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COVID-19 Patient & Caregiver Collaborative Care Workbook

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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:

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

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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.

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

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.

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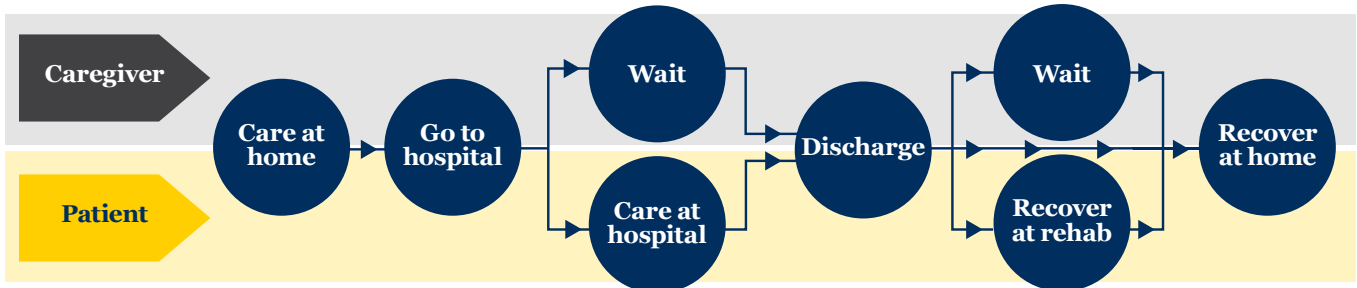
Above: A diagram of a common "journey" that patients and caregivers might experience before, during, and after a COVID-19-related hospital stay.

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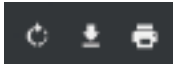
3. Click on the middle icon (the underlined arrow). This will download the document as a PDF onto your computer.
4. Open your file explorer, then navigate to your "Downloads" folder:

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).

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 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) or email UMHS-PFCC@umich.edu.

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