

## **Ma'avar on COVID-19**

The Ma'avar Committee is tasked with helping you with end of life conversations and planning, as well as, other life transitions. We started thinking about how we could help you in your planning for the worst possible eventualities if you or your loved ones become infected with COVID-19.

The Pandemic has changed how we think, eat, exercise, and time we spend alone. It has changed how we work and interact with others. Fortunately, most people have become their better selves through this challenge. People are reaching out to friends, family and loved ones to maintain meaningful lives and finding new ways to stay in contact.

We offer you 3 articles in the COVID 19 section of the Havurah Website to help you to form ideas about what might happen during a COVID 19 illness. When we started these articles, so much more was unknown. As we have weathered this pandemic, we have learned more about it and how it effects people. We are lucky to live in Oregon where the number of infections and deaths have been low, even based on population size. We have seen rises in infection rates since restrictions were lifted.

The hardest thing to master in times like these is the unknown. One way to combat this is to take control of what you can control. Making a plan for how you would like to be treated if you become infected with COVID 19 relieves some of the anxiety. You may already have an advanced directive but feel that risks involved with becoming infected with COVID 19 are different enough that you want specific instructions for this possibility. If you do not have an advance directive, we urge you to write one. I have always told my patients that writing the advance directive is important but talking to your family or loved ones is a critical step in this planning.

The 3 articles are:

1. Looking at the Future through COVID 19 Pandemic
2. Preparing your Advance Directive and POLST
3. What is happening when you get sick with COVID 19?

I encourage you all to read article 1. Article 2 is useful if you need more information about filling out our Advance Directive and wonder if a POLST is right for you. Article 3 was prepared to give very in-depth details of what being sick with COVID 19 means for the small percentage of people who end up in ICU and on respirators. It can be upsetting to some people.

If you have questions about these articles and want to speak to a member of our team, please contact the Havurah office to be directed to us.

## Looking at the Future through COVID 19 Pandemic

We are faced with the daunting task of navigating a new reality. This is stressful and causes worry, sadness, and fear, which can look different for each of us. You may be thinking:

- I'm worried about COVID 19 infecting me and my family and friends?
- I'm worried about my family and friends who are infected with COVID 19?
- I'm sad about all the changes in our world and my life. My family and friends are not here to support me.
- I've lost so much. (jobs, economic stability, usual freedoms etc.)
- If I contract the virus how will I know what is the best treatment for me? Is going to the hospital and possibly going on a ventilator the best treatment for me? For my loved ones?
- I'm scared that the right treatment will not be available for me or my loved ones?
- I'm scared that I will die if I become infected. I am over 65. I have hypertension (asthma or COPD, diabetes, heart disease, kidney disease, liver disease, severe obesity)
- I can't properly say goodbye to people I know who have died in the past month of COVID 19 or other causes.
- If I get the virus, become very ill and on a ventilator, I may not be able to say goodbye to my family. How can I share with my family and prepare now?
- I am now faced with death and the idea that this viral infection could happen to anyone. I still have more living to be done.

"On the upside (if there's one to find in all this), feeling stressed right now is a sign that your brain is working properly. Stress, like a pandemic, puts our brains into "fight or flight" mode, disrupting attention, memory, breathing and sleep. But experts say it's all very normal."

Inger Burnett-Zeigler, an associate professor of psychiatry at Northwestern University says, "Chronic stress can also cause fatigue, problems concentrating, irritability and changes in sleep and appetite.... There are also significant psychological benefits to reframing the way you think about the things you're already doing. **A lot of the pieces of this are out of our control, and that's very unsettling, but there are some factors that are in our control:** staying in, wearing a mask, social distancing, taking care of the body, taking care of our minds." **Recasting them as conscious choices you're making to protect public health can help restore a sense of order to the chaos you may be feeling inside.** (-Corinne Purtill <https://www.nytimes.com/2020/04/09/us/quarantine-mental-health-gender.html>)

People often think about preparing advanced directives or living wills when they have experienced a personal loss like the death of a family member or receive a life changing diagnosis. This is a good time to think about this for yourself and your loved ones. Thinking about how you want to live, and die takes away some of the anxiety around your future in a pandemic.

If you feel you are not prepared to make these decisions by yourself, there are many resources available. The Ma'avar committee has held several groups using methods designed by The Conversation Project. The Conversation Project and Ariadne Labs, a palliative care think tank, has created a form: **"Being Prepared in the Time of COVID-19. Three Things You Can Do Now."** <https://theconversationproject.org/wp-content/uploads/2020/04/tcpscovid19guide.pdf>

1. Pick your person to be your health care decision maker

2. Talk about what matters most to you. (Ask your Ma'avar Committee for individualized help in navigating these conversations.)
3. Think about what you would want if you become seriously ill with COVID 19.

If you would like to learn more about how to make these decisions, you can access the full Conversation Project starter kit here: <https://theconversationproject.org/starter-kits/>. In addition, at this same URL you will find kits to help you choose a health care proxy and how to make decisions for someone you love who is unable to make decisions due to dementia. Kits are available in several different languages.

There is also a video resource available to help you get a basic understanding of these difficult issues that are upon us, in an organized way. This presentation offers conversation starters for the discussions you need to have with "yourself" and with your family and loved ones. Gretchen Brauer-Reike, RN, MSN who runs Coda Conversations, <http://codaconversations.com/>, a Portland resource for helping people make end-of-life health care decisions created this video. "The Importance and Urgency of Considering the Unthinkable" is free Webinar on how our advance planning for decisions in a health crisis may need to be modified in this COVID-19 pandemic.

[https://zoom.us/rec/share/xvVwCODZ6l1IGK\\_Pq3rYCqAeA6vraaa81CcZrKZbmhv\\_p5IXp9QuT9MRhr3qDvng](https://zoom.us/rec/share/xvVwCODZ6l1IGK_Pq3rYCqAeA6vraaa81CcZrKZbmhv_p5IXp9QuT9MRhr3qDvng).

If you already have an advance directive and would like to add addendum specific to COVID 19\*, Compassion and Choices has an excellent document you can use.

<https://compassionandchoices.org/wp-content/uploads/COVID-19-Addendum.pdf>

If you would like to make formal and legal documents to ensure your wishes are honored and make sure your family, friends and health care providers know what you want you need to fill out and Advance Directive . This is not only for people who are high risk to become ill with COVID 19, but for everyone.

- An **Advance Directive** (also known as an Advance Health Care Directive (AHCD)<sup>+</sup> can be completed by anyone age 18 or over, and serves one or both of these functions:
  - Durable Power of Attorney for Healthcare (to appoint a health care agent)
  - Instructions for Health Care (to indicate your wishes)

Each state has their own forms, due to minor variations in the laws. There are two forms you have heard about that are legal in Oregon.

You can access paperwork to complete your advanced directive easily online and print at home.

- OREGON Advance Directive (free downloadable) + Planning for Important Health Care Decisions from National Hospice and Palliative Care Organization  
<https://www.nhpco.org/wp-content/uploads/Oregon.pdf>
- Downloadable free advanced directive  
<https://www.oregon.gov/oha/PH/ABOUT/Documents/Advance-Directive.pdf>

If you do not have a printer, a form/ booklet with advice about how to fill it out are available to be mailed

- Oregon Health Decisions Advance Directives for purchase(sent by mail) or download [Does your family know your wishes? Have you had the conversation? Help your loved ones make important decisions.]  
<https://www.oregonhealthdecisions.org/shop/standard-pricing/advance-directives/>

You've written your advanced directive and spoken to your family, and want to know what else to think about to decrease your stress:

- OHSU Center for Ethics - A Nation's Grief: Loss in the Time of COVID-19: by Susan Hedlund, MSW. This Webinar is less about traditional grief as we know it, but instead a consideration of the collective grief we feel as a nation during this pandemic. <https://vimeo.com/404585829>
- Mental health and wellness tips during COVID-19 | Energy Resourcing <https://energyresourcing.com/blog/mental-health-wellness-covid-19/?fbclid=IwAR15LyvQUiFj4MT7NuzB-kJmfmZjPndutF1LEMOWxYaFG6ezrusG14Pyxw>

**\*Need more information about Advanced Directives or POLST? See Next Article in this series: Preparing your Advance Directive and POLST**

**\*Have questions about treatments, medical decision making, and limited supplies and equipment during the COVID 19 Pandemic? See Article 3 in this series: When you get sick with COVID 19.**

## What is happening when you get sick with COVID?

*Attention: This article is written to organize worse case scenario thoughts to assist you in filling out your advance directive and a COVID 19 addendum. It is very direct and straight forward and may be upsetting for some people. I recommend you read the other articles in this series first, "Looking at the Future through COVID 19 Pandemic" and "Preparing your Advance Directive and POLST". I and the Ma'avar Committee are available if you have questions or concerns. I also recommend you discuss this with your health care team ( PCP, specialists, etc) Karen Erde*

This article was updated 8/8/20

**There is so much information coming out in the media that it is overwhelming.**

Most of us, fortunately, if we do catch the virus that causes COVID 19, will have asymptomatic or mild infections. Another 20% will become very sick. And a smaller percentage will require hospitalization, possibly including intensive care and assistance breathing. An estimated 3% to 4% may need ventilators.

This virus affects the lungs primarily, but like many viruses (think cold or flu) it also causes fever and the achy muscles (myalgia) that go along with this. COVID 19 also affects heart, liver, brain and kidneys.

People are at higher risk to have severe effects if they have preexisting chronic disease. Treating all your chronic diseases to keep them in best control is helpful. The CDC, as of 7/17/2020, reports **people of any age** with certain underlying medical conditions are at increased risk for severe illness from COVID-19: Cancer, Chronic kidney disease, COPD (chronic obstructive pulmonary disease), Immunocompromised state (weakened immune system) from solid organ transplant, Obesity (body mass index [BMI] of 30 or higher), Serious heart conditions, such as heart failure, coronary artery disease, or cardiomyopathies, Sickle cell disease, Type 2 diabetes mellitus

The CDC further states "COVID-19 is a new disease. Currently there are limited data and information about the impact of underlying medical conditions and whether they increase the risk for severe illness from COVID-19. Based on what we know at this time, people with the following conditions might be at an increased risk for severe illness from COVID-19: Asthma (moderate-to-severe), Cerebrovascular

disease (affects blood vessels and blood supply to the brain), Cystic fibrosis, Hypertension or high blood pressure, Immunocompromised state (weakened immune system) from blood or bone marrow transplant, immune deficiencies, HIV, use of corticosteroids, or use of other immune weakening medicines, Neurologic conditions, such as dementia, Liver disease, Pregnancy, Pulmonary fibrosis (having damaged or scarred lung tissues), Smoking, Thalassemia (a type of blood disorder), Type 1 diabetes mellitus

Children who have medical complexity, who have neurologic, genetic, metabolic conditions or who have congenital heart disease might be at increased risk for severe illness from COVID-19 compared to other children

Many of us have also heard that being over 65 seems to be a risk factor. This may be due to a higher likelihood of having one or more chronic diseases, but also that the immune system is less well able to mount a response to fight viral infection. The National Center for Health Statistics Mortality Reporting System (as of 6/6/2020) reports that in hospitalized patients, the rate of people dying from COVID 19 were less than 1 in 1000 of those in their forties, 1.5 in 100 of those in their fifties, 1 in 50 in their sixties, 1 in 3 in their seventies, and 1 in 2 in their eighties. Oregon Health Authority reports that there is a pretty equal spread of disease by age groups, but a doubling of the number of cases that require hospitalization once you get beyond age 60. As numbers have surged in Oregon in past 2 months, there is a much larger proportion of case that do not require hospitalization.

Stress impairs the immune system, and this may increase the risk of infection, or worsen outcomes to the infection. Our [own](#) immune response may be the primary driver of damage to the lungs and other organs during coronavirus infection—somewhat akin to an autoimmune reaction where the body over-reacts and the lungs get caught in the crossfire as the coronavirus is attacked.

What does a mild-moderate infection look like?

There are many accounts in the media of what it is like to be infected with COVID 19.

A typical story of what COVID 19 infection looks like comes from Michael S. Saag, MD, an infectious disease doctor and associate dean for global health and the director of the Center for AIDS Research at the University of Alabama at Birmingham. He went through a typical course with 5-7 days of mild symptoms including fatigue, cough, headache, fuzzy thinking and loss of my sense of smell. Then around day 6-10, the illness took a turn for the worse with high fevers, chills, severe muscle aches, loss of appetite, inability to concentrate.

Dr. Saag writes, “What did I learn? First, despite all of my knowledge of infectious diseases and how this virus was predicted to behave, I was not prepared for the personal battle and the toll it takes. The horror of going through the symptoms is less about how I felt moment to moment, but rather the fear of the unknown...”

### ***Severe Infections, overactive immune system and ventilators***

The big problem with this infection is that the worst reactions are often caused by your immune system. Your immune system normally protects your body from bacterial and viral infections. In COVID 19, there is an overexuberant response of the immune system. You may have heard of cytokine storm and ARDS (Acute Respiratory Distress Syndrome). These are a result of overproduction of cytokines, which are the chemicals released by the immune cells to fight infection. This results in severe lung disease that prevents the body from getting enough oxygen to the vital organs. Due to this inflammation, the lungs which normally are delicate clusters of air sacs, become filled with gummy fluid that prevents them from absorbing oxygen.

A ventilator can deliver more oxygen, but it takes high pressure to get the oxygen through the thickened tissue and fluid. To connect a person to a ventilator requires intubation, inserting a long tube into the windpipe, and sedation. It is very uncomfortable to be on a ventilator at high pressure, and patients are put into a medically induced coma. **The machines can't fix the damage caused by the virus; they just buy time.** They keep oxygen going to the brain, heart and kidneys.

In general, patients hospitalized in the ICU on a ventilator for ARDS, do not all survive. People with COVID-19 have even worse statistics than other causes of ARDS. Reports from all over the world are finding that 66%-86% of people will NOT survive despite being put on ventilators. The reason is not clear, but some doctors are speculating that the higher pressure and longer than usual reliance on ventilators may be causing damage over time. Doctors are trying other measures including different positions to improve oxygen flow to the lungs. Avoiding intubation, using a simple technique of turning people face down (proning) has been very effective in COVID-19 and kept people off of ventilators.

People who do survive supportive treatment will not be the same as they were before becoming infected with COVID 19. Organs can be damaged during the severe, intense illness that takes people to the ICU, due to the infection and lack of oxygen. On autopsy, the lung's respiratory surface appears obliterated by scar tissue. Pulmonary fibrosis (lung scarring) is expected to be a long-term complication among survivors of serious COVID-19 infection, making it more difficult to breathe than normal. Some may die within days of discharge for ICU due to heart damage, or other complications to major organs.

"Even before COVID-19, for those lucky enough to leave the hospital alive after suffering acute respiratory distress syndrome, recovery can take months or years. The amount of sedation needed for COVID 19 patients can cause profound complications, damaging muscles and nerves, making it hard for those who survive to walk, move or even think as well as they did before they became ill. Many spend most of their recovery time in a rehabilitation center, and older patients often never go home. They live out their days bed bound, at higher risk of recurrent infections, bed sores and trips back to the hospital."

As we have more people surviving COVID -19 we are learning that recovery is often plagued by persistent neurological problems ( brain fog, headache, insomnia, vertigo), shortness of breath, chest pain and cough, irregular heartbeats and heart muscle inflammation, high blood pressure, persistent fever, and joint pain.

"We also understand that ARDS survivors can face a constellation of issues — anxiety, depression, post-traumatic stress, even cognitive dysfunction (dementia) — after they recover from their critical illness."

"Patients with COVID-19 typically stay on ventilators for prolonged periods which increases the likelihood of long-term complications... Even a year after leaving the intensive care unit, many people experience post-traumatic stress disorder, Alzheimer's-like cognitive deficits, depression, lost jobs and problems with daily activities such as bathing and eating"

"All this does not mean we shouldn't use ventilators to try to save people. It just means we have to ask ourselves some serious questions:

- What do I value about my life? If I will die if I am not put in a medical coma and placed on a ventilator, do I want that life support?
- If I do choose to be placed on a ventilator, how far do I want to go?
- Do I want to continue on the machine if my kidneys shut down?
- Do I want tubes feeding me so I can stay on the ventilator for weeks?"

**It can help enormously to have thought about these questions and to have these conversations with your family members in advance so their wishes are known — and ideally to have those wishes in written form — if you do become sick. Talk to your PCP and other members of your health care team about how your body might react to getting infected with COVID 19.**

Advanced Directives and Addendums specific to COVID 19 are readily available.

<https://compassionandchoices.org/wp-content/uploads/COVID-19-Addendum.pdf>  
<https://theconversationproject.org/wp-content/uploads/2020/04/tcpcovid19guide.pdf>  
<https://www.nhpco.org/wp-content/uploads/Oregon.pdf>  
<https://www.oregon.gov/oha/PH/ABOUT/Documents/Advance-Directive.pdf>  
<https://www.oregonhealthdecisions.org/shop/standard-pricing/advance-directives/>

If you want to read more about what happens during a COVID 19 infection, here are the articles I borrowed from.

[What an infectious disease specialist learned about getting COVID 19

[https://www.washingtonpost.com/opinions/2020/04/06/what-an-infectious-disease-specialist-learned-about-virus-getting-it/?arc404=true&itid=lk\\_inline\\_manual\\_28](https://www.washingtonpost.com/opinions/2020/04/06/what-an-infectious-disease-specialist-learned-about-virus-getting-it/?arc404=true&itid=lk_inline_manual_28)]

[Prone to reduce use of ventilators

<https://www.cuimc.columbia.edu/news/prone-covid-19-patients-reduces-need-ventilators>

[What You Should Know Before You Need a Ventilator - Dr. Daniela Lamas is a critical care doctor at Brigham and Women's Hospital <https://www.nytimes.com/2020/04/04/opinion/coronavirus-ventilators.html>]

[Is Ventilator the best treatment for you?

<https://www.nytimes.com/aponline/2020/04/08/health/ap-us-med-virus-outbreak-ventilator-deaths.html?searchResultPosition=1>]

[What You Should Know Before You Need a Ventilator

<https://www.nytimes.com/2020/04/04/opinion/coronavirus-ventilators.html>]  
[https://nutritionfacts.org/2020/04/16/takeaways-from-my-webinar-on-covid-19/?mc\\_cid=42393e58dd&mc\\_eid=511a60cd8d](https://nutritionfacts.org/2020/04/16/takeaways-from-my-webinar-on-covid-19/?mc_cid=42393e58dd&mc_eid=511a60cd8d)]

Is cardiac resuscitation in COVID 19 worth the risks?

[<https://www.washingtonpost.com/health/2020/03/25/coronavirus-patients-do-not-resuscitate/>]

[CDC

<https://www.cdc.gov/coronavirus/2019-ncov/need-extra-precautions/people-at-increased-risk.html>  
<https://www.cdc.gov/coronavirus/2019-ncov/need-extra-precautions/older-adults.html>]

[Lingering Symptoms

<https://www.sciencemag.org/news/2020/07/brain-fog-heart-damage-covid-19-s-lingering-problems-alarm-scientists>]