gov/coronavirus/2019-ncov/symptoms-testing/symptoms.html#seek-medical-attention>. Published May 13, 2020. Accessed November 11, 2020.



Help improve these materials

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

[Share your feedback here \(http://michmed.org/YlvXl\)](http://michmed.org/YlvXl), 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.

Support for the creation of these materials provided by: the University of Michigan Institute for Social Research, Michigan Medicine, and the Procter & Gamble Company.

Authorship: The BioSocial Methods Collaborative and HEART Research Project Team
(<https://heart.isr.umich.edu/meet-our-research-team/>)

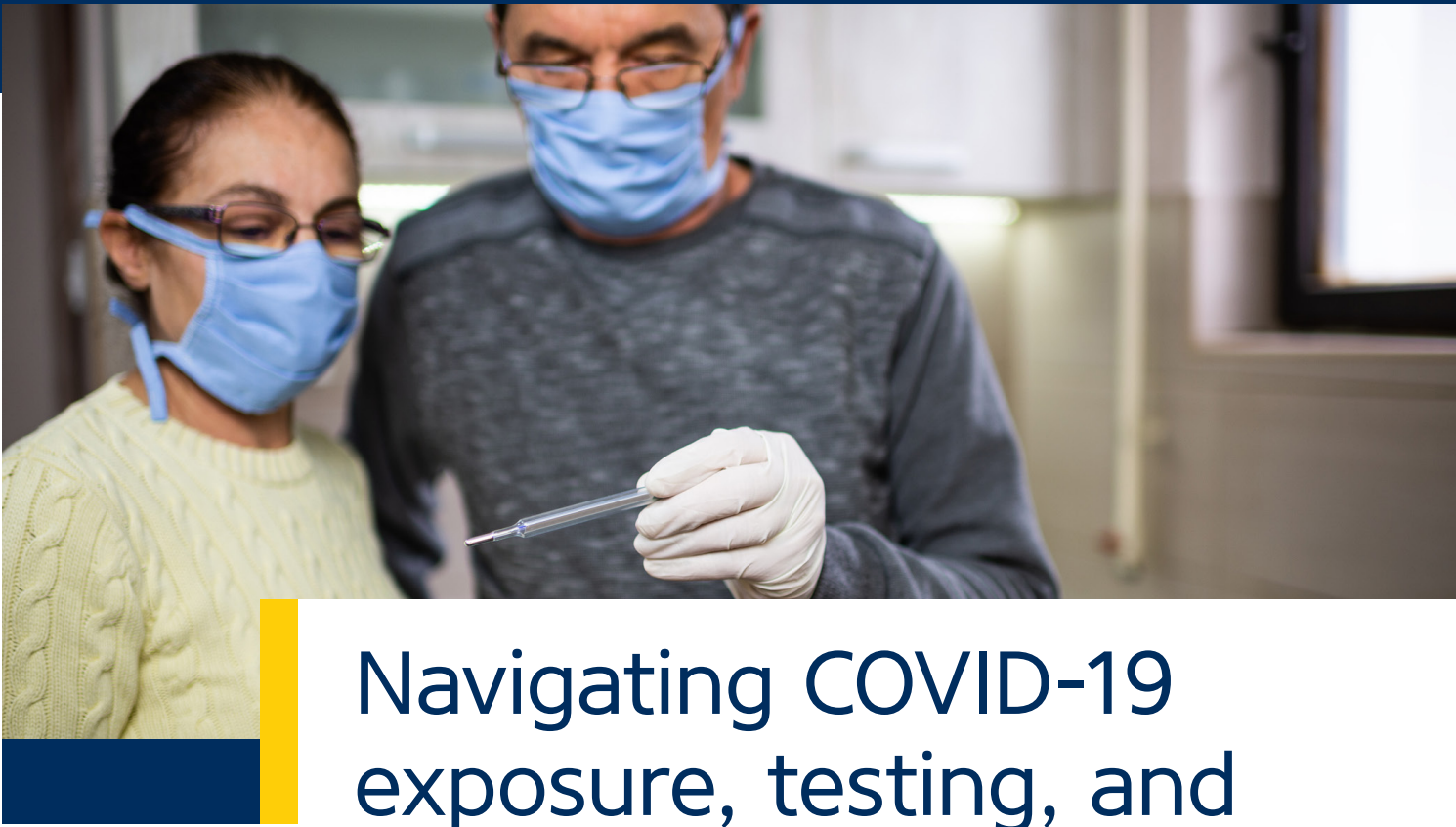
How to cite:

BioSocial Methods Collaborative and HEART Research Project Team. COVID-19 facts, symptoms, and prevention. In: *COVID-19 Patient & Caregiver Collaborative Care Workbook*. Ann Arbor: Michigan Medicine; 2020: 1-9. doi:[10.3998/2027.42/163715](https://doi.org/10.3998/2027.42/163715)

Patient Education by [Michigan Medicine](#) is licensed under a [Creative Commons AttributionNonCommercial-ShareAlike 4.0 International Public License](#).

Last Revised 12/2020, Version 1.0.0





Navigating COVID-19 exposure, testing, and quarantine

This section* will answer the following questions:

- [What should I do if I have symptoms of COVID-19? \(page 22\)](#)
- [What are the long-term effects of COVID-19? \(page 23\)](#)
- [How do I manage COVID-19 symptoms? \(page 24\)](#)
- [How do I seek medical advice for COVID-19? \(page 25\)](#)
- [How can I protect myself and others from COVID-19? \(page 26\)](#)
- [What should I do if I was exposed to COVID-19? \(page 27\)](#)
- [How do I quarantine or isolate at home? \(page 29\)](#)
- [What should I do if I live with someone who has COVID-19? \(page 31\)](#)
- [What should I do when I get my COVID-19 test results? \(page 33\)](#)
- [What is contact tracing? \(page 34\)](#)
- [Where can I get additional help? \(page 35\)](#)

*Access the other sections of [this workbook](#) by visiting: <http://michmed.org/ng2W1>

State of Michigan COVID-19 Hotline: 888-535-6136 | COVID19@michigan.gov
Michigan Medicine COVID-19 Hotline (for Michigan Medicine patients who want to be evaluated for COVID-19): 734-763-6336 (7:00AM - 6:00PM)



What should I do if I have symptoms of COVID-19?

How do I check for symptoms of COVID-19?¹

The most common symptoms of COVID-19 include:

- Fever
- Cough
- Headaches
- Fatigue
- Muscle or body aches
- Loss of taste or smell
- Sore throat
- Nausea
- Diarrhea

For non-emergency situations:

- Access the [Centers for Disease Control \(CDC\) Coronavirus Self-Checker](http://michmed.org/05mm4) (<http://michmed.org/05mm4>) to check for symptoms. This Self-Checker can help you make decisions on when to seek testing and medical care.
- Call or email the State of Michigan COVID-19 Hotline for guidance (888-535-6136; COVID19@michigan.gov).
- Existing patients at Michigan Medicine can call the Michigan Medicine COVID-19 Hotline (734-763-6336; 7:00AM - 6:00PM).

If you have trouble breathing, chest pain or pressure, new confusion, bluish lips or face, or difficulty staying awake, [get medical care immediately](#).

If you have symptoms of COVID-19, you should isolate for at least 10 days. If you have severe symptoms or other health conditions, you may need to isolate for longer. Stay home and separate from people (even in your own household), except for medical appointments. You may also consider getting a test for COVID-19.²

What is the difference between quarantine and isolation?

Quarantine is for those who may feel well, but still need to keep away from others because:

- They had close contact with someone who has COVID-19, or
- They want to make sure they aren't getting sick.

Isolation is for those who need to keep away from others (even in their own home) because:

- They are sick or have symptoms of COVID-19, or
- They tested positive for COVID-19 (even without symptoms).

Note: Some people may be **asymptomatic**: they may have COVID-19 but not have symptoms.

¹Adapted from: Centers for Disease Control and Prevention. Things to Know about the COVID-19 Pandemic. <https://www.cdc.gov/coronavirus/2019-ncov/your-health/need-to-know.html>. Published 2020. Accessed November 19, 2020.

²Adapted from: Centers for Disease Control and Prevention. COVID-19: Quarantine vs. Isolation. Atlanta; 2020. <https://www.cdc.gov/coronavirus/2019-ncov/downloads/COVID-19-Quarantine-vs-Isolation.pdf>.

Centers for Disease Control and Prevention. What to Do If You Are Sick. <https://www.cdc.gov/coronavirus/2019-ncov/if-you-are-sick/steps-when-sick.html>. Published 2020. Accessed December 2, 2020



What are the long-term effects of COVID-19?

What if my symptoms last longer than two weeks?³

Symptoms can be mild or irregular and last for weeks or even months after recovery from acute illness. Even people who are not hospitalized and who have mild illness can experience ongoing symptoms. This is sometimes referred to as **Long-COVID**.

The most commonly reported long-term symptoms include:

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

Other reported long-term symptoms include:

- Difficulty with thinking and concentration, also known as **brain fog**
- Depression
- Muscle pain
- Headache
- Intermittent fever
- Fast-beating or pounding heart, also known as **heart palpitations**

More serious long-term complications appear to be less common but have been reported. These complications include heart, lung and kidney issues, hair loss, difficulty with concentration, and depression. There is still much that is unknown about the long-term effects of COVID-19, but support is available:

- Contact your doctor if you feel you need help
- Join an online COVID-19 support group on Facebook:
 - [Long COVID Support Group: https://www.facebook.com/groups/longcovid/](https://www.facebook.com/groups/longcovid/)
 - [Long Haul COVID Fighters - Round 2](https://www.facebook.com/groups/650553172199572) (Onset of illness **after** 04/01/20): <https://www.facebook.com/groups/650553172199572>
- For more support groups, see Appendix A: "Building Your Support Network."

³Adapted from: Center for Disease Control and Prevention. Long-Term Effects of COVID-19. <https://www.cdc.gov/coronavirus/2019-ncov/long-term-effects.html>. Published 2020. Accessed December 2, 2020.



How do I manage COVID-19 symptoms?

How do I manage symptoms at home?⁴

Many people can manage mild symptoms of COVID-19 at home. Talk to your doctor about how to manage your symptoms. Your doctor may have different recommendations for you based on your medical history, but many people can manage COVID-19 symptoms by:

- Taking acetaminophen (Tylenol) or ibuprofen (Motrin/Advil) for fever. Follow label instructions and do not exceed the maximum dose per day for any medication.
- Getting rest
- Staying hydrated by drinking water or sports drinks
- Eating when possible

Call your doctor if you have any concern about COVID-19 symptoms, including:

- Fever that does not come down with medication
- Vomiting or diarrhea lasting more than 24 hours or any bloody diarrhea
- Shortness of breath
- Any other symptoms that keep getting worse or feel unmanageable, including: chills, repeated shaking with chills, severe tiredness, muscle pain, headache, sore throat, runny nose, and/or a new loss of taste or smell.

COVID-19 treatment and prevention myths

Researchers are testing a variety of COVID-19 treatments. You may have heard about a food, drug, or other method that claims to prevent, treat, or cure COVID-19. It may be tempting to use a questionable method or product to stay healthy during the pandemic, but it is extremely unlikely to work and might cause serious harm. For more information about [COVID-19 treatment and prevention myths](#), visit:

<http://michmed.org/6doYV>

“Home remedies and natural therapies have an important part to play in COVID-19 treatment, but folks need to be thoughtful about whether or not these remedies are safe or can cause harm. If you have any questions, you should check in with a healthcare provider.”

- Sheria G. Robinson-Lane, PhD, RN, Assistant Professor at the University of Michigan School of Nursing

⁴Adapted from: Washtenaw County Health Department. What to do if You're Sick with COVID-19. <https://www.washtenaw.org/3104/What-to-do-if-Youre-Sick>. Published 2020. Accessed December 2, 2020.



How do I seek medical advice for COVID-19?

How can I get medical advice about COVID-19?⁵

If you are a Michigan Medicine patient, there are three ways you can get medical advice about COVID-19:

1. Schedule a Virtual Care Visit: Submit an E-Visit or Urgent Care Video Visit request for prompt evaluation for COVID-19. Visit [Michigan Medicine's Virtual Care page](https://www.uofmhealth.org/virtualcare) (<https://www.uofmhealth.org/virtualcare>) or log in to the [MyUofMHealth patient portal](http://michmed.org/xoWYR) (<http://michmed.org/xoWYR>) to get started.
2. Call the Michigan Medicine COVID-19 Hotline for patients: 734-763-6336 (7 a.m. to 6 p.m., 7 days a week)
3. Contact your primary care provider. Patients with a U-M primary care doctor may contact their doctor's clinic for evaluation of COVID-19 symptoms. Find your doctor using the [Michigan Medicine Find a Doctor tool](http://michmed.org/Wn28L) (<http://michmed.org/Wn28L>) or search for a [Michigan Medicine doctor by location](https://www.uofmhealth.org/our-locations) (<https://www.uofmhealth.org/our-locations>).

There are other ways you can get medical advice about COVID-19 outside of Michigan Medicine:

1. Contact your primary care provider
2. Call or email the State of Michigan COVID-19 Hotline: 888-535-6136 or COVID19@michigan.gov

When should I seek emergency medical care?⁶

If you have an emergency warning sign (including trouble breathing), get emergency medical care immediately. Call 911 or call ahead to your local emergency facility:

1. Tell the operator: I have or may have COVID-19.
2. Put on a mask before emergency personnel arrive or before going to the hospital.

Emergency warning signs* for COVID-19

If someone is having trouble breathing, persistent pain or pressure in the chest, new confusion, inability to wake or stay awake, or bluish lips or face, seek emergency medical care immediately.

*This list does not include all of the possible symptoms of COVID-19. Please call your medical provider for any other symptoms that are severe or concerning to you.

To decide whether and how you should get a COVID-19 test, continue reading in “When should I get a COVID-19 test?” on page 28.



⁵Adapted from: Michigan Medicine. COVID-19. <https://www.uofmhealth.org/conditions-treatments/infectious-disease/covid-19>. Published 2020. Accessed December 2, 2020.

⁶Adapted from: Centers for Disease Control and Prevention. Symptoms of Coronavirus. <https://www.cdc.gov/coronavirus/2019-ncov/symptoms-testing/symptoms.html#seek-medical-attention>. Published May 13, 2020. Accessed November 11, 2020.



How can I protect myself and others from COVID-19?

Precautions to take at home

- Cover your mouth and nose with a mask when around others (see how: <https://youtu.be/VMlrfTvcnAI>)
 - The mask is meant to protect other people in case you are infected.
 - You could spread COVID-19 to others even if you do not feel sick.
 - Continue to keep about 6 feet between yourself and others. The mask is not a substitute for social distancing.
- Clean and disinfect
 - Clean and disinfect frequently touched surfaces daily. This includes tables, doorknobs, light switches, countertops, handles, desks, phones, keyboards, toilets, faucets, and sinks.
 - Use detergent or soap and water to clean and then use a household disinfectant.
- Wash your hands with soap and water for 20 seconds or use hand sanitizer with at least 60% alcohol

How do I safely throw away used, disposable PPE, such as masks and gloves?

- Do not touch your face while removing your PPE
- Remove your PPE and throw it in a lined trash can
- Wash hands after touching used PPE
- Do not throw used PPE on the ground
- PPE is NOT recyclable (except cloth masks which must be washed)

For more information about disposing of PPE, visit:

- [Washtenaw County's "How to safely throw away used PPE" guide:](http://michmed.org/KkRPV) <http://michmed.org/KkRPV>
- [CDC's "Caring for Someone Sick at Home" page:](http://michmed.org/yO095) <http://michmed.org/yO095>



What should I do if I was exposed to COVID-19?

What should I do if I had close contact with someone who has COVID-19, but I don't have symptoms?

If you had close contact with someone who has COVID-19, you should quarantine (stay home) and consider getting a test for COVID-19. Even if you test negative for COVID-19 or feel healthy, you should still quarantine since symptoms may appear 2 to 14 days after exposure to the virus.

Any of the following counts as “close contact” with someone who has COVID-19:⁷

- You were within 6 feet of the person for a total of 15 minutes or more
- You provided care at home to someone who is sick with COVID-19
- You had direct physical contact with the person (hugged or kissed them)
- You shared eating or drinking utensils
- They sneezed, coughed, or somehow got respiratory droplets on you

What is the difference between quarantine and isolation?⁸

Quarantine is for those who may feel well, but still need to keep away from others because:

- They had close contact with someone who has COVID-19, or
- They want to make sure they aren't getting sick.

Isolation is for those who need to keep away from others (even in their own home) because:

- They are sick or have symptoms of COVID-19, or
- They tested positive for COVID-19 (even without symptoms).

Note: Some people may be **asymptomatic**: they may have COVID-19 but not have symptoms.

To learn how to best quarantine or isolate, continue reading in “How do I quarantine or isolate at home?” on page 29.



⁷Adapted from:

Centers for Disease Control and Prevention. COVID-19: Quarantine vs. Isolation.

<https://www.cdc.gov/coronavirus/2019-ncov/downloads/COVID-19-Quarantine-vs-Isolation.pdf>. Published 2020. Accessed December 1, 2020.

Centers for Disease Control and Prevention. COVID-19: When to Quarantine.

<https://www.cdc.gov/coronavirus/2019-ncov/if-you-are-sick/quarantine.html>. Published 2020. Accessed December 1, 2020.

⁸Adapted from:

Centers for Disease Control and Prevention. COVID-19: Quarantine vs. Isolation.

<https://www.cdc.gov/coronavirus/2019-ncov/downloads/COVID-19-Quarantine-vs-Isolation.pdf>. Published 2020. Accessed December 1, 2020.

Centers for Disease Control and Prevention. COVID-19: When to Quarantine.

<https://www.cdc.gov/coronavirus/2019-ncov/if-you-are-sick/quarantine.html>. Published 2020. Accessed December 1, 2020.



What should I do if I was exposed to COVID-19?

When should I get a COVID-19 test?⁹

To avoid bringing COVID-19 home or spreading it to others in the community, it is especially important to consider getting tested if any of the following is true:

- You feel sick
- Someone close to you feels sick

Some testing sites have restrictions for who can get tested. Generally, if you work outside the home, you should be eligible for testing. For updated information about [State of Michigan COVID-19 testing criteria](#), visit: <http://michmed.org/2GXz1>

There are many locations where you can get tested at no charge to you. To learn more about [COVID-19 testing in Michigan](#) and find a testing location:

- Visit: <http://michmed.org/5L4z6>
- Call the State of Michigan COVID-19 Hotline at 888-535-6136 and press 1

.....
: **Remember:** you cannot test your way out of quarantine. It can take up to 14 days after :
: exposure for an infection to develop, so you could end up testing positive later on. It's :
: important to stay in quarantine for the full 14 days to prevent spreading COVID-19! :
:

What should I do while I'm waiting for my COVID-19 test results?¹⁰

While you wait for your COVID-19 results, protect your family, friends and community. Isolation and quarantine are two reliable ways to prevent the spread of a contagious disease, like COVID-19. Isolation and quarantine help keep people who are sick or have been exposed separate from people who have not been exposed. Continue reading for information about how to quarantine and isolate.

⁹Adapted from: State of Michigan. Coronavirus - Should I get tested for COVID-19? <https://www.michigan.gov/coronavirus/0,9753,7-406-98810-532894--,00.html>. Published 2020. Accessed December 3, 2020.

¹⁰Adapted from: State of Michigan. Coronavirus - Protect. https://www.michigan.gov/coronavirus/0,9753,7-406-99891_99914---,00.html. Published 2020. Accessed December 3, 2020.

State of Michigan. You Were Tested for COVID-19: Now What? https://www.michigan.gov/documents/coronavirus/Accessible_-_2020_MDHHS_COVID_Testing_PostTest_Flyer_June_B_FINAL_696360_7.pdf. Published 2020. Accessed December 3, 2020.



How do I quarantine or isolate at home?¹¹

If you are quarantining at home:

Do:

- **Stay home until 14 days*** after your last contact (except to get medical care).
- **Take your temperature** twice a day to check for fever (100.4°F or 38°C).
- **Watch for symptoms of COVID-19** including fever, cough, shortness of breath, or other.
- **Stay away from others**, as much as possible, especially people who are at higher risk for getting very sick from COVID-19.
- **Wear a mask or cloth face covering if you need to leave your house.** Make sure it covers your nose and mouth. Remember to stay 6 feet away from people and pets. People who are near you should also wear a mask or cloth face covering that covers their nose and mouth.

Don't:

- **Leave home**, unless you need medical care.
- **Use public transportation**, if you have another choice.

.....
: **Remember:** you cannot test your way out of quarantine. It can take up to 14 days after :
: exposure for an infection to develop, so you could end up testing positive later on. It's :
: important to stay in quarantine for the full 14 days to prevent spreading COVID-19! :
.....

Visit the [CDC's "When to Quarantine" page](https://www.cdc.gov/quarantine/) for more information about how to quarantine:
<http://michmed.org/Wn24L>

*Your [quarantine time](#) may need to be extended under certain circumstances. For example, if you live with someone who has COVID-19 and cannot avoid continued close contact, quarantine for 14 days after the person who has COVID-19 meets the criteria to end home isolation (<http://michmed.org/9alwo>).

¹¹Adapted from:

State of Michigan. Coronavirus - Protect. https://www.michigan.gov/coronavirus/0,9753,7-406-99891_99914---,00.html. Published 2020. Accessed December 3, 2020.

State of Michigan. You Were Tested for COVID-19: Now What? https://www.michigan.gov/documents/coronavirus/Accessible_-_2020_MDHHS_COVID_Testing_PostTest_Flyer_June_B_FINAL_696360_7.pdf. Published 2020. Accessed December 3, 2020.



How do I quarantine or isolate at home?

If you are sick and need to isolate:¹²

Do:

- **Limit interaction with those around you.** Stay in a separate room, like a bedroom, away from others in your home. Use a different bathroom if you can. If having separate bathrooms isn't possible, keep your toothbrushes separate.
- **Monitor your symptoms.** If you have trouble breathing, chest pain or pressure, new confusion, bluish lips or face, or difficulty staying awake, **get medical care immediately.**
- **Wear a mask or cloth face covering if you need to leave your room.** Make sure it covers your nose and mouth. Remember to stay 6 feet away from people and pets. People who are near you should also wear a mask or cloth face covering that covers their nose and mouth.
- **Use meal or grocery delivery services when possible** or ask family and friends for help.
- **Clean and disinfect things you touch,** like light switches, doorknobs, tables and remotes. Clean and disinfect your "sick room" and bathroom yourself.
- **Wash your hands often.** Use soap and water for at least 20 seconds. If you do not have soap and water, use hand sanitizer with at least 60% alcohol. Don't touch your face unless you've just cleaned your hands.
- **Cover coughs and sneezes.** Cough or sneeze into your elbow or a tissue, then wash your hands.
- **Consider people living with you.** If you live with someone with health conditions, think about whether there are other places you can stay while you get well. (See Temporary Shelter Resources)
- **Continue isolating** until you meet the [criteria to end home isolation](http://michmed.org/9alwo) (<http://michmed.org/9alwo>).

Don't:

- **Leave home,** unless you need medical care.
- **Use public transportation,** if you have another choice.
- **Share personal items.** Things like dishes, towels, and bedding should not be shared, even with family.

¹²Adapted from:

State of Michigan. Coronavirus - Protect. https://www.michigan.gov/coronavirus/0,9753,7-406-99891_99914---,00.html. Published 2020. Accessed December 3, 2020.

State of Michigan. You Were Tested for COVID-19: Now What? https://www.michigan.gov/documents/coronavirus/Accessible_-_2020_MDHHS_COVID_Testing_PostTest_Flyer_June_B_FINAL_696360_7.pdf. Published 2020. Accessed December 3, 2020.



What should I do if I live with someone who has COVID-19?

“When you’re living with someone who you think or know has COVID-19, you should support them physically and emotionally, while at the same time avoiding getting close, touching them or touching things they have touched that haven’t been cleaned yet. And be sure to check on them often, either by phone or without entering their room all the way, because they can take a turn for the worse very quickly.”

-Tammy Chang, M.D., M.P.H., M.S., Assistant Professor of Family Medicine at Michigan Medicine¹³

If you live with someone who is sick and needs to isolate:

Do:

- **Help cover basic needs.** These needs might include helping the person who is sick follow their doctor’s instructions for care and medicine or helping them with grocery shopping, filling prescriptions, and getting other items they may need.
- **Know the COVID-19 danger signs, and what to do if they happen.** If they have trouble breathing, chest pain or pressure, new confusion, bluish lips or face, or difficulty staying awake, **get medical care immediately.**
- **Protect yourself.** Protecting yourself includes making sure the person who is sick is isolating, and you or others with close contact are quarantining. You should also:
 - Wear a mask if you are in the same space as someone who is sick.
 - Wash your hands often.
 - Clean and disinfect “high-touch” surfaces and shared spaces. Note: The person who is sick should clean and disinfect after themselves. If this is not possible, wear a mask and wait as long as possible before coming in to clean.
- **Track your own health.** You should stay home and monitor your health for COVID-19 symptoms while caring for the person who is sick. You should continue to stay home for 14 days after your last close contact with the person who is sick (based on the time it takes to develop illness), or 14 days after the person who is sick meets the [criteria to end home isolation](http://michmed.org/9alwo) (<http://michmed.org/9alwo>).

Don’t:

- **Have visitors,** especially visits by people who are at higher risk for severe illness.
- **Share personal items.** Things like dishes, towels, and bedding should not be shared, even with family.
- **Be afraid to ask for help or moral support.** It’s OK to let friends, neighbors and family know that someone you live with is sick, and to seek and accept their help while not letting them near the person who is sick.

¹³ Gavin K. 14 Things to Do If Someone You Live With Has COVID-19. Mich Med. April 2020. <https://healthblog.uofmhealth.org/wellness-prevention/14-things-to-do-if-someone-you-live-has-covid-19>. Accessed December 3, 2020.



What should I do if I live with someone who has COVID-19?

For detailed instructions about caring for someone in isolation, please visit the following resources:

- [CDC's "Caring for Someone Sick at Home" page: http://michmed.org/yO095](http://michmed.org/yO095)
- ["14 Things to Do If Someone You Live With Has COVID-19" by Kara Gavin](http://michmed.org/L1zAr), with tips for helping a family member or roommate cope with COVID-19 effects, while protecting yourself and others: <http://michmed.org/L1zAr>
- [CDC's "Sick Parents and Caregivers" page: http://michmed.org/BvyBz](http://michmed.org/BvyBz)

Washtenaw County's temporary shelter resources for COVID-19

Along with housing, the Health Department will provide:

- Three meals a day
- A thermometer and a mask
- Personal care items such as toothpaste, soap, and feminine hygiene products, if needed
- Clothing, if needed

You may qualify if:

- You have COVID-19 and, if you returned home, you would put a family member at risk for COVID-19
- You are homeless and have COVID-19 or are at-risk for COVID-19

For more information about [temporary shelter for COVID-19 in Washtenaw County](http://michmed.org/wOovm), visit: <http://michmed.org/wOovm>



What should I do when I get my COVID-19 test results?

If you get a negative test result:¹⁴

If you test NEGATIVE, BUT still have symptoms of an illness:

- Stay home and away from others until at least 24 hours after symptoms are gone
- Call your doctor and ask if you should be tested again, or for another illness, if you continue to have COVID-19 symptoms.

If you test NEGATIVE and do not have symptoms, but were asked to quarantine by your local health department, continue to follow their instructions.

.....
: **Remember:** you cannot test your way out of quarantine. It can take up to 14 days after
: exposure for an infection to develop, so you could end up testing positive later on. It's
: important to stay in quarantine for the full 14 days to prevent spreading COVID-19!
:

If you get a positive test result:¹⁵

Start isolating yourself right away, plus:

- **Answer your health department's call.** They will reach out to begin contact tracing. They can also answer your questions.
- **Tell your close contacts** so they can quarantine themselves.
- **Tell your employer you have COVID-19.** If you need an isolation or quarantine letter for your employer, email L-wchdcontact@washtenaw.org or call 734-544-6700 and leave a message. For more guidance, see:
 - **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.
- **Watch for severe symptoms** or other health emergencies. If you need to call 911, let them know that you have COVID-19.
- **Detailed information on [how and when to end isolation](#)** is available here: <http://michmed.org/galwo>

¹⁴Adapted from: State of Michigan. You Were Tested for COVID-19: Now What? https://www.michigan.gov/documents/coronavirus/Accessible_-_2020_MDHHS_COVID_Testing_PostTest_Flyer_June_B_FINAL_696360_7.pdf. Published 2020. Accessed December 3, 2020.

¹⁵Adapted from: State of Michigan. You Were Tested for COVID-19: Now What? https://www.michigan.gov/documents/coronavirus/Accessible_-_2020_MDHHS_COVID_Testing_PostTest_Flyer_June_B_FINAL_696360_7.pdf. Published 2020. Accessed December 3, 2020.

Washtenaw County Health Department. If You Test Positive for COVID-19.; 2020. https://www.washtenaw.org/DocumentCenter/View/18539/If-you-test-positive-for-COVID-11-6-20-updated?fbclid=IwAR3ABfmQIt31X2bEpEj76yarobDt_6kLKaN0VPx3Dzroom-z_BTulZ96n6M. Accessed December 3, 2020.

Washtenaw County Health Department. What to do if You're Sick with COVID-19. <https://www.washtenaw.org/3104/What-to-do-if-Youre-Sick>. Published 2020. Accessed December 2, 2020.



What is contact tracing?

Contact tracing¹⁶

To break the chain of infection, the Michigan Department of Health and Human Services is calling anyone who has been exposed. This is called **contact tracing** and it has been used to control the spread of diseases for decades. If you get a call from 866-806-3447, MI COVID HELP or your local health department **please answer** to protect your family, friends, neighbors and coworkers. Here is how it works:

- Your name will not be shared with anyone.
- You will never be asked for personal information like a Social Security number, driver's license, immigration status or credit card information.
- The contact tracer will ask how you are feeling and about people you were in contact with recently.

¹⁶Adapted from: State of Michigan. Coronavirus - Trace. https://www.michigan.gov/coronavirus/0,9753,7-406-99891_99913---.00.html. Published 2020. Accessed December 3, 2020.



Where can I get additional help?

Quarantining or isolating can upset your work, finances, and health. 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.

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://www.michigan.gov/StayWell) for more information. Counseling is free, confidential, and available 24/7.

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

Additional COVID-19 Information

The following websites provide additional, accurate information about COVID-19:

- **CDC's COVID-19 page:** <http://www.cdc.gov/coronavirus>
- **State of Michigan's COVID-19 page:** <http://www.michigan.gov/coronavirus>
- **Michigan Medicine's COVID-19 Updates page:** <https://www.uofmhealth.org/covid-19-update>
- **Michigan Medicine's COVID-19 Patient Education page:** <http://careguides.med.umich.edu/coronavirus>



Help improve these materials

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

[Share your feedback here \(http://michmed.org/ZbVnd\)](http://michmed.org/ZbVnd), 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.

Support for the creation of these materials provided by: the University of Michigan Institute for Social Research, Michigan Medicine, and the Procter & Gamble Company.

Authorship: The BioSocial Methods Collaborative and HEART Research Project Team
(<https://heart.isr.umich.edu/meet-our-research-team/>)

How to Cite:

BioSocial Methods Collaborative and HEART Research Project Team. Navigating COVID-19 exposure, testing, and quarantine. In: *COVID-19 Patient & Caregiver Collaborative Care Workbook*. Ann Arbor: Michigan Medicine; 2020: 1-18. doi:[10.3998/2027.42/163715](https://doi.org/10.3998/2027.42/163715)

Patient Education by [Michigan Medicine](#) is licensed under a [Creative Commons AttributionNonCommercial-ShareAlike 4.0 International Public License](#).

Last Revised 12/2020, Version 1.0.0





Preparing to go to the emergency department for COVID-19

This section* will answer the following questions:

- [When should I seek emergency medical care? \(page 39\)](#)
- [How do I check for signs of COVID-19? \(page 39\)](#)
- [What should I bring to the emergency department? \(page 42\)](#)
- [How do I safely get to the emergency department? \(page 45\)](#)
- [What happens when I get to the emergency department? \(page 46\)](#)

*Access the other sections of [this workbook](#) by visiting: <http://michmed.org/ng2W1>

Michigan Medicine Emergency Department:
1500 East Medical Center Drive, Ann Arbor, MI 48109
Phone: 734-936-6666



Signs of COVID-19

When should I seek emergency medical care?¹

If you have an emergency warning sign (including trouble breathing), **get emergency medical care immediately. Call 911 or call ahead to your local emergency facility:**

- Tell the operator: I have or may have COVID-19.
- Put on masks before emergency personnel arrive or before going to the hospital.

Emergency warning signs* for COVID-19

If someone is showing any of these signs, seek emergency medical care immediately:

- Trouble breathing
- Persistent pain or pressure in the chest
- New confusion
- Inability to wake or stay awake
- Bluish lips or face

*This list does not include all of the possible symptoms of COVID-19. Please call your medical provider for any other symptoms that are severe or concerning to you.

How do I check for signs of COVID-19?

For non-emergency situations, access the [Centers for Disease Control \(CDC\) Coronavirus Self-Checker](http://michmed.org/05mm4) (<http://michmed.org/05mm4>) to help you make decisions on when to seek testing and medical care.



**Centers for Disease Control (CDC)
Coronavirus Self-Checker**

<http://michmed.org/05mm4>

How am I protected from getting COVID-19 in the emergency department?

Hospitals have long-standing commitments to your health care needs. For information on how Michigan Medicine is handling [hospital safety during COVID-19](http://michmed.org/wOopm), visit: <http://michmed.org/wOopm>

¹Adapted from: Centers for Disease Control and Prevention. Symptoms of Coronavirus. <https://www.cdc.gov/coronavirus/2019-ncov/symptoms-testing/symptoms.html#seek-medical-attention>. Published May 13, 2020. Accessed November 11, 2020.



Thinking about going to the emergency department

Be on the lookout for...

Uncertainty and disagreement

Deciding whether to go to the hospital can be stressful for everyone involved. You and your family may be conflicted about the seriousness of symptoms, the fear of catching COVID-19 at the hospital, or worry about burdening others. Tensions can be high and people may not act the way they normally do.

Strategies that can help:

- The CDC has published guidelines to help you make this decision. In this section, read [“When should I seek emergency medical care?” \(page 39\)](#)
- Think about why you want to or are opposed to going to the hospital. Have an honest and clear conversation with someone you trust about these feelings
- Reach out to an expert for advice. You could call:
 - Your primary care physician,
 - Michigan Medicine COVID-19 Hotline (734-763-6336)
 - State of Michigan COVID-19 Hotline (888-535-6136)

“The bottom line is, if you can’t breathe, go directly to the emergency department. Do not wait.”

-Theodore J. Iwashyna, MD, PhD, Pulmonary & Critical Care Medicine, Michigan Medicine



How do I prepare for a visit to the emergency department?



If you are a patient

- Monitor yourself for the CDC's Emergency Warning Signs (see [“When should I seek emergency medical care?” on page 39](#))
- Identify the hospital you will go to
- Ask your doctor to call the emergency department ahead of your arrival
- Plan for household tasks to be taken care of, including childcare or petcare, if needed
- Pack an emergency bag with personal items including a cell phone charger
- Bring a written list of emergency contact information and current medications
- Arrange for safe transportation to the hospital; **wear masks in the car**



If you are a caregiver

- Monitor the patient for the CDC's Emergency Warning Signs (see [“When should we seek emergency medical care?” on page 39](#))
- Identify the hospital the patient will go to
- Plan for household tasks to be taken care of, including childcare or petcare, if needed
- Pack an emergency bag with personal items for yourself and the patient, include a cell phone charger
- Keep a notebook and pen with you to keep track of information you may receive
- Identify a point person who will share information with family and friends so you can focus on the patient

Continue reading for more information to help you with these steps.





What should I bring to the emergency department?²

Pack an emergency bag

When you are going to the emergency department, you should prepare as if you might stay in the hospital overnight. Consider bringing the following items.

Packing a bag for the patient

- Photo ID
- Health insurance card
- List of medications
- Medical history (health conditions and surgeries)
- Change of clothes
- Glasses
- Toiletries
 - Toothbrush
 - Hairbrush
 - Other: _____
- Phone
- Phone charger
- Headphones
- Something to keep you warm such as a coat or small blanket
- Dentures and case
- Any other medical equipment you usually use, such as a C-PAP

Packing a bag for the caregiver

Hospital rules about visitors and caregivers can change frequently.

Prepare as if you are not allowed to enter the hospital due to COVID-19 and need to find a place to wait outside.

You may be waiting for quite a long time.

- Water bottle
- Phone
- Phone charger
- A book or something to keep you occupied while you wait

NOTE: Due to the changing nature of restrictions required by COVID-19, caregivers may not be allowed to enter the hospital. For the latest [visitor policies at Michigan Medicine](https://www.michiganmedicine.org/visitor-policies), visit: <http://michmed.org/gkmcqW>

Before you leave, don't forget to also include:

- Your own daily medications
- Reading glasses
- Hearing aids
- Mask
- Hand sanitizer
- Snacks, such as protein or granola bars

Please note, there are times when you may move rooms or leave your room and may not be able to secure your things. Consider leaving jewelry and other high value items at home. Clearly label important belongings with your name and information. The hospital is not responsible for loss of such items.

² Adapted from: Leukemia & Lymphoma Society. Worksheet 1: Emergency Room (ER) Plan. In: Caregiver Workbook. 2019:1-3. https://www.lls.org/sites/default/files/National/USA/Pdf/Publications/Caregiver_Worksheet_1_ER_2019.pdf. Accessed November 11, 2020.



Write down your childcare and pet care plans

If you have children, make a plan for childcare. Think of the short-term and longer-term.

Example Plan: My neighbor can stay with my children (short-term) until my family member arrives (longer-term).

My childcare plan

My short-term plan is: _____

Name: _____

Phone Number(s): _____

Email: _____

Notes: _____

My longer-term plan is: _____

Name: _____

Phone Number(s): _____

Email: _____

Notes: _____

My pet care plan

If you have pets, you may want to consider asking a neighbor, friend, or family member to check in on them. Give them a spare key and your veterinarian's contact information, in advance, in case your visit to the emergency department lasts for more than a few hours.

Name: _____

Phone Number(s): _____

Email: _____

Notes: _____



How do I safely get to the emergency department?³

If the situation is an emergency, call 911 immediately for an ambulance. Notify the operator that you are seeking care for someone who has or may have COVID-19.

If you decide to drive to the emergency department:

- ✓ Do **not** drive yourself if you are experiencing any of the CDC's Emergency Warning Signs (see "[When should we seek emergency medical care?](#)" on page 39)
- ✓ Ask your doctor to call the emergency department ahead of your arrival
- ✓ Also call ahead yourself to let the emergency department know you are coming (for Michigan Medicine, call 734-936-6666)
 - ✓ Tell the operator that you or someone with you has or may have COVID-19
 - ✓ Ask "Where can I park?"
 - ✓ Ask "Will I be allowed to come into the hospital?"
- ✓ Wash or sanitize your hands, both before you leave home and when you arrive
- ✓ Bring cleaning supplies (such as wipes and hand sanitizer) to wipe down commonly touched areas in the car

While driving to the emergency department:

- ✓ Go directly to the hospital. Do NOT go on errands along the way
- ✓ Wear a mask
- ✓ Masks should not be worn by:
 - ✓ Those having difficulty breathing
 - ✓ Children under 2 years old
 - ✓ Those unable to take off their own mask
- ✓ Sit as far away from each other in the vehicle as possible
- ✓ Open the car windows and turn your fan on to increase air circulation
- ✓ After you drop off the patient, clean commonly touched areas with wipes and use hand sanitizer

³ Adapted from:

Centers for Disease Control and Prevention. Considerations for Non-emergency Vehicle Transportation for Tribal Communities During COVID-19. <https://www.cdc.gov/coronavirus/2019-ncov/community/tribal/non-ems-transportation.html>. Published 2020. Accessed November 11, 2020.

Department of Public Health City of Philadelphia. Guidance for Transport of Patients with Confirmed or Suspected COVID-19 by Family Members or Other Non-Professionals. Philadelphia; 2020. <https://www.phila.gov/media/20200329105204/Guide-for-transport-of-patients.pdf>. Accessed November 11, 2020.



What happens when I get to the Michigan Medicine emergency department?



Above: The entrance to the U-M Hospital Emergency Department.⁴

How does drop-off and parking work?

- Go directly to the hospital Adult Emergency entrance
- If the caregiver is allowed to enter the hospital:
 - The valet at the Emergency entrance can park your car for free
 - If the valet is not able to park your car, they can tell you where to go to park
- If the caregiver is not allowed to enter the hospital:
 - Many people wait in their car in the parking lot
- To learn more about [parking at U-M Hospital](http://michmed.org/XrvOj) (call 734-764-7474 or visit <http://michmed.org/XrvOj>)
- Due to the changing nature of COVID-19, visitors may not be allowed to enter the hospital. For the latest [visitor policies at Michigan Medicine](http://michmed.org/gkmqW), visit: <http://michmed.org/gkmqW> or call 734-936-6666

Michigan Medicine Emergency Department:

1500 East Medical Center
Drive, Ann Arbor, MI 48109

Phone: 734-936-6666

For the latest [visitor policies at Michigan Medicine](http://michmed.org/gkmqW), visit: <http://michmed.org/gkmqW> or call 734-936-6666

⁴ Michigan Medicine Security. Security Car Hospital Entrance. https://storage.googleapis.com/dpss-wordpress-prod/2/2017/06/Sec_CarHos_Entrance.jpg. Published 2014. Accessed November 14, 2020.



What happens when I get to the Michigan Medicine emergency department?

Be on the lookout for...

Helplessness, guilt, and relief

Due to COVID-19 restrictions, many hospitals only allow patients to enter the emergency department. Some caregivers may feel guilty that they cannot accompany their family member inside the hospital. On the other hand, many feel relieved knowing the patient is now receiving the care they need. Both patients and caregivers may feel uncertainty about what will happen next or how to stay in touch with each other.

Strategies that can help:

- Call a family member or friend, journal about your experience, or reach out to your faith community
- Find the best way to stay in touch. Visit workbook sections “Helping Patients and Caregivers Stay Connected” and “Communicating With Your Care Team”
- For non-urgent professional help, you can call a warmline, a telephone line to provide assistance for those whose need is not urgent. Find your [local warmlines](#) by visiting: <http://michmed.org/48mY4>

How can I find a place to stay overnight while the patient is in the hospital?

- Contact the [UMHS Patient & Visitor Accommodations Program](#) to find a room in Ann Arbor at lower cost (call 800-544-8684 or visit www.med.umich.edu/hotels)
- If lodging or meals related to appointments is causing a financial burden, the [Guest Assistance Program](#) may be able to help (call 800-888-9825 or visit <http://michmed.org/q4kRz>)

Patient and Visitor Michigan Medicine General Help Line

800-888-9825



What happens when I get to the Michigan Medicine emergency department?

If you are a patient

What happens once you are at the emergency department may change depending on the number of COVID-19 cases in the area. For the latest information about [what to expect at the Michigan Medicine emergency department](http://michmed.org/48mXq), visit: <http://michmed.org/48mXq>

Usually, you will be asked questions related to COVID-19 and have your temperature taken. Next, you may move through four stages⁵:

1. Triage: Hospital staff determine who needs to be evaluated first given their condition and the urgency of their wounds or illness. You may have a long wait between Triage and the next stage (Evaluation).

2. Evaluation: Nurses and technicians will determine your health problems.

- You may be given a COVID-19 test
- You will be asked about your symptoms
- Your vital signs will be taken (blood pressure, pulse, oxygen levels, etc.)

3. Registration:

The hospital registrar will ask you to confirm your:

- Address
- Primary care doctor
- Insurance information
- Preferred pharmacy

4. Discharge or hospitalization: After being evaluated in the emergency department, you may be sent home with care instructions (**discharge**) or moved to another room in the hospital (**hospitalization**). If you are hospitalized, a member of the hospital security team can help you secure any personal belongings that you are not able to send home.



Above: Stages of care in the emergency department, from Triage to Discharge or Hospitalization.⁶

⁵ Adapted from: Michigan Medicine. Emergency Department Patient Guide. <https://www.uofmhealth.org/conditions-treatments/emergency/emergency-department-patient-guide>. Published 2020. Accessed November 12, 2020.

⁶ Michigan Medicine. Emergency Department Patient Guide: Triage Process Flowchart. https://www.uofmhealth.org/sites/default/files/triage_process_flowchart-2.png. Published 2020. Accessed November 14, 2020.



Help improve these materials

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

[Share your feedback here \(http://michmed.org/lApBN\)](http://michmed.org/lApBN), 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.

Support for the creation of these materials provided by: the University of Michigan Institute for Social Research, Michigan Medicine, and the Procter & Gamble Company.

Authorship: The BioSocial Methods Collaborative and HEART Research Project Team
(<https://heart.isr.umich.edu/meet-our-research-team/>)

How to cite:

BioSocial Methods Collaborative and HEART Research Project Team. Preparing to go to the emergency department for COVID-19. In: *COVID-19 Patient & Caregiver Collaborative Care Workbook*. Ann Arbor: Michigan Medicine; 2020: 1-14. doi:[10.3998/2027.42/163715](https://doi.org/10.3998/2027.42/163715)

Patient Education by [Michigan Medicine](#) is licensed under a [Creative Commons AttributionNonCommercial-ShareAlike 4.0 International Public License](#).

Last Revised 12/2020, Version 1.0.0





Communicating with your care team while in the hospital with COVID-19

This section* will answer the following questions:

- [How do I communicate with my care team? \(page 52\)](#)
- [How can I advocate for the best care? \(page 54\)](#)
- [How do I access online health records? \(page 55\)](#)
- [How do I navigate advance directives? \(page 56\)](#)
- [Who is on my hospital care team? \(page 57\)](#)

*Access the other sections of this workbook by visiting: <http://michmed.org/ng2W1>



How can I communicate with my care team effectively?



If you are a patient

- Identify your care team (doctors, nurses, etc.) and write down or take a picture of their contact information
- Identify your **key support person(s)**: people who should communicate with your care team, often family members
 - Share their contact information with your care team
 - Give your support person(s) access to your online health records ([see page 55](#))
- Complete your advance directives (a social worker can help you with this)
- Ask the care team questions you have about your health problems and treatment options



If you are a caregiver

- Write down the hospital name and patient's room number
- Identify the patient's care team, write down their contact information, and ask for the best way to reach them
- Get access to the patient's online health records ([see page 55](#))
- Ask the patient about their advance directives
- Ask the care team questions you have about the patient's health problems and treatment options
- Answer any calls or texts from your local health department if they reach out to you for contact tracing (see workbook section "Navigating COVID-19 Exposure, Testing, and Quarantine" for more information)

Continue reading for more information to help you with these steps.





Write down important information

Write down the names of the members of your care team (doctors, nurses, etc.). You can print this document to write in the lines below, or write this on your own paper. You may wish to keep a journal of conversations you have with these people.

Hospital name: _____

Room number: _____ Nurses' station phone number: _____

Care team members

Name	Role	Phone	Email

Note: Your room number or care team members may change during your time in the hospital. You can record this information here.



How can I advocate for the best care?

It's important to work with your care team to make sure your needs and preferences are being heard.

If you are a patient

Take an active role in your care.

- ✓ **Be honest and direct.** You know yourself best. Describe how you feel physically and emotionally. If you have concerns, let your care team know.
- ✓ **Ask questions.** If you do not understand what someone is saying, ask them to clarify. It may be helpful to make a list of questions so you cover everything with your care team. Do not worry if your question seems silly or does not make sense – your care team is there to help.
- ✓ **Take notes or record your conversations with your care team.** Taking notes can help you remember what you have talked about with your care team. If allowed, record your conversations. If you cannot take notes, ask someone else to help.
- ✓ **Discuss your wishes with your caregiver.** If there is a point when you are unable to make medical decisions, it is important that your caregiver knows how to represent you to your care team.

If you are unable to speak, try other ways to communicate with your care team such as:

- Using your phone or tablet to type or text
- Writing with paper and pencil
- Writing with a whiteboard and marker
- Using body language (e.g. blinking, hand gestures)

If you are a caregiver

During COVID-19, there may be restrictions on visiting a patient. You can still take an active role in their care.

- ✓ **Ask the care team about their schedule and the best time for updates.** Find a time that works for both you and the care team to talk every day or every other day.
- ✓ **Communicate directly with the patient.** Communicate directly with the patient. Reach out by video call, phone call, text, or email. The care team may be able to help you connect.
- ✓ **Access information through the electronic health portal.** Use the online portal or phone app to view test results, medications, billing, etc.
- ✓ **Ask the care team how you can help.** Care providers really appreciate this question.
- ✓ **Take notes.** Keep a notebook to track the patient's progress and note important information. If allowed, it may be helpful to record discussions with members of the care team
- ✓ **Discuss the patient's wishes with them.** It is important that you know the patient's wishes in case you ever need to represent them when they are unable to make medical decisions.



How do I access and share online health records?

Did you know?

With permission, you can get access to someone else's health records. Read below to see how.

If you are a patient

You can contact your care team and view your health records through the MyUofMHealth Patient Portal. Select "For myself only" to make an account for yourself, or select "Adult granting access to another adult" to give your caregiver access.

If you are a caregiver

With the patient's permission, you can also contact the care team and view the patient's health records. See the contact information below for help.

For questions or information about the MyUofMHealth Patient Portal:

Email: HIM-PatientPortal@med.umich.edu,

Phone: 734-615-0872

Hours: Monday-Friday 7:00 am - 7:00 pm,
Saturday and Sunday 8:00 am - 5:00 pm



Visit

<http://michmed.org/xoWYR>

(or scan the QR code)



How can I make sure the care team knows my health preferences?

Prepare your Advance Directive

An **Advance Directive** is a written statement about your wishes regarding medical treatment. In the State of Michigan, the Durable Power of Attorney for Health Care is the most widely used Advance Directive. This is a legal document and allows you to name your Patient Advocate.

If you are a patient

You always have the right to be included in any decisions related to the healthcare you receive. However, there may be a time where you are unable to make your own decisions. Complete an Advance Directive and designate your Patient Advocate to ensure that your wishes are known.

What is a Patient Advocate?

A **Patient Advocate** is the person who can:

- Make medical decisions for you when you are too sick to make them for yourself
- Make medical decisions when two doctors agree that you cannot make your own decisions
- Make medical decisions that are stated in your Advance Directive

If you do not choose a Patient Advocate, your doctors may ask your closest family members to make decisions. If your family members cannot make or agree on a decision, a judge may appoint someone in your family to make decisions for you. It is important for you to know that even if you do not choose a Patient Advocate, you will still receive care from your care team.

If you are a Patient Advocate

You will be able to agree to, say no to, change, stop or choose any of the following:

- Doctors, nurses, social workers
- Hospitals or clinics
- Medications, tests, or treatments
- Whether or not the patient will receive life support treatments
- Whether or not the patient will receive surgery
- Whether or not to take the patient to a hospital or nursing home
- What kind of comfort care the patient will receive, including hospice care



Patients & caregivers

Ask your care team about completing the U-M Advance Directive and Durable Power of Attorney worksheet (michmed.org/xoWYW). A social worker may be especially helpful.



Who is on my hospital care team?

During your hospital stay, many healthcare professionals may care for you by working together as a care team. Each care team member plays a different role to support your mental and physical health. Your care team can:

- Help you make medical decisions
- Answer your questions
- Support you and your family
- Find additional information and resources for you

Continue reading to learn what each care team member can do for you and what questions you might want to ask them.



Doctors

While in the hospital, you will probably have more than one doctor caring for you. Depending on your health history, you may have doctors who specialize in caring for different parts of the body and the mind. Doctors can:

- Give direction to your care team
- Identify your health problems
- Teach you about your health, treatments, or procedures you may go through

Questions to ask

- What are my treatment options?
- What do the different medications do?
- What will this disease do to me?
- How and when will you share information with my caregiver?
- How and when will we decide if I am responding to the treatment or if we need to change treatments?

Notes or additional questions & answers



Who is on my hospital care team?



Nurses

Nurses are members of the care team who directly care for you at the bedside. Nurses can also give updates on how you are doing. Nurses can:

- Provide direct care for you during your hospital stay
- Monitor your labs, vital signs and symptoms
- Give you your medications, perform treatments, and provide information about your overall care plan

Questions to ask

- What medications am I currently taking? What do they do? What are their side effects?
- How do I contact my family or friends while I am in the hospital?
- What can I expect to happen next?
- What can I do to recover faster?
- Can my caregiver send in personal items for me?

Notes or additional questions & answers



Who is on my hospital care team?



Social workers

Social workers focus on personal and often non-medical issues that may arise during your stay in the hospital. Social workers can:

- Offer counseling and helps you cope with care needs
- Advocate for you and your family
- Coordinate going home or to other care facilities
- Assist with financial needs and job concerns

Questions to ask

- There are the changes I am noticing in my mood and thinking/memory, are they normal?
- I am worried about my family. How can I support them?
- I am worried about my job. Are there things I can do to protect it?
- I am worried about being able to pay my bills at home. How can I get assistance?
- What can I do if I'm bored?
- Will my insurance cover my hospitalization?
- Can you tell me about Advance Directives?

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
- Costs for medications, supplies and equipment
- Lodging assistance
- Meal Assistance and Food Insecurity
- Transportation assistance
- Durable medical equipment/supplies
- Parking



Guest Assistance Program:

Ph: 800-888-9825
(9 a.m.-5 p.m., M-F), or
Visit michmed.org/q4kRz
(scan the QR code)

Notes or additional questions & answers



Who is on my hospital care team?



Physical and occupational therapists

Physical and occupational therapists work together to help you regain your ability to do daily tasks.

Physical therapists can:

- Help you improve your overall movement and manage pain
- Teach you exercises that improve strength, balance, or endurance

Occupational therapists can:

- Work with you to recover and relearn the things you do everyday. This includes dressing, eating, bathing, and other activities

Questions to ask

- How long will it take for me to get better?
- What should I practice in between our sessions?
- Is rehab painful? Am I safe to do rehab while I'm recovering medically?
- What are reasonable goals for me? How long will it take me to achieve these goals?

Notes or additional questions & answers



Who is on my hospital care team?



Dietitian

Dietitians make sure you get the proper nutrition during your hospital stay. You may need to give the dietitian information about your regular eating habits. Dietitians can:

- Monitor and assess your nutritional status
- Make recommendations for dietary supplements or tube and intravenous feedings if necessary
- Teach you how to select foods that meet your needs in the recovery process

Questions to ask

- How do I get the nutrition I need while I'm at the hospital?
- Are there foods I can't or shouldn't eat right now?
- What should I know about feeding tubes or eating after ventilation?
- Are there foods that conflict with my medications?
- How do my pre-existing conditions/diabetes affect my diet?

Notes or additional questions & answers



Who is on my hospital care team?



Additional members of my care team

Certified nursing assistants

- Assist you with daily activities such as bathing, dressing, grooming, toileting, eating, and moving
- Work closely with your nurses

Respiratory therapists

- Help you with your lungs and breathing
- Manage your ventilator settings if you have one
- Help set and check oxygen levels

Hospital chaplains

- Support patients of all belief systems
- Can provide spiritual support and religious services
- Can help you connect with your community and family

You do not have to be religious to connect with a chaplain.

Pharmacists

- Prepare your medications
- Give you information on when, how much, and how long to take your medications
- Explain possible side effects

Notes or additional questions & answers



Help improve these materials

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

Share your feedback here (<http://michmed.org/xoWap>), 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.

Support for the creation of these materials provided by: the University of Michigan Institute for Social Research, Michigan Medicine, and the Procter & Gamble Company.

Authorship: The BioSocial Methods Collaborative and HEART Research Project Team (<https://heart.isr.umich.edu/meet-our-research-team/>)

Plain Language Editing: Karelyn Munro, BA

How to Cite:

BioSocial Methods Collaborative and HEART Research Project Team. Communicating with your care team while in the hospital with COVID-19. In: *COVID-19 Patient & Caregiver Collaborative Care Workbook*. Ann Arbor: Michigan Medicine; 2020:1-14. doi: [10.3998/2027.42/163715](https://doi.org/10.3998/2027.42/163715)

Patient Education by [Michigan Medicine](#) is licensed under a [Creative Commons AttributionNonCommercial-ShareAlike 4.0 International Public License](#).

Last Revised 12/2020, Version 1.1.0





Helping patients & caregivers stay connected during COVID-19

This section* will answer the following questions:

- [How can I stay connected? \(page 65\)](#)
- [How can I use a personal device to connect with people I care about? \(page 66\)](#)
- [How can I manage contact fatigue? \(page 69\)](#)
- [How can I manage loneliness and isolation? \(page 70\)](#)

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



How can I stay connected?

I can't be with the patient in the hospital, how can I stay in touch?

Michigan Medicine offers caregivers several strategies for keeping track of the patient and their records:

1. Emergency Department text messaging system
2. Online health records
3. Communicating with hospital staff (see section [“Communicating with your care team while in the hospital”](#): <http://michmed.org/ng2W1>)
4. Patient and Visitor Michigan Medicine Help Line (800-888-9825)

When the patient is in the emergency department, remember that they will be receiving care but it may take awhile before information on their condition is available.

How do I access the Michigan Medicine text messaging system?

If you are unable to be in the hospital with the patient, you can still stay updated on the patient's progress. The Michigan Medicine texting system can provide you text updates regarding the patient while they are in the Emergency Department. You may need to contact the Emergency Department (734-936-6666) to receive these updates.

How do I access online health records?

If you are a patient

You can contact your care team and view your health records through the [MyUofM-Health Patient Portal](http://michmed.org/xoWYR) (<http://michmed.org/xoWYR>). Select “For myself only” to make an account for yourself, or select “Adult granting access to another adult” to give your caregiver access.

If you are a caregiver

With the patient's permission, you can also contact the care team and view the patient's health records. See the contact information below for help.

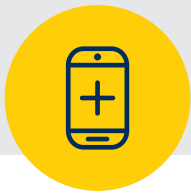


For questions or information about the MyUofMHealth Patient Portal:

Email: HIM-PatientPortal@med.umich.edu,

Phone: 734-615-0872 (Monday-Friday 7:00 am - 7:00 pm, Saturday and Sunday 8:00 am - 5:00 pm), or

Visit: <http://michmed.org/xoWYR> (or scan the QR code)



How can I use a personal device to connect with people I care about?

Note about cell phone service:

- Cell phone service is often poor in the Emergency Department
- If cell phone service is poor, try using the free hospital WiFi

To connect to free hospital WiFi:

- The wireless network is called "MGuest-UMHS."
- Enter the address of any Web site into the browser of your laptop or mobile device.
- A login page will load onto your device.
- Enter your last name and email address, and click "Accept."
- On the next page, click "Continue" and you will be directed to the Health Systems Website.
- You can explore our site, or go to any other Web site by typing in the address or using your own "bookmarks" list.
- To learn more about [accessing WiFi at Michigan Medicine](http://michmed.org/18mgd), ask a nurse or visit: <http://michmed.org/18mgd>
- To call the patient's room: Ask the hospital operator to connect you by calling 734-936-4000
- To call from a patient room: Dial 97 for an outside line or dial 0 to ask the hospital operator for assistance

There are also many [apps and websites](#) you can use to connect with friends and family through video, voice, or text. To learn more about these options, visit: <http://michmed.org/G24Jy>

Be on the lookout for...

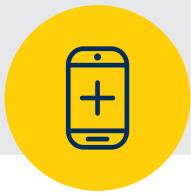
Video calls can be emotionally challenging

Video calls can be comforting, but they can also be emotionally difficult due to the possible physical and mental changes of the patients while they are in the hospital. Even if it might be difficult, some also find it helpful to understand the reality of what the patient is going through.

Strategies That Can Help

When deciding how to communicate, put the patient first.

- **Video** - ask the patient if it is okay
- **Calling** - this is sometimes preferred if the patient is worried about how they look and would feel more comfortable communicating via phone
- **Texting** - If the patient finds talking difficult, texting is a good method of communication



How can I use a personal device to connect with people I care about?

Common video chat apps on smartphones and devices:

If your personal device has a camera but does not have FaceTime or Google Duo, you can download one of the apps below to connect via video, voice or text:

Apple Devices



FaceTime



[Facebook Messenger](https://messenger.com)
messenger.com



[WhatsApp](https://whatsapp.com)
whatsapp.com

Android Devices



Google Duo



[Google Hangouts](https://hangouts.google.com)
hangouts.google.com



[Skype](https://skype.com)
skype.com



[Signal Messenger](https://signal.org)
signal.org



[Google Duo](https://duo.google.com)
duo.google.com

Above: Apps that may help you communicate with patients or caregivers while in the hospital. To [learn more about these options](http://michmed.org/G24Jy), visit: <http://michmed.org/G24Jy>

Remember, if you are in the hospital, you can connect to the free WiFi Internet called "MGuest-UMHS." To learn more about [accessing WiFi at Michigan Medicine](http://michmed.org/18mgd), ask a nurse or visit: <http://michmed.org/18mgd>

"And then a nurse said, 'Hey, you can do FaceTime with your wife on [your iPod Touch]' 'What's FaceTime?' Sure enough. Those nurses were angels. And, of course, they're like half my age, if not less than that, so they know all this stuff. It's something you should've filmed because this nurse in all her hazmat gear and everything is showing this 55 year old gentleman who's infected with COVID how to do FaceTime. It made my day."

- COVID-19 Patient, July 2020

**Patient and Visitor
Michigan Medicine Help Line
Phone: 800-888-9825**



How can I manage contact fatigue?

Be on the lookout for...

Contact fatigue, loneliness, and distress due to physical and mental changes

Although family and friends may mean well, sometimes their questions and phone calls can become overwhelming. This feeling is called “contact fatigue.”

At the same time, COVID-19 can cause a sense of isolation for both patients and their caregivers. Even if you feel overwhelmed by too much contact from family and friends, you can still feel lonely and isolated.

Patients can undergo both physical and mental changes during their hospital stay (due to weight loss, confusion, delirium, and presence of medical equipment). These changes can be hard for both the patient and the caregiver to see, especially if the patient and caregiver have been separated from each other.

Strategies that can help

- For emotional support related to COVID-19, you can call a warmline.
 - [Michigan Stay Well Counseling](#):
 - Free, confidential emotional support available 24/7
 - Call 1-888-535-6136 and press “8” or visit Michigan.gov/StayWell
 - Michigan Crisis Text Line:
 - Text the keyword **restore** to 741741
 - Find [your local warmlines](#) by visiting: <http://michmed.org/48mY4>
- Access the [COVID-19 Mental Health Toolkit](#): <http://michmed.org/Bvj9l>
- Read on for other strategies and resources for contact fatigue, isolation, and distress over physical changes



How can I manage contact fatigue?

You may feel stressed, irritated, or distracted by the number of calls and texts you receive from well-meaning friends and family. At the same time, you may also feel guilty that you cannot respond to everyone.

Here are some strategies that can help if you experience contact fatigue:

Set and communicate your boundaries

- Remember you can ask for what **you** need; you are not just a source of news
- Limit topics of conversation, frequency of contact, or time of day
- Schedule a time to interact with others and commit to a log-off time

Limit exposure

- Turn off alerts or limit use of social media such as Facebook and Twitter
- Don't respond to non-urgent texts, calls, or posts
- Use group texts and emails instead of individual texts and emails
- Commit to fewer updates only at certain times of day
- Pick a "point person" who will communicate news to family and friends for you

Picking a point person⁷

Ask a family member or friend to act as a point person. This person will take messages and provide updates to concerned family and friends so you only have to update one person.

Name: _____ **Phone Number(s):** _____

Email: _____

Notes: _____

Example of an update platform: CaringBridge

CaringBridge is an example of an online platform that can help with contact fatigue. You can use CaringBridge to post updates for selected family and friends, request help with specific things you need, and many other features. Download the free [CaringBridge app for Apple](http://myumi.ch/xmjno) (<http://myumi.ch/xmjno>) or free [CaringBridge app for Android](http://myumi.ch/Plonj) (<http://myumi.ch/Plonj>), or visit the [CaringBridge website: https://www.caringbridge.org/](https://www.caringbridge.org/)

Note: Michigan Medicine has no connection to CaringBridge and has not reviewed its services. This is intended as an example for informational purposes only, not an endorsement of CaringBridge services.

⁷ Adapted from: Leukemia & Lymphoma Society. Worksheet 1: Emergency Room (ER) Plan. In: Caregiver Workbook. 2019:1-3. https://www.lls.org/sites/default/files/National/USA/Pdf/Publications/Caregiver_Worksheet_1_ER_2019.pdf. Accessed November 11, 2020.



How can I manage loneliness and isolation?

You may feel lonely and isolated even if family and friends are reaching out to you. You aren't just a source of news, but have emotional needs, too. You need conversations that aren't just a "medical report."

Here are some strategies that can help you manage loneliness and isolation

- Recognize that what you are feeling is okay
- Communicate your needs and boundaries with the people who support you
- Maintain your mental and spiritual health
 - Prayer
 - Meditation
 - Self-reflection
 - Spend time with nature
 - Connect with people who renew your spirit
- Connect with professionals who can help
 - Social workers
 - Chaplains
 - Psychotherapy or psychiatry services
- Explore the [COVID-19 Mental Health Toolkit: http://michmed.org/AO49j](http://michmed.org/AO49j)
- As a caregiver, prioritize self-care
 - Keep a regular sleep, diet, and exercise schedule
 - Spend 5 minutes of your day doing something you enjoy
 - Read a book
 - Listen to music
 - Enjoy a hobby
 - Connect with a friend

"I had to make certain decisions. And it was a very lonely, isolated feeling [...] When you do have a spouse or significant other that you make these decisions and all of a sudden you find yourself, overnight, alone."

**- COVID-19 Caregiver,
December 2020**

Talk with peers going through the same experience:

- **Join an online support group.**
There are online communities for COVID-19 where people can connect about their experiences. For more information, go to section [Appendix A: Building Your Support Group \(http://michmed.org/ng2Wl\)](http://michmed.org/ng2Wl).
- **Seek peer support.**
Michigan Medicine's Office of Patient Experience can connect you with people who were also COVID-19 patients or caregivers. These are people who understand the journey and have volunteered to help others. To ask about peer support, email: patient-experience@med.umich.edu



Share feedback on this document

<http://michmed.org/v1Xlo>

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.

Support for the creation of these materials provided by: the University of Michigan Institute for Social Research, Michigan Medicine, and the Procter & Gamble Company.

Authorship: The BioSocial Methods Collaborative and HEART Research Project Team
(<https://heart.isr.umich.edu/meet-our-research-team/>)

How to cite:

The BioSocial Methods Collaborative and HEART Research Project Team. Helping Patients and Caregivers Stay Connected during COVID-19. In: *COVID-19 Patient & Caregiver Collaborative Care Workbook*. Ann Arbor: Michigan Medicine; 2020: 1-10. doi:[10.3998/2027.42/163715](https://doi.org/10.3998/2027.42/163715)

Patient Education by [Michigan Medicine](#) is licensed under a [Creative Commons AttributionNonCommercial-ShareAlike 4.0 International Public License](#).

Last Revised 12/2020, Version 1.0.0





Preparing to go home after a COVID-19 hospital stay

This section* will answer the following questions:

- [What is the discharge process? \(page 74\)](#)
- [How am I involved in the discharge process? \(page 75\)](#)
- [What should be included in the discharge plan? \(page 76\)](#)
- [What if I feel it's too soon to leave the hospital? \(page 76\)](#)
- [As a caregiver, how should I prepare for discharge day? \(page 77\)](#)

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



What is the discharge process?

To leave a hospital or care facility, you must go through a process called **discharge**. The **discharge process** has 3 parts:

1. Alerting you that the discharge process has started
2. Holding a discharge planning meeting
3. Sending you home on discharge day

All the work done in preparation to leave a healthcare facility is called **discharge planning**. The doctor decides when you can be discharged, but nurses, social workers, discharge planners, and others also play a role in creating the **discharge plan**. Together, these people make up your **discharge team**. Your discharge team may provide you with a **discharge packet** that includes information such as medications, future appointments, and diet restrictions.

University of Michigan Care Management

At the University of Michigan, you may also receive assistance from **Care Management**. Care Management is a team led by a registered nurse and a social worker. The Care Management team can connect you with services and resources to support you during your hospital stay, as well as after discharge.

Care Management will:

- Offer counseling on how illness, disability, and grief can impact you and your family
- Problem-solve with you on social and financial barriers that impact your medical care
- Provide community resources, information, and referrals
- Connect you with the following services:
 - Home care services, such as: visiting nurses, physical therapy, occupational therapy, speech therapy, and private duty nursing
 - Out-of-hospital placement referrals, such as: skilled nursing facilities and acute rehab facilities
 - Durable medical equipment, such as: wheelchairs, oxygen, medical supplies



How am I involved in the discharge process?¹

I'll be caring for someone who is coming home after a COVID-19 hospital stay.

This document addresses anyone who is providing care to someone during or after a hospital stay as a “caregiver.” This may be the first time you find yourself in a caregiving role, or you may have been a caregiver to this person (or others) for a long time. The purpose of this section is to help you and the patient navigate the transition home, whether from the hospital or from a different healthcare facility.

During the discharge process, your discharge team should:²

- **Include** you and the patient in conversations
- **Discuss** key areas to prevent problems at home
- **Educate** you and the patient on their condition, the discharge process, and next steps
- **Assess** how well the information above was explained and understood
- **Listen** to your and the patient’s goals, preferences, observations, and concerns

When starting the discharge process, talk to the discharge team about your willingness and ability to provide care. You may have physical, financial, or other limitations that affect your caregiving capabilities. You may have other obligations such as a job or childcare that impact the time you have available. It is extremely important to tell the discharge team about these limitations.

How has COVID-19 changed the discharge process?

Because of COVID-19, the process of leaving the hospital or care facility may be faster than usual. You may not be able to enter the hospital or care facility for safety reasons. You should advocate to:

- Have the most accurate information about the steps it takes to be discharged
- Be involved in discharge planning and conversations with the discharge team
- Have your questions and concerns addressed before the patient is sent home

Some of the care the patient needs might be quite complicated. It is essential that you get any training you need in special care techniques, such as wound care, feeding tube or catheter care, or transferring someone from a bed to a chair.¹ To make sure you get the information you need:

- Ask that conversations about going home be scheduled at times that you can attend
- Use phone or video calls to attend conversations when you are unable to go in person
- Ask for written documents and summaries of plans for care at home and ask for a phone number to call if you have any questions

¹ Adapted from: Family Caregiver Alliance. Hospital Discharge Planning: A Guide for Families and Caregivers. <https://www.caregiver.org/hospital-discharge-planning-guide-families-and-caregivers>. Published 2009. Accessed December 5, 2020.

² Adapted from: Agency for Healthcare Research and Quality. IDEAL Discharge Planning Overview, Process, and Checklist. https://www.ahrq.gov/sites/default/files/wysiwyg/professionals/systems/hospital/engagingfamilies/strategy4/Strat4_Tool_1_IDEAL_chklist_508.pdf. Accessed December 5, 2020.



What should be included in the discharge plan?

A basic discharge plan should include:³

- **Evaluation** of your current health status and ongoing issues
 - Ask for a written list of all tubes/lines/drains so you know what the different bumps and bruises and holes are from and what to look for regarding healing/infection risk
- **Planning** for your return home
- **Review** of medications and equipment you may need
- **Determination** of whether you need training or other support
- **Referrals** to home care agencies or other support organizations
- **Arrangements** for follow-up appointments or tests

If you are a caregiver, remember that the discharge team will not be familiar with all aspects of the patient's situation. You may be able to help by providing information about the patient's medical history and home environment. Sharing this information with the discharge team can help them make a safe and effective discharge plan.

This section provides basic information about discharge planning. For other tools and conversation starters, visit:

- **Agency for Healthcare Research and Quality:** [IDEAL “Be Prepared to Go Home Booklet”](http://michmed.org/O5J70) (<http://michmed.org/O5J70>)
- **Medicare:** [Your Discharge Planning Checklist](http://michmed.org/Ylw75): For patients and their caregivers preparing to leave a hospital, nursing home, or other care setting (<http://michmed.org/Ylw75>)

What if I feel it's too soon to leave the hospital?³

If you feel it's too soon to leave the hospital, you have the right to appeal the decision. The hospital must let you know how to get your case reviewed. Here are some steps you can take:

- Talk to your doctor and other discharge team members about your worries
- Ask to talk to a Patient Advocate
- Contact Medicare, Medicaid, or your insurance company

³ Adapted from: Family Caregiver Alliance. Hospital Discharge Planning: A Guide for Families and Caregivers. <https://www.caregiver.org/hospital-discharge-planning-guide-families-and-caregivers>. Published 2009. Accessed December 5, 2020.



Preparing for discharge: safety

How do I get the patient home from the hospital?

The patient may go home by themselves, with you, or with another family member, friend, or transportation resource or service. If the patient needs help getting home, please let your discharge team know.

If the patient is still contagious and will be driving or riding in a personal vehicle, take appropriate precautions:

- Wash or sanitize your hands before and after entering and exiting the vehicle
- Bring cleaning supplies (such as wipes and hand sanitizer) to wipe down commonly touched areas in the vehicle
- Go directly home (do not go on errands along the way)
- Wear a mask (note: masks should not be worn by those having difficulty breathing, children under 2 years old, or those unable to take off their own mask)
- Sit as far away from other people in the vehicle as possible
- Open the car windows and turn your fan on to outside air to increase air flow
- Clean and disinfect surfaces you have touched

How do I prepare the patient's home?

The patient's physical ability when they leave the hospital will be different than when they were admitted to the hospital. They may need time and help to regain their strength and ability to do daily activities. Additionally, the patient may need to isolate once they are home. Before discharge day, ask the care team whether or not the patient will need to isolate and ask the patient's physical and occupational therapists for advice on preparing the home.

You may need to:

- **Clear the path from the bed to the bathroom.** Check that doorways and hallways are completely clear. You may need to move furniture around to make this possible. You may also need to temporarily put a bed on the first floor.
- **Reduce trip hazards.** Remove clutter from the floor and securely fasten or remove rugs.
- **Increase lighting.** Increase lighting in areas the patient will frequently use, such as entrances or staircases.
- **Install grab bars.** Grab bars are especially important in the bathroom, especially around the toilet and the shower.
- **Check any steps or stairs.** Add rails or bannisters next to all steps that don't have them. You may need to add a ramp or slope up to the front door.

Talk to the patient's physical and occupational therapists, and visit HealthinAging.org for [instructions on setting up a room and assisting a frail person](https://michmed.org/axgG1) in bed and in the bathroom (<http://michmed.org/axgG1>).



Preparing for discharge: safety

How do I keep myself and others safe once the patient is home?

Depending on the discharge team's instructions, the patient may be asked to isolate. For a guide to quarantining and isolating, visit the workbook section "[Navigating COVID-19 Exposure, Testing, and Quarantine](http://michmed.org/ng2WI)": (<http://michmed.org/ng2WI>).

Additionally, many people who have had COVID-19 have questions about whether or not they can get sick from COVID-19 again (**reinfection**). Currently, there is not enough information available about COVID-19 reinfection.⁵ Unless you have been told to isolate, the best way to prevent infection or reinfection is to take steps to protect yourself:

- Wear a mask in public places
- Stay at least 6 feet away from other people
- Wash your hands
- Avoid crowds and confined spaces

For the latest [information about COVID-19 reinfection](https://www.cdc.gov/coronavirus/2019-ncov/your-health/reinfection.html), visit:

<https://www.cdc.gov/coronavirus/2019-ncov/your-health/reinfection.html>

⁵ Centers for Disease Control and Prevention. Reinfection with COVID-19. <https://www.cdc.gov/coronavirus/2019-ncov/your-health/reinfection.html>. Published 2020. Accessed December 9, 2020.



Preparing for discharge: equipment and supplies

What medical equipment and supplies do I need?

After a COVID-19-related hospital stay, the patient may need medical equipment at home that they do not already use or have. You may also need certain supplies for their care, such as bandages for bed sores, masks, and gloves. Your discharge team can help you understand what medical equipment and supplies you will need, as well as how to get these items.

Equipment prescribed by your doctor is called **durable medical equipment (DME)**. Examples of DME include wheelchairs, oxygen, and devices for exercising breathing. Equipment must meet these criteria in order to be considered DME:⁶

- Can withstand repeated use (**durable**)
- Used for a medical reason
- Not usually useful to someone who isn't sick or injured
- Used in your home
- Generally has an expected lifetime of at least 3 years

Before discharge day, ask your discharge team these questions about equipment and supplies:

- What durable medical equipment will the patient need at home?
- What equipment will help the patient move around more easily?
- What supplies will I need in order to care for the patient?
- What equipment and supplies will the patient come home with?
- How do I get the equipment and supplies the patient does not come home with?
- Can you show or tell me how to use the equipment and supplies properly?
- What happens if there is an issue with the equipment I receive?
- How do I return equipment once I am done using it?

⁶ U.S. Centers for Medicare & Medicaid Services. Durable Medical Equipment (DME) Coverage. <https://www.medicare.gov/coverage/durable-medical-equipment-dme-coverage>. Accessed December 9, 2020.



Preparing for discharge: equipment and supplies

How do I get the equipment and supplies I need?

To find out how much your equipment will cost, talk to your doctor and your insurance company. The specific amount you'll owe may depend on several things:⁶

- The type of insurance you have
- Where you get your equipment and supplies

Many times, orders will be placed for the DME that you need. A social worker can also help you identify places to get your DME and resources to help with the cost. Ask if there will be a cost to you. You can contact that company directly or contact your discharge team to assist.

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
- Costs for medications, supplies and equipment
- Lodging assistance
- Meal Assistance and Food Insecurity
- Transportation assistance
- Durable medical equipment/supplies
- Parking



Guest Assistance Program:

Phone: 800-888-9825

Hours: Monday-Friday 9 a.m.-5 p.m.,

Visit: michmed.org/q4kRz (scan the QR code)

⁶ U.S. Centers for Medicare & Medicaid Services. Durable Medical Equipment (DME) Coverage. <https://www.medicare.gov/coverage/durable-medical-equipment-dme-coverage>. Accessed December 9, 2020.



Preparing for discharge: medications

How do I manage medications?

It is likely that the patient will be discharged home with a list of new or changed medications. Ahead of time, decide who will pick up their medications, what pharmacy you will use, and when you will pick them up. Making a plan will help you avoid missing a dose of important medications or taking the dose late.

Before or on discharge day, ask your discharge team these questions about medications:

- What medication(s) should I be taking at home?
- Should I take the medications I was taking before my hospital stay?
- What is this medicine for? How and when should I take it?
- What are potential side effects? How do I look for them?
- Is this medicine safe to take with my other medications and supplements?
- Is there a way to minimize the number of medications or supplements?
- What alternative therapies are available?

For questions about your medications, call your healthcare provider.

How can I keep track of medications?

Patients who leave a hospital or care facility after a lengthy stay often have changes to their medications. Depending on their health conditions, it is not unusual for patients to take 15 medications or more after an extended hospital stay. During the first few weeks home, it is common for a doctor, nurse, or pharmacist to change which medications the patient takes, how often they take them, and how much they take.

As a caregiver, you can help the patient keep track of these medication changes:

- Use a journal to keep track of medications. See example on the next page.
- Use a pill organizer to make it easier to prepare medications in advance.
- Use a pill splitter to cut larger pills into smaller dosages (amounts).
- Try a free mobile app, such as [Medisafe \(www.medisafeapp.com\)](http://www.medisafeapp.com)*, to remind both you and the patient when it's time to take their medications.

* Note: Michigan Medicine has no connection to Medisafe and has not reviewed its services. This is intended as an example for informational purposes only, not an endorsement of Medisafe services.



Write down your current medications, vitamins, and supplements

Medication Name	Reason Taken	Dosage	Frequency
-----------------	--------------	--------	-----------

_____	_____	_____	_____
_____	_____	_____	_____
_____	_____	_____	_____
_____	_____	_____	_____
_____	_____	_____	_____
_____	_____	_____	_____
_____	_____	_____	_____
_____	_____	_____	_____
_____	_____	_____	_____
_____	_____	_____	_____
_____	_____	_____	_____
_____	_____	_____	_____
_____	_____	_____	_____
_____	_____	_____	_____
_____	_____	_____	_____
_____	_____	_____	_____
_____	_____	_____	_____
_____	_____	_____	_____
_____	_____	_____	_____
_____	_____	_____	_____



Preparing for discharge: care coordination

Who should I tell that the patient is home?

When the patient is coming home, you should make sure you notify their primary care doctor and any other specialists. These people can help you with the transition of care.

What care services do I need at home?

After discharge, the responsibility of coordinating the patient's care often transfers from the hospital to you. At this point, you may first feel the weight of being a caregiver. Talk to your discharge team about what home care services are available to help you. For some of these services, the patient must be referred by a doctor.

At Michigan Medicine, home care services include:

- **HomeMed:** A home infusion provider and licensed pharmacy that provides a range of services in the comfort of your home. For more information about HomeMed, visit: <https://homecare.med.umich.edu/HomeMed>
- **HouseCalls:** A team that provides care to patients that are homebound or have limited mobility. For more information about HouseCalls, visit: <https://homecare.med.umich.edu/HouseCalls>
- **Michigan Visiting Nurses (MVN):** A home care provider of skilled nursing and rehabilitation services to patients. For more information about Michigan Visiting Nurses, visit: <https://homecare.med.umich.edu/Michigan-Visiting-Nurses>
- **Patient Monitoring @ Home:** A team that works closely with your doctor to ensure your plan of care helps you to remain healthy and happy in the comfort of your home. For more information about Patient Monitoring @ Home, visit: <https://homecare.med.umich.edu/PatientMonitoringAtHome>
- **Wheelchair Seating Service:** A leading provider of custom mobility products in the area. For more information about Wheelchair Seating Service, visit: <https://homecare.med.umich.edu/Wheelchair-Seating-Service>



Preparing for discharge: care coordination

U-M PULSE Clinic

Services for COVID-19 patients after leaving the intensive care unit (ICU)

The University of Michigan Post-ICU Longitudinal Survivor Experience (U-M PULSE) Clinic works with post-ICU patients and their caregivers, including COVID-19 patients, to help streamline all of the services you might need after leaving the ICU.

The U-M PULSE team works to:

- Identify the changes that are most disruptive to the patient's life.
- Identify the patient's strengths and supports.
- Develop a comprehensive care plan that addresses the patient's goals.
- Assess the impact of the patient's illness on you as a caregiver.
- Help you access additional services and support.

For [more information](http://med.umich.edu/cvc/pdf/UM-Pulse.pdf) visit <http://med.umich.edu/cvc/pdf/UM-Pulse.pdf> or call 1-888-287-1084 and ask for Dr. Jakob McSparron.



What can I expect during the care transition?

When the patient first comes home, coordinating their care may seem like a full-time job. You may be balancing new caregiving responsibilities on top of employment, childcare, and self-care. You may also be wondering how to help the patient and at the same time encourage, motivate, and enable them to care for themselves. During this time, you may feel a wide range of emotions. You may feel:

- **Euphoric** that the patient survived
- **Anxious** or fearful that the patient may get sick again
- **Worried** over the patient's well being and the need to constantly check that they are okay
- **Unsettled** due to disruption of normal schedules and routines
- **Relieved** when changes to medications reduces symptoms
- **Overwhelmed** from coordinating appointments, medications, and other care
- **Concerned** about how to manage dietary needs that may have changed

Strategies that can help:⁷

- **Acknowledge that the patient has the right to make decisions about their life.** Respect that right unless your loved one is no longer capable of making decisions or could put themselves or others in danger through their behavior.
- **Whenever possible, offer choices.** Making choices is a basic freedom and enables us to express ourselves. Provide choices for your loved one when possible.
- **Do only those things your loved one can't do.** If your loved one is still capable of performing certain activities, such as paying bills or cooking meals, encourage them to do so. Helping your loved one feel some independence will make them feel better about being in a care-receiving situation.
- **Take care of yourself so you can take care of others.** Caregivers often exhaust themselves due to the caregiving responsibilities on top of normal daily routines. Take time to sleep and to do things you enjoy so you can be there for the long haul.
- **Don't be afraid to ask for help.** There can be deep emotional currents when a loved one becomes ill. Relatives and friends can do a lot to ease your caregiving burden. You can also ask a faith leader, social worker, or therapist for support processing your thoughts and feelings.

⁷Adapted from: Leukemia & Lymphoma Society. Caregiver Workbook Chapter 1: Introduction to Caregiving. Rye Brook; 2019. https://www.lls.org/sites/default/files/National/USA/Pdf/Publications/Caregiver_Workbook_Ch1_Introduction_to_Caregiving_2019.pdf. Accessed December 9, 2020.



Preparing for discharge: care coordination

How can I keep track of upcoming appointments?⁸

Patients who leave a hospital or care facility after an extended stay often have many follow-up appointments with healthcare providers. These healthcare providers may be specialists the patient has never talked to before.

As a caregiver, you can help the patient keep track of their new healthcare providers and upcoming appointments using a paper calendar or calendar app. Below is a blank calendar template and a logbook to write down healthcare provider contact information.

How do I access online health records?

If you are a patient

You can contact your care team and view your health records through the [MyUofM-Health Patient Portal](http://michmed.org/xoWYR) (<http://michmed.org/xoWYR>). Select “For myself only” to make an account for yourself, or select “Adult granting access to another adult” to give your caregiver access.

If you are a caregiver

With the patient’s permission, you can also contact the care team and view the patient’s health records. See the contact information below for help.



For questions or information about the MyUofMHealth Patient Portal:

Email: HIM-PatientPortal@med.umich.edu,

Phone: 734-615-0872 (Monday-Friday 7:00 am - 7:00 pm, Saturday and Sunday 8:00 am - 5:00 pm), or

Visit: <http://michmed.org/xoWYR> (or scan the QR code)



Preparing for discharge: care coordination

Monthly Appointment Calendar⁸

Month: _____

Sunday	Monday	Tuesday	Wednesday	Thursday	Friday	Saturday

⁸ Leukemia & Lymphoma Society. Caregiver Worksheet 6a: Appointment Calendar, By Month. Rye Brook; 2019.
https://www.lls.org/sites/default/files/National/USA/Pdf/Publications/Caregiver_Worksheet_6a_AppointmentsMonth_2019.pdf.
Accessed December 7, 2020.



Healthcare team contact information⁹

Type of healthcare provider:
Name:
Phone:
Email:
Address:
Notes:

Type of healthcare provider:
Name:
Phone:
Email:
Address:
Notes:

Type of healthcare provider:
Name:
Phone:
Email:
Address:
Notes:



Healthcare team contact information⁹

Type of healthcare provider:
Name:
Phone:
Email:
Address:
Notes:

Type of healthcare provider:
Name:
Phone:
Email:
Address:
Notes:

⁹ Leukemia & Lymphoma Society. Caregiver Worksheet 5: Healthcare Team Contact List. Rye Brook; 2019. https://www.lls.org/sites/default/files/National/USA/Pdf/Publications/Caregiver_Worksheet_5_HCPcontacts_2019.pdf. Accessed December 7, 2020.



Share feedback on this document

<http://michmed.org/pxwgb>

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.

Support for the creation of these materials provided by: the University of Michigan Institute for Social Research, Michigan Medicine, and the Procter & Gamble Company.

Authorship: The BioSocial Methods Collaborative and HEART Research Project Team
(<https://heart.isr.umich.edu/meet-our-research-team/>)

How to Cite:

The BioSocial Methods Collaborative and HEART Research Project Team. Preparing to Go Home After a COVID-19 Hospital. In: *COVID-19 Patient & Caregiver Collaborative Care Workbook*. Ann Arbor: Michigan Medicine; 2020:1-20. doi:[10.3998/2027.42/163715](https://doi.org/10.3998/2027.42/163715)

Patient Education by [Michigan Medicine](#) is licensed under a [Creative Commons AttributionNonCommercial-ShareAlike 4.0 International Public License](#).

Last Revised 12/2020, Version 1.0.0





Recovering at home after a COVID-19 hospital stay

This section* will answer the following questions:

- [What can I expect while recovering? \(page 93\)](#)
- [What are the common issues following a hospital stay? \(page 94\)](#)
- [What is post-COVID syndrome? \(page 95\)](#)
- [What are the long-lasting symptoms of COVID-19? \(page 99\)](#)
- [How can I improve symptoms and strength at home? \(page 100\)](#)
- [How do I find the motivation to reach my goals? \(page 102\)](#)
- [What are some feelings and emotions I might have? \(page 106\)](#)
- [Who can I turn to for support during recovery? \(page 111\)](#)
- [Where can I find mental health resources? \(page 116\)](#)

*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:¹

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:²

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:¹

- 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

¹Adapted 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.

²Adapted 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?³

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.

³Adapted 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.



What is post-COVID syndrome?⁴

In addition to these common health issues, you may have ongoing symptoms after your COVID-19-related hospital stay. These 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 you 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

⁴Adapted 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?⁵

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

⁵Adapted 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?⁶

Mental health symptoms:

- **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 physician 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

⁶Adapted 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?⁶

“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”



What are the long-lasting symptoms of COVID-19?⁷

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>

⁷Adapted 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?^{8,9}

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

⁸Adapted 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.

⁹Adapted 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?¹⁰

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?

¹⁰Adapted 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 and/or looks 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.

Continue reading for information about finding motivation and managing expectations





My recovery planning guide

My goals for recovery are:

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

People who can help me reach my goals:

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	Generally Daily Schedule (Example)
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:¹¹

- **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.

¹¹Adapted 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...

“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

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.

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:¹²

- **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.
- **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.

¹²Adapted 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):¹³

- **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 precautionary so that no one in your family has to experience COVID-19 firsthand again.

¹³Adapted 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)

Patients of Michigan Medicine may also receive help through the Guest Assistance Program. The program offers connections to several types of resources (all based on eligibility) for social needs related to medical care at Michigan Medicine:

- Liaison 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. The Peer Mentor Program will offer:

- Help connecting COVID-19 patients and caregivers to resources
- Support for COVID-19 patients and caregivers across journey
- An outlet for socialization and friendship
- A chance to 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.

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.

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://www.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: <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](#) (available 24/7):**
 - Call: 1-800-273-8255
 - Text: TALK to 741741
 - Visit: 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

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.

Support for the creation of these materials provided by: the University of Michigan Institute for Social Research, Michigan Medicine, and the Procter & Gamble Company.

Authorship: The BioSocial Methods Collaborative and HEART Research Project Team
(<https://heart.isr.umich.edu/meet-our-research-team/>)

How to Cite:

BioSocial Methods Collaborative and HEART Research Project Team. Recovering at home after a COVID-19 hospital stay. In: *COVID-19 Patient & Caregiver Collaborative Care Workbook*. Ann Arbor: Michigan Medicine; 2020: 1-29. doi:[10.3998/2027.42/163715](https://doi.org/10.3998/2027.42/163715)

Patient Education by [Michigan Medicine](#) is licensed under a [Creative Commons AttributionNonCommercial-ShareAlike 4.0 International Public License](#).

Last Revised 12/2020, Version 1.0.0





Appendix A: Building your support network

This *appendix will answer the following questions:

- [How can I connect with other patients and caregivers? \(page 121\)](#)
- [Where can I find caregiving support? \(page 123\)](#)
- [Where can I find COVID-19 support? \(page 125\)](#)

*Access the other sections of [this workbook](#) by visiting: <http://michmed.org/ng2W1>



Building your support network

How can I connect with other patients and caregivers?

This document is a curated list of support resources. While not directly endorsed by the University of Michigan or Michigan Medicine, these support groups have become quite popular over the past few months as a means of sharing information about common experiences. We hope you find these resources helpful as you navigate your journey together.

In this document you will find both caregiving and COVID-19 support groups. 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.

COVID-19 Hotlines

This document is not meant as a replacement for emergency or medical care. **For any emergency, dial 911 immediately.**

State of Michigan and National Phone Lines: The Michigan Department of Health and Human Services (MDHHS) has set up a hotline to answer questions regarding COVID-19 illness, Executive Orders, or related issues.

- Call: **1-888-535-6136** / 8 am – 5 pm, Monday through Friday
- Email: COVID19@michigan.gov / 8 am – 5 pm, Monday through Friday (closed on state holidays)

Michigan Stay Well Counseling via the COVID-19 Hotline: Get help if you are experiencing emotional distress in the context of the COVID-19 crisis.

- Call: **1-888-535-6136** and press "8" to talk to a Michigan Stay Well counselor
- Available 24/7 - confidential and free

For additional information about the State of Michigan Stay Well program, visit: <http://michmed.org/R1Ywo>



Building your support network

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.

The Peer Mentor Program will offer:

- Help connecting COVID-19 patients and caregivers to resources
- Support for COVID-19 patients and caregivers across journey
- An outlet for socialization and friendship
- A chance to 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>) or email UMHS-PFCC@umich.edu.

Mutual aid societies

Mutual aid societies are organizations formed to benefit its members and their community. Those in these societies have an equal opportunity to give and receive benefits depending on their need. Benefits may include resources, services, and social activities.

USA COVID-19 Mutual Aid: Covid Mutual Aid USA is a collective of volunteers who are devoted to equity, advocacy, inclusivity, and mobilization. You can find out more here at <https://www.usacovidmutualaid.org>

Mutual Aid Hub: A place you can find Mutual Aid Networks and other community self-support projects near you. Reach out to get involved, offer resources, or submit need requests at <https://www.mutualaidhub.org>

Washtenaw County Mutual Aid + Resources: A mutual aid group that is based in Washtenaw county. Learn more and join at <https://www.facebook.com/groups/2424471741198383>



Where can I find caregiving support?

Support groups

Note: Some of the COVID-19 support groups are private Facebook groups and have not been reviewed by our team as they can only be accessed through a personal Facebook account.

Caregivers Connect: A group created to give a voice to caregivers of parents, spouses, or other loved ones. Members share their stories and experiences with each other to provide support and inspiration. Join the private Facebook group at <https://www.facebook.com/groups/CaregiversConnect/>

The Caregiver Space Community: A private space for those caring for someone elderly, ill or disabled within (<https://thecaregiverspace.org/>), a nonprofit for caregivers, by caregivers. View or join the public Facebook group at <https://www.facebook.com/groups/216161412165764>

Caregivers Assist Support Group: An online community of dedicated caregivers with a purpose of sharing best caregiving practices and how to live a healthy, prosperous life as a caregiver. View or join the public Facebook group at <https://www.facebook.com/groups/CaregiversAssistSupportGroup>

Caring for the Caregiver Support Group: A support group intended to be a private setting for caregivers to express their thoughts and feelings. View or join the closed Facebook group at <https://www.facebook.com/groups/1491221791165989>

Well Spouse Association: A support group for spousal caregivers where members can find support, sharing, and a social community through face-to-face or telephone support groups and online support forums. Find more information at <https://wellspouse.org/>

Caregiver-online (from FCA): An email based support and discussion group. Subscribing adds your email address to the group list and when you send messages they get forwarded to the entire group. Learn more and subscribe at <https://www.caregiver.org/caregiver-online-faq>



Where can I find caregiving support?

National caregiving resources

AARP Family Caregiving: A family caregiving page with resources and information about caring at home, stories, communities and more. Find more information, create an account, or join the AARP for membership benefits at <https://www.aarp.org/caregiving/>

Caregiver Action Network: An organization where you can find support and get information about caring for someone during the COVID-19 pandemic. Find more information at <https://caregiveraction.org/>

Family Caregiver Alliance: A resource with helpful information for caregivers across the nation who care for adult friends and family with chronic, disabling health conditions. You can find educational tools and connect to resources in your area at <https://www.caregiver.org/>

Smart Patients: Caregivers Community: An online community for patients and caregivers to ask a question and support others. Find more information <https://www.smartpatients.com/partners/fca>

National Alliance for Caregiving: An organization that conducts research, does policy analysis, develops national best-practice programs, and works to increase public awareness of family caregiving issues. Find more information at <https://www.caregiving.org/>

Caregiver Support and Resources: A website providing social outlets, validation, and a confidential support community along with other, more formal resources and organizations for caregivers. Find these resources at <https://www.caring.com/caregivers/caregiver-support/>

Local caregiving resources

AARP - Local Resources: Resources targeted to the Ann Arbor area as well as the State of Michigan as a whole. You can find information about in-home care, medical services, housing options, and community services at <https://www.aarp.org/caregiving/local/>

Aging & Adult Services Agency - MDHHS: Information on a variety of free or low-cost programs and services that could help with caregiving from Michigan's 16 Area Agencies on Aging (AAA). For more information, visit: <http://michmed.org/Xr6ba>

Help for the Helper - Caregiving Resources: University of Michigan specific resources available for caregivers ranging from eldercare to mental health counseling and consultation services. Learn more at <http://michmed.org/axgkX>



Where can I find COVID-19 support?

Support groups

Note: Some of the COVID-19 support groups are private Facebook groups and have not been reviewed by our team as they can only be accessed through a personal Facebook account.

Survivor Corps: A not-for-profit, grassroots movement educating and mobilizing COVID-19 survivors and connecting them with the medical, scientific, and academic research community. Find information about their mission, ongoing research opportunities, and news at www.SurvivorCorps.com. View or join the public Facebook group at <https://www.facebook.com/groups/COVID19survivorcorps/>.

Body Politic COVID-19 Support Group: A support group on Slack consisting of people from all over the world who have tested positive, are experiencing symptoms, or are recovering from COVID-19. Find out more about the group at <https://www.wearebodypolitic.com/covid19>.

COVID-19 Recovery Awareness: A collection of featured articles and research projects that offer support and educational opportunities for patients to be able to advocate for themselves, especially as people experience unexpectedly long recoveries. Explore these resources at <https://www.c19recoveryawareness.com/>.

Long COVID: A website and private Facebook group with information and support for those suffering from prolonged, debilitating and sometimes serious symptoms following infection with suspected or confirmed Covid-19. Find stories and resources at <https://www.longcovid.org/> or join the private Facebook group at <https://www.facebook.com/groups/longcovid/>.

COVID-19 Recovery Collective: A UK based website dedicated to helping others on their recovery journey by sharing stories and resources. Read stories about other survivors' recovery experiences and explore their resources at <https://covid19-recovery.org/>.

Covid-19 Recovered - Survivors: An international and private Facebook group founded for people to connect around COVID-19, specifically for sharing stories and useful information. Join the private Facebook group at <https://www.facebook.com/groups/supportgroupcovid19/>.

Covid-19 Support Group: A private Facebook group providing a place for people to share their stories related to COVID-19. Join the private Facebook group at <https://www.facebook.com/groups/517530815866036>

Covid-19 Survivors: A Facebook group to connect people living through a COVID-19 diagnosis, with friends and family living through it, or for people who want first hand knowledge of what it is like. Find this group at <https://www.facebook.com/groups/1518619431626293>



Where can I find COVID-19 support?

Reddit groups

The following resources are on a social news platform called Reddit. A “subreddit” is a special-topic community hosted on Reddit ([reddit.com](https://www.reddit.com)).

COVID19 positive Subreddit: A large (100,000+ member), moderated online support group for people who test positive for COVID-19 to share stories, experiences, answer questions and vent. Find this group at <https://www.reddit.com/r/COVID19positive/>

COVID19 Testimonials Subreddit: A small (7,000+ member), moderated online community for COVID-19 patients to share their experience, symptoms and best practices to help the general population prepare for COVID-19. This group includes both COVID-19 survivors and members of the community. Find this group at https://www.reddit.com/r/COVID19_Testimonials/

COVID19 Survivors Subreddit: A small (1,000+ member), moderated online community for COVID-19 survivors to share experiences if they have tested positive for COVID-19, are on the road to recovery, or are back to full health. Find this group at <https://www.reddit.com/r/CoronavirusSurvivors/>



Share feedback on this document

<http://michmed.org/2G3ax>

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.

Support for the creation of these materials provided by: the University of Michigan Institute for Social Research, Michigan Medicine, and the Procter & Gamble Company.

Authorship: The BioSocial Methods Collaborative and HEART Research Project Team
(<https://heart.isr.umich.edu/meet-our-research-team/>)

How to Cite:

The BioSocial Methods Collaborative and HEART Research Project Team. Appendix A: Building Your Support Network In: *COVID-19 Patient & Caregiver Collaborative Care Workbook*. Ann Arbor: Michigan Medicine; 2020: 1-10. doi:[10.3998/2027.42/163715](https://doi.org/10.3998/2027.42/163715)

Patient Education by [Michigan Medicine](#) is licensed under a [Creative Commons AttributionNonCommercial-ShareAlike 4.0 International Public License](#).

Last Revised 12/2020, Version 1.0.0





COVID-19 Peer Mentors

The Michigan Medicine Office of Patient Experience will be launching a Peer Mentor program for COVID-19 patients and caregivers. Peer support is rooted in the belief that no one needs to travel their health care journey alone.

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.



MICHIGAN MEDICINE
UNIVERSITY OF MICHIGAN



University Hospital
1500 E Medical Center Dr
Ann Arbor, MI 48109
Scan QR code for
more information or visit:
med.umich.edu