

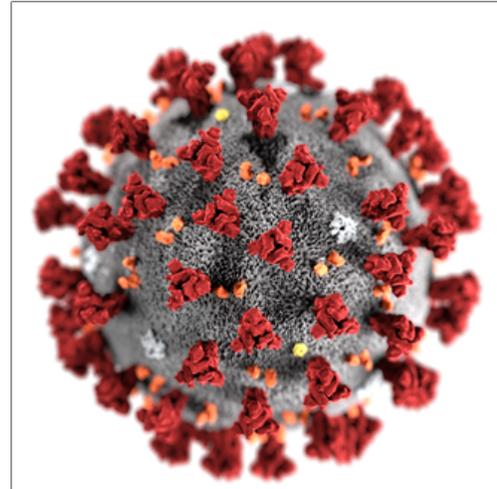
COVID-19: Understanding Your Options

A lot of information is circulating about the coronavirus and the disease it causes — COVID-19. Understanding the facts can help you make decisions about how to plan for the type of care you want in the event you contract the virus.

Who is most affected by the coronavirus?

While COVID-19 presents alarming concerns for our country and for those who are terminally ill, Centers for Disease Control and Prevention statistics confirm:

- Most people (97–98%) who contract COVID-19 will survive. Eight out of 10 will have symptoms that can be managed at home.¹
- Eight out of 10 deaths reported in the U.S. have been among those ages 65 and older. Data suggest older adults most at risk are those with underlying health conditions, like diabetes, heart disease and lung disease.²
- Hispanics and African Americans are dying from the coronavirus at disproportionate rates. In Wisconsin, for example, Hispanics make up



26% of people who have died of the virus but only 7% of the population. Blacks make up 23% of those who have died, but only 6% of the population. These disparities are similarly high for other populations, such as American Indians/Alaska Natives, and in other states, like Louisiana.³

What are the symptoms of COVID-19?

The coronavirus hijacks the cells of the throat and lungs, causing COVID-19. Symptoms range from a fever and dry cough to the inability to breathe. You may not require hospitalization if you have mild to moderate symptoms. In those cases, your provider may

¹ Centers for Disease Control and Prevention. 2020, April. Coronavirus At-A-Glance. Available at: <https://www.cdc.gov/coronavirus/2019-ncov/cases-updates/cases-in-us.html#2019coronavirus-summary>

² Centers for Disease Control and Prevention. 2020, April. Coronavirus At-A-Glance. Available at: <https://www.cdc.gov/coronavirus/2019-ncov/cases-updates/cases-in-us.html#2019coronavirus-summary>

³ New York State Department of Health. COVID-19 Fatalities. Available at: <https://covid19tracker.health.ny.gov/views/NYS-COVID-19-Tracker/NYSDOHCOVID-19Tracker-Fatalities?%3Aembed=yes&%3Atoolbar=no&%3Atabs=n>

encourage you to stay home and isolate yourself from others to manage your illness.

For some patients COVID-19 progresses, damaging the lungs and making it harder for oxygen to travel into the bloodstream and organs. You may hear this referred to as acute respiratory distress syndrome, or acute respiratory distress syndrome (ARDS).

What do I need to think about if I were to become seriously ill with COVID-19?

- COVID-19 is a disease that progresses very quickly. Most people who get COVID-19, 97-98%, will survive. However, the percentage who die are often dying lonely, isolated deaths. Planning in advance could help ensure that you get care consistent with your values and priorities.
- Determine your goals of care. Think about what matters to you most. It's best to do this before you are confronted with COVID-19. But if you already have the disease, it's not too late. Ask yourself the following questions. The descriptions of the [different treatment options](#) listed below, as well as your health status, may help as you try to answer these questions. While anyone with COVID-19 can die, a person in reasonably good health is very likely to survive. Weighing your values along with your health status will help give you the full picture as you make treatment decisions.

Each of us may choose a different path. The point is to think about what matters to you:

- ◆ If I begin to have difficulty breathing from coronavirus, would I prefer to be in the hospital with immediate access to life-saving interventions and around-the-clock medical care, but isolated from my loved ones? Or would I want to explore whether I can be cared for in the comfort of my home?
 - ◆ If my disease progresses and less invasive treatments are no longer working, do I want to go to the hospital and attempt additional life-saving treatments? Or would I prefer to forgo life-prolonging treatments and instead choose comfort care, so that I can die at home?
 - ◆ If I end up at the hospital, do I want the doctors to attempt to extend my life using mechanical ventilation?
 - ◆ Do I want doctors to attempt to restart my heart through resuscitation?
- Contact your healthcare team now to talk about your options, including:
- ◆ When and how you could receive medical care at home if you have COVID-19 symptoms. For example, you may be able to receive care, including prescriptions, using [telehealth \(communication through a phone or computer\)](#).
 - ◆ Whether you can receive oxygen at home, should you need it. Your doctor may ask you to go to the office, emergency room or urgent care clinic so your oxygen levels can be tested. If your levels are low, you may be

- able to get oxygen through hospice or home care.
- ◆ How quickly you can receive hospice care, should you qualify.
 - ◆ If you decide you want to go to the hospital in the event the disease becomes severe, when would be appropriate to go.

What do I need to know about different treatment options?

There is no specific cure for COVID-19 and no vaccine is currently available. However, COVID-19 is also not a death sentence. The vast majority of people who get COVID do recover; your likelihood of survival depends on your health status, which is discussed further below.

Healthcare providers can treat symptoms to make you more comfortable and may try a range of treatments from antibiotics to experimental drugs depending on your circumstances. There are several options for treating acute respiratory distress syndrome (ARDS) — non-invasive respiratory care, intubation with ventilation, and comfort care.

Non-Invasive Respiratory Care

What is it?

Patients with milder symptoms may be given oxygen through facemasks, nasal masks or mouthpieces, which allow air to be pushed into the lungs. These devices still allow you to speak and eat, although some report the masks are tight-fitting and uncomfortable. You may be given medicine to help you stay calm.

To receive oxygen, your doctor may ask you to go to the office, emergency room or urgent

care to get your oxygen levels tested. Levels below 88% qualify for oxygen. If you require oxygen, you may be able to get it through home or hospice care.

Bottom line: Non-invasive respiratory care can provide oxygen to people who have mild to moderate symptoms. It sometimes can be provided at home allowing you to avoid a hospital stay. If your condition worsens, you will need to make a choice between intubation with ventilation (at the hospital) and comfort care.

Feeding Tubes

What is it?

For patients who are not able to eat or drink, the doctor might suggest a feeding tube. This⁴ is more common for patients with severe COVID disease admitted to the ICU. There are two types of feeding tubes:

- Nasogastric or NG tube is threaded through the nose down to the stomach to give nutrition for a short time.
- Gastric or G tube (sometimes called PEG or percutaneous endoscopic gastrostomy tube) is put directly into the stomach through an opening in the side or abdomen.

Hand feeding is often an alternative to tube feeding. But, patients with COVID-19 are often unable to have loved ones or aides nearby to help due to the possibility of transmission of the virus.

What else should I consider?

⁴ Nutrition of the COVID-19 patient in the intensive care unit (ICU): a practical guidance Critical Care BMC. Available from: <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC7369442/>

In the short-term, getting nutrition from a feeding tube can be helpful. They may cause discomfort and may lead to bleeding, infection, skin irritation, or leaking around the tube, as well as nausea, vomiting and diarrhea.

Bottom line: When it is likely the patient will get better, getting nutrition from a feeding tube can be helpful. However, when someone is in the last stage of an illness, tube feeding can be uncomfortable if not painful. Instead of feeding tubes, some patients choose to [refuse food and water](#). The action of stopping food and drink is a natural part of the dying process and can be considered as one of the options for care.

Intubation with Ventilation

What is it?

Intubation with ventilation is for people who are severely ill and not able to breathe well on their own. It is used when other methods of treatment are no longer working. The procedure is performed in the hospital. You'll remain in the intensive care unit (ICU) throughout the ventilation process.

With intubation, a tube goes into your mouth or nose, down your throat and into your windpipe. It is connected to a machine called a ventilator. You cannot speak or swallow. You would be in a medically induced coma and given pain-relieving medications before and throughout the process.

Ventilation, sometimes called mechanical ventilation, is a life support treatment. It pushes oxygen into your lungs to help you breathe and sustain your heart and kidneys so they can work properly. It is the last line of defense for the coronavirus. However, it is not a cure.

Ventilation helps keep you alive, giving the lungs a longer time to recover on their own. It essentially buys time.

Ventilation is a relatively common treatment. For example, it is given when a patient undergoes heart surgery and in severe cases of chronic obstructive pulmonary disease, pneumonia, congestive heart failure, sepsis, cardiac arrest, etc. In general, duration and recovery time are shorter and survival more likely for people receiving ventilation for reasons other than COVID-19.

What else should I consider?

Data on mechanical ventilation for COVID-19 patients continues to emerge. People with COVID-19 who receive ventilation have varying levels of recovery.

- Ventilator duration. Most patients with COVID-19 spend on average 10 days to 3 weeks in the ICU on a ventilator. For most other conditions, the average time on a ventilator is 3 to 7 days. Ventilation can damage the heart and lungs; the longer someone is on a ventilator, the greater the risk of organ damage.
- Ventilator recovery. Recovery is not always easy. Some patients die from heart problems within a few days of beginning ventilation, require dialysis due to kidney failure or have permanent lung or heart damage. Others still are no longer able to walk, move or think the way they previously did and show signs of mental impairment.⁵ The longer a person is on a ventilator, the likelihood of these adverse effects increases and survival decreases.

⁵ Dreger, K. [What You Should Know Before You Need a Ventilator](#). 2020 Apr. New York Times Opinion Piece.

Ventilator survival. Survival rates for people who receive ventilation have steadily increased since the initial reports in March, largely because providers have become more skilled at treating people with the virus. Studies show that on average, 60-70% of patients with COVID-19 who receive mechanical ventilation survive.^{6 7} The survival rate decreases for people with any of the following factors: older age and underlying conditions, such as hypertension, chronic kidney disease and diabetes.

Bottom Line: Intubation with ventilation will sustain your life and may allow you to recover from COVID-19. However, it is an invasive procedure that has the potential to diminish the quality of life for those who do survive. People least likely to recover are those who are seriously ill from heart, lung, liver or kidney failure, who are over age 65, or who have a terminal illness like cancer or advanced dementia.

Cardiopulmonary Resuscitation or CPR

What is it?

For some people with COVID-19, despite ventilation, the heart stops beating. The primary treatment in this case is cardiopulmonary resuscitation (CPR). During CPR, you may receive compressions (pushing) on your chest, or electrical shock and drugs, to restart your heart.

⁶ ICU and Ventilator Mortality Among Critically Ill Adults With Coronavirus Disease 2019. Crit Care Med. <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC7255393/>

⁷ Factors associated with hospital admission and critical illness among 5279 people with coronavirus disease 2019 in New York City: prospective cohort study BMJ <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC7243801/>

CPR may also be necessary for people with COVID-19 who have not received ventilation. In those cases, once CPR has been given, ventilation will also be performed.

What should I consider?

Survival rates for people who receive CPR vary:

- **CPR recovery.** After CPR, more likely than not you will need to be moved to the ICU. You may also have damaged or broken ribs caused by the chest compressions. If your heart and breathing are stopped for a while, brain damage may occur.
- **CPR survival.** Research suggests that only 10–20% of all people who get CPR will survive and recover enough to leave the hospital. For chronically ill elderly patients, one study has shown a less than 5% chance of surviving long enough to leave the hospital after receiving CPR.⁸ The study does not evaluate the quality of life for those who leave the hospital. We also do not have data on CPR survival rates for patients with coronavirus.
- **CPR practices.** Given how contagious the coronavirus is, CPR, which is an invasive procedure, puts healthcare workers at considerable risk. Since there is only a small chance of making a full recovery, some hospitals have automatic do-not-resuscitate orders in place for patients with the coronavirus. Practices vary by health system, so it is important that you document your preferences to increase the likelihood

⁸ Khullar, Dhruv. [The CPR We Don't See on TV](#). 2014. New York Times Well Blog.

they will be followed in an emergency situation.

Bottom Line: In a small number of cases, CPR can save a patient's life and allow them to recover fully and leave the hospital. The likelihood of surviving resuscitation for chronically ill elderly patients is very low.⁹

Comfort-Focused Treatment

What is it?

Comfort care focuses on symptom control, pain relief and quality of life. If you have COVID-19 and choose comfort care, you may receive pain relievers, oxygen to help you breathe, fever reducers, and medicine to reduce anxiety and fear. In many cases, you may be able to choose to stay at home, which will increase the likelihood that you will not die alone.

If you select this care option, you will not be given invasive treatments or be kept alive on a ventilation machine and you may decide you do not want to go to the hospital at all. It is a more common option for people who are already receiving hospice care or who already have terminal or worsening conditions, such as advanced dementia. However, it is an option for everyone.

If you choose this option, talk with your provider about how you will receive care, such as pain medication. If you have a caregiver in your home, they will be encouraged to remain in a separate part of the house with minimal interaction; however, it will not be as isolating as it will be in the hospital.

⁹ Ouellette L, Puro A, Weatherhead J, Chassee T, Whalen D, Jones J. 2018, October. Public knowledge and perceptions about cardiopulmonary resuscitation (CPR): Results of a multicenter study. *American Journal of Emergency Medicine*. 36(10): P1900-1901.

What should I consider?

There are several things to consider if you are receiving or considering hospice care:

- If you are already receiving hospice care, your assigned hospice provider will likely continue to come to your home regularly to provide the care you need. The hospice physician can prescribe pain relieving medicine and offer other comfort care measures during this time.
- If you are not yet on hospice care, ask about it when you first talk to your doctor in the case that symptoms from COVID-19 progress. If you are not able to access hospice care, home-based palliative care may be an option. Palliative care doctors can provide the same or similar type of comfort care that is provided by hospice care.

Bottom Line: With comfort treatment you are choosing not to have aggressive treatments like ventilation and CPR. Instead, you are choosing care to relieve your symptoms and keep you comfortable. This care will not extend your life, but it will increase the likelihood that you die at home.

More Resources

From Compassion & Choices:

- [COVID-19: Using Telehealth to Reduce Your Risk](#)
- [COVID-19: Advanced Care Planning](#)
- [COVID-19: Dying in the Age of the Pandemic](#)
- [Plan Your Care Resource Center](#)
- [COVID-19: Impact on Underserved Communities](#)

→ [COVID-19: Spanish Language Toolkit](#)

From Other Organizations:

- [Ventilators are No Panacea for Critically ill COVID-19 Patients](#) National Public Radio.
- [COVID-19 Resources for Individuals Respecting Choices](#)
- [Get Palliative Care](#)
GetPalliativeCare.org

From the Centers for Disease Control and Prevention (CDC):

- [Learn How the Virus is Spread](#)
- [How to Protect Yourself](#)
- [Steps to Take When You Are Sick](#)
- [Warning Signs](#)
- [Creating a Household Plan](#)