

# Appendix A: Building your support network

# This \*appendix will answer the following questions:

- How can I connect with other patients and caregivers? (page 3)
- Where can I find caregiving support? (page 5)
- Where can I find COVID-19 support? (page 7)

\*Access the other sections of this workbook by visiting: http://michmed.org/ng2Wl



# How to use this section

This workbook is for patients with COVID-19 and for anyone assisting in their care. 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.

# 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. Icons will appear in the top right corner. Click on the middle icon (the underlined arrow). This will download the document as a PDF onto your computer.
- **3.** Open your file explorer, then navigate to your "Downloads" folder. Double-click on the document name. This will open the PDF in a PDF viewer, such as Adobe Acrobat.
- **4.** 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.

# Increasing text size

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

- **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.

# 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: <a href="https://www.cdc.gov/">https://www.cdc.gov/</a>.

## Using QR codes

This workbook contains **QR codes**: a type of "square barcode" that takes you to an online resource. 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, open your camera app on your smartphone, hold your smartphone camera over the QR code, and click on the link that should appear on your screen.

## Interactive 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.



# 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: <a href="mailto:COVID19@michigan.gov">COVID19@michigan.gov</a> / 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 (<a href="http://myumi.ch/E3wAp">http://myumi.ch/E3wAp</a>) or email <a href="http://myumi.ch/E3wAp"><u>UMHS-PFCC@umich.edu</u></a>.

#### 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.

<u>USA COVID-19 Mutual Aid:</u> 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 <a href="https://www.usacovidmutualaid.org">https://www.usacovidmutualaid.org</a>

**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 <a href="https://www.mutualaidhub.org">https://www.mutualaidhub.org</a>

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



# 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.

<u>Caregivers Connect:</u> 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 <a href="https://www.facebook.com/groups/CaregiversConnect/">https://www.facebook.com/groups/CaregiversConnect/</a>

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

<u>Caregivers Assist Support Group:</u> 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 <a href="https://www.facebook.com/groups/CaregiversAssistSupportGroup">https://www.facebook.com/groups/CaregiversAssistSupportGroup</a>

<u>Caring for the Caregiver Support Group:</u> 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 <a href="https://www.facebook.com/groups/1491221791165989">https://www.facebook.com/groups/1491221791165989</a>

**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 <a href="https://wellspouse.org/">https://wellspouse.org/</a>

<u>Caregiver-online (from FCA)</u>: 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 <a href="https://www.caregiver.org/caregiver-online-faq">https://www.caregiver.org/caregiver-online-faq</a>



# 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 <a href="https://www.aarp.org/caregiving/">https://www.aarp.org/caregiving/</a>

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

**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 <a href="https://www.caregiver.org/">https://www.caregiver.org/</a>

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

**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 <a href="https://www.caregiving.org/">https://www.caregiving.org/</a>

<u>Caregiver Support and Resources:</u> 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

<u>AARP - Local Resources:</u> 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 <a href="https://www.aarp.org/caregiving/local/">https://www.aarp.org/caregiving/local/</a>

**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: <a href="http://michmed.org/Xr6ba">http://michmed.org/Xr6ba</a>

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.

<u>Survivor Corps:</u> 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 <a href="https://www.facebook.com/groups/coviD19survivorcorps/">www.facebook.com/groups/coviD19survivorcorps/</a>.

**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 <a href="https://www.wearebodypolitic.com/covid19">https://www.wearebodypolitic.com/covid19</a>.

**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 <a href="https://www.c19recoveryawareness.com/">https://www.c19recoveryawareness.com/</a>.

**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 <a href="https://www.longcovid.org/">https://www.longcovid.org/</a> or join the private Facebook group at <a href="https://www.facebook.com/groups/longcovid/">https://www.facebook.com/groups/longcovid/</a>.

**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 <a href="https://covid19-recovery.org/">https://covid19-recovery.org/</a>.

<u>Covid-19 Recovered - Survivors:</u> 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 <a href="https://www.facebook.com/groups/supportgroupcovid19/">https://www.facebook.com/groups/supportgroupcovid19/</a>.

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 <a href="https://www.facebook.com/groups/517530815866036">https://www.facebook.com/groups/517530815866036</a>

<u>Covid-19 Survivors:</u> 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 <a href="https://www.facebook.com/groups/1518619431626293">https://www.facebook.com/groups/1518619431626293</a>



# 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 (<u>reddit.com</u>).

**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 <a href="https://www.reddit.com/r/COVID19positive/">https://www.reddit.com/r/COVID19positive/</a>

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 <a href="https://www.reddit.com/r/COVID19\_Testimonials/">https://www.reddit.com/r/COVID19\_Testimonials/</a>

**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 <a href="https://www.reddit.com/r/CoronavirusSurvivors/">https://www.reddit.com/r/CoronavirusSurvivors/</a>

Notes	



#### 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

Patient Education by <u>Michigan Medicine</u> is licensed under a <u>Creative Commons AttributionNonCommercial-ShareAlike 4.0 International Public License</u>. Last Revised 12/2020, Version 1.0.0





