



## **PREPARATION AND CHOICE IN THE TIME OF COVID-19**

Most people who contract COVID-19 have mild or moderate symptoms and don't need intensive medical treatment or hospitalization. This advisory is for the significant number of people who have serious symptoms, who definitely need medical treatment, and who may not survive this disease.

During this challenging time, there are things one can do to be prepared and empowered to make good choices.

### **To be prepared, you should know:**

1. As long as you are conscious and capable of making decisions, you have the right to agree to or decline medical treatment of any kind. For example, if you have strong feelings about not being put on a ventilator or any other form of life-sustaining treatment, you can decline it. You also have the right to change your mind at any time.
2. Advance Directives (a Living Will and Durable Power of Attorney for Health Care) only take effect when you cannot speak for yourself and usually apply to a serious illness or terminal condition. If your values related to end-of-life choices haven't changed, there is probably no need to revise your Advance Directives.
  - ◆ Advance Directives: [bit.ly/eolwa-ad](https://bit.ly/eolwa-ad)
  - ◆ Living Will: [bit.ly/eolwa-lw](https://bit.ly/eolwa-lw)
  - ◆ Durable Power of Attorney for Health Care: [bit.ly/eolwa-dpaforhc](https://bit.ly/eolwa-dpaforhc)
3. If you named someone to be your health care agent in a Durable Power of Attorney for Health Care and haven't spoken to them for a while, now would be a good time to reach out to your agent to ensure that they have a copy of your Advance Directives and know where they are located.
4. If you have named a health care agent, make sure your family knows who that person is and understands that the agent has the authority to make decisions about your medical care, if you are unable to do so. If you don't have a health care agent, know who your legal surrogate decision-maker is (for example, your spouse or adult child) and make sure they have a copy of your Advance Directives and know where they are.
5. Think about what medical treatment and care you want and talk to your family and your health care agent about your wishes. If you become so ill with COVID-19 that you can no longer speak for yourself, your health care agent or family will know what you want and what to do.
6. Understand your treatment options if you should become ill enough to need intensive medical care:
  - ◆ Do you want to decline all life-sustaining treatment, get optimal palliative care, and die at home, if possible?

- ◆ Or do you want every possible effort made to save your life, including hospitalization and being put on a ventilator? [bit.ly/ccccc-ventilator](http://bit.ly/ccccc-ventilator)
- ◆ If you want to be sedated and connected to a ventilator, how long would you want to stay connected? COVID-19 patients on ventilators spend on average ten days to three weeks on the machine. There is evidence that the longer a person stays on a ventilator, the less likely they are to survive, and the more likely they will need months of rehabilitation—and they may never return to their prior health status. For example, a recent study in New York indicated that more than 80 percent of people 80 years of age and older with COVID-19 who were put on a ventilator did not survive. In California, a different study showed that only 50 percent of people of any age survived. Many who do survive more than 48 hours on a ventilator develop “post-intensive care syndrome,” a combination of cognitive decline, muscular-skeletal weakness, and psychiatric problems like depression and post-traumatic stress. [*Kaiser Health article: “‘No Intubation’: Seniors Fearful of COVID-19 Are Changing Their Living Wills.”*] <https://spotlight.kaiserpermanente.org/population-level-estimates-of-adults-covid-hospitalized/>
- ◆ Would you want to stay on a ventilator if your kidneys or other organs shut down or you develop other complications that further reduce your chance of surviving?
- ◆ Or are you wanting hospitalization for medical treatment not including sedation and connection to a ventilator? Treatment may include morphine for pain, anti-anxiety medication, and supplemental oxygen to assist with breathing (but not mechanically inflating the lungs as with a ventilator).
- ◆ Using Washington’s Death with Dignity Act is not an end-of-life choice for people with COVID 19. People dying from an acute, fast-acting illness generally do not live long enough to fulfill the 15 day waiting period and other requirements necessary to be eligible for Death With Dignity. For more information, watch this video: Coronavirus and Aid in Dying, [bit.ly/vimeo-covid-aid](http://bit.ly/vimeo-covid-aid)

**Choices for people with COVID-19 who are unlikely to survive and whose priority is a peaceful death:**

1. **Staying home or in the home of a family member or other loved one.** People with COVID-19 can deteriorate rapidly, and dying of respiratory illness can be a grim experience without proper care. Remaining at home is probably only feasible with hospice care. To qualify for hospice, your physician will need to certify that you have six months or less to live. It is helpful, though not required at some hospices, to have in-home caretakers since hospice nurses only make periodic visits. Due to the risk of corona virus transmission, hiring caretakers through an agency or independently is extremely difficult, if not impossible, at this time. However, a family or friend caretaker can wear PPE when near you if they are willing to assume that risk. Thus, getting hospice care in the home can be challenging, although it is currently being provided for many COVID-19 patients in Washington. Hospice provides treatment and medication to keep you comfortable, but not ongoing in-home care. Hospice nurses can make in-person visits wearing PPE or visit with you virtually (telehealth). Because COVID-19 sometimes can lead to acute respiratory distress, it is possible that your symptoms could become unmanageable at home. If so, you usually will be transferred to an in-patient hospice care center or a hospital with rooms set aside for hospice patients, if a care center is not available. Hospice care centers are peaceful and attractive and will allow visitors wearing PPE. Hospice rooms within hospitals usually permit visitors for hospice patients at end-of-life, even though visitors are not

generally allowed in the hospital due to COVID-19. If possible, it is best to select a hospice provider with its own hospice care center. If you are transferred due to severe respiratory distress, be sure to take your Advance Directives, Power of Attorney form, and POLST form, if you have one, with you. And be proactive: Before you become ill, contact your doctor and explain that if you contract COVID-19, you intend to decline treatment and hope to die at home. Ask the doctor how soon you could be referred to hospice and say which hospice you prefer

- ◆ The Importance of Hospice: [bit.ly/eolwa-hospice](http://bit.ly/eolwa-hospice)
- ◆ Washington State Hospice and Palliative Care hospice locator webpage: [bit.ly/wshpco-directory](http://bit.ly/wshpco-directory)

Following are the 10 hospice care centers in the State:

<b>Bellingham:</b> Whatcom Hospice (part of PeaceHealth)	<b>Spokane:</b> Hospice of Spokane (two centers)
<b>Everett:</b> Providence Everett	<b>Yakima:</b> Cottage in the Meadow (Virginia Mason Yakima)
<b>Kirkland:</b> Evergreen Health Hospice	<b>Richland/Kennewick:</b> Chaplaincy Health Hospice
<b>Longview:</b> Community Home Health and Hospice Care Center	<b>Vancouver:</b> (1) Ray Hickey Hospice Care Center (part of Peacehealth) and (2) Community Home Health and Hospice Care Center

2. **Staying in your long-term care facility such as an assisted living facility or nursing home.** Currently, it is almost impossible to be newly admitted to long-term care facilities unless you have a negative COVID-19 test. If you are already living in an assisted living facility or nursing home and contract the virus, you should be able to receive medical treatment and palliative care to be kept comfortable. If your goal is to have a peaceful death, then request hospice care in your facility. However, if you want all life-sustaining treatment options, including being put on a ventilator, you will be transferred to a hospital. Due to the risk of virus transmission, many long-term care facilities do not permit visitors.
3. **Being admitted to a hospital.** A hospital is the only place where you have access to the full range of life-sustaining medical treatments, including sedation and connection to a ventilator. A hospital is not, however, the optimal place for a peaceful death. If you do go to an emergency room or hospital:
  - ◆ Take a copy of your Advance Directives and Power of Attorney form with you so that you can provide them if you are admitted to the hospital.
  - ◆ Like long-term care facilities, hospitals are not allowing visitors; bring a phone, tablet or laptop so that you can communicate with your family and other loved ones.
  - ◆ If you have a Physician Orders for Life-Sustaining Treatment (POLST), take it with you. POLST forms must be signed by you and your physician and should be posted on your refrigerator in case emergency medical providers come to your home. EMS providers are required to look for a POLST form. POLST Form: [bit.ly/eolwa-polst](http://bit.ly/eolwa-polst)
  - ◆ Get all the information you need from your doctors to make a fully informed decision. Ask your doctors to be honest about your chance of recovery, especially if they recommend a ventilator. Also,

ask what are the chances you will be able to return to a normal life and be able to do the things you enjoy. Ask your doctor about remdesivir and any other treatments that will help you recover faster or reduce the chance of dying.

- ◆ Make sure your medical providers understand what your goal of care is and that it's documented in your medical record. An example of a goal of care is: "I want any medical treatment that will help me get well, except being put on a ventilator. If I don't recover with those treatments, I want to be allowed to die as peacefully and comfortably as possible."
- ◆ Remember: Even during hospitalization, you have the right to decline treatment and receive whatever palliative care is necessary for a peaceful death. This includes palliative sedation (being sedated to unconsciousness until you die) if that is required to keep you comfortable.
- ◆ Understand that if you want to be put on a ventilator, you will be heavily sedated until you recover enough to be taken off the ventilator. If ventilator treatment is not successful, you will probably die within minutes after removal of the ventilator. Therefore, if you die, your final opportunity to communicate with family or other loved ones will occur prior to being sedated for ventilation. [*National Post*: "Some critically ill COVID-19 patients choosing to die at home rather than be treated with ventilator in ICU."] [bit.ly/natpostcovid](https://bit.ly/natpostcovid)

### **COVID-19-Related Grief and Loss:**

While family members may not be able to be physically present with people who are hospitalized or residing in long-term care facilities during their final days and hours, families are creating alternative ways to say goodbye and to honor and mourn their loved ones. Technology enables us to communicate using apps like FaceTime, Zoom, and Skype and share stories. Photographs, prayer, music, and letters can create meaning, even while we are not able to be together in person. [*Death with Dignity National Center "Dying and Grieving During a Pandemic"*]. [bit.ly/dwdcovid](https://bit.ly/dwdcovid)

*Individuals and organizations are encouraged to copy and distribute this guidance in any medium or format in unaltered form only, for noncommercial purposes only, and only so long as attribution is given to End of Life Washington.*