



## TALKING TO YOUR FAMILY ABOUT DYING

To ensure a peaceful death, you must talk to your family and others who should know your wishes. Even with the best medical care, you probably won't be able to make all your medical decisions at the end, and you will want people you trust to make sure your wishes are followed.



Long before you need their help, you should begin talking with your family, preferably before you become terminally ill. They must know your wishes in advance for end-of-life care. The best way of doing this is to discuss your advance directives (living will and durable power of attorney for health care) with them. Children don't like to talk about your dying, but it's not threatening to say, "I have no intention of dying soon, but it's important for you to understand my wishes – just in case something unexpected should happen."

By going through your advance directives carefully, your family will know how you want to die. Talk about your wishes for treatment should you become terminally ill, incapable of making decisions, or permanently unconscious. Do this every two or three years, so that your family fully understands your directives and has opportunities to ask questions. Talking to your loved ones about dying also helps you know who will support you at the end of life. If you do not think your immediate family will honor your wishes, it is especially important for you to name someone else in your Durable Power of Attorney for Health Care who will act as your healthcare agent. Contact End of Life Washington for advice.

Tell your family your preference about dying in a nursing home, a hospital, or at home. Talk about hospice care. If you want no artificial life support, such as a ventilator, feeding tube, or antibiotics for pneumonia, clearly say so. If your family fully understands your wishes well in advance, they will almost certainly follow them.

Talk about palliative (comfort) care. If you want maximum pain control, tell your loved ones you will want enough medication to eliminate pain – even if it results in drowsiness, unconsciousness, or hastens the dying process. If the medication cannot control your pain, tell them you would want continuous sedation to the end. These are not easy directives for

caregivers to carry out, so they must have time to wrestle with them in advance, not when there is an immediate need.

If you become terminally ill, be sure your primary caregiver and medical providers are very familiar with your advance directives and that you have a completed Physician Orders for Life Sustaining Treatment (POLST) form posted in a visible place.

Toward the end, when a reasonable quality of life is no longer feasible and you are ready to die, you must let your family know this. They may not understand your condition or share your decision to let go. They do not want to lose you, and some of them may feel that the best way to show their love for you is to “help you” by trying to keep you alive or convincing you to continue living. Share with them your reasons and your determination to stop all attempts to cure the illness. Assure them that they and the doctors have done everything possible to reverse your course, and now it’s time to come to terms with your inevitable death. Remember, they are grieving for you, and grieving takes time.

## **CONCERNING THE OPTION OF HASTENING DEATH**

Do not try to do this alone; you will need your family’s help. It is imperative to have someone knowledgeable advise you on the procedure, and it is highly recommended that you be on hospice. Contact End of Life Washington and ask for help by going to [endoflifewa.org](http://endoflifewa.org) and click the “Request Support” button.

Should you choose to actively hasten your death by stopping eating and drinking or by using the Death with Dignity Act (DWDA), it is best to discuss this plan with all close family or friends, even though there is no legal duty to do so. Many families have reported deep appreciation for the opportunity to tie up loose ends and to be present with their loved ones when they died using the DWDA.

By now, you may have a good idea what your family thinks about hastening your death. If one of them objects, tell her you respect her feelings, and that she does not have to approve. Ask her to respect your wishes by not interfering. Even if an objection is based on religious or ethical principle and not just fear of losing you, she will usually come around to “loyal opposition.” In this case, the loved one is not only grieving, but also must set aside her scruples on the issue.

If you feel you must exclude a family member from your decision to hasten death because he or she will not honor your choice, understand that enduring family discord and complications to the grieving process could result. Unless this person is estranged from the rest of the

family or living far away, it will also require careful concealment, and there is still a high risk that the person will find out anyway.



Your life. Your death. Your choice.

## TALKING TO YOUR DOCTOR ABOUT DYING



All of us would like to die peacefully, but we can't do it alone. If you want some control over how you die, start talking to your family and doctors, and make your goals known – especially if you want the option of using Washington's Death with Dignity Act.

The two major strategies for peaceful dying are to keep the dying phase short and get optimal palliative (comfort) care.

**If you have received a serious diagnosis, ask your doctor for accurate information about your prognosis.** Physicians sometimes shy away from telling patients they are dying, especially when no one raises the issue. Ask for your physician's honest opinion about your prognosis so you can make informed decisions about your end of life. Asking questions such as "If you had my diagnosis and prognosis, what would you do?" may elicit a more honest response because the physician isn't put in the position of telling you what to do. Be cautious and make well-informed decisions about accepting any treatments offered that would extend your life while ruining your remaining quality of life. If you prefer quality over quantity of life, you should tell your physician.

**If you are dying, let your doctors know that you understand your condition and wish to avoid any treatment designed to prolong your life** if, in your judgment, doing so would prolong your suffering. A good way to start this dialogue is with a Physician Orders for Life-Sustaining Treatment (POLST) form, a document signed by you and your physician that can prevent unwanted life-sustaining treatment. Take a blank POLST form and your completed healthcare directive (also known as a living will) and durable power of attorney for health care and discuss the major points with your doctors. You might say to your doctor: "I know I am dying, and I appreciate all you have done to help me. But now my goal is to die peacefully. It's all right for you not to use treatments to prolong my life."

Another approach is to **write a letter to your doctor stating your wish to avoid life-prolonging treatments**, including, "I give you permission not to prolong my life." A simple statement like that will give you the necessary understanding with most doctors.

If you want aggressive palliative care (comfort care including pain or symptom control) at the end, **let your doctor know your preference between relief of pain or alertness.** For example, you could ask your doctor, "If I am having a lot of pain or uncontrolled symptoms, such as shortness of breath, will you be willing to give me enough medication to make me comfortable, even if it results in unconsciousness?" Your doctor may answer, "Yes, of course," but you have to ask the question to get the doctor's commitment. By doing so, you are signaling a desire for him to let you determine when

and how much pain medicine or sedation is enough, on an ongoing basis. Otherwise, he might assume you want the least amount of pain medications possible so as to avoid drowsiness or development of tolerance to the drug. And **don't worry about broaching the subject in advance; both you and your doctor have a better chance of doing it right if you have had prior discussions.**

Ask your doctor if she will be willing to give you enough medication to eliminate hunger or thirst if you elect to hasten the natural dying process by voluntarily stopping eating and drinking. Ask her if she will be willing to sedate you to unconsciousness if that is necessary to manage your suffering. Ask her if she will honor the same request from your health care agent or your family if you become incapable of making decisions. **If she says, "Let's talk about that when the time comes," tell her: "No, we need to discuss it now."** And remember, medical professionals don't like to commit to anything in advance; so they may hedge their answers. By your questions, your physician will know your wishes and will be more likely to honor them as the time approaches.

If your doctor hesitates or disagrees, give your reasons for and feelings about what you are requesting. **If you cannot reach agreement with your doctor, you should find a new doctor.** Ask for a referral to a physician who will honor your wishes.

If you get hospice care (which is highly recommended), ask the hospice nurse the same questions about palliative care at your first meeting. Hospice usually provides palliative care in your home and can help ensure that you remain in control (and out of the hospital) at the end of life. For more information about hospice, request our handout, **The Importance of Hospice.**

**If you intend to use Washington's Death with Dignity Act, request our handout, Talking to Your Doctor About Death with Dignity.** The conversation about using the Death with Dignity Act should be handled with preparation and care.

It's also important to make all your end-of-life wishes clear in advance with your family and caregivers. To facilitate this conversation, request our handout, **Talking to Your Family About Dying.**

Most importantly, contact **End of Life Washington and request a Volunteer Client Advisor by going to [endoflifewa.org](http://endoflifewa.org) and Request Support.** Our volunteer can help you achieve a peaceful death. There is never a fee for any service, and all contact with End of Life Washington is confidential.

All of the documents mentioned here and many other patient resource documents are available at our website: [endoflifewa.org](http://endoflifewa.org) or for more information about end-of-life options please contact End of Life Washington.

Dying peacefully takes a little work. To have a good death, you need to be your own forceful advocate.



## **END-OF-LIFE OPTIONS IN ADDITION TO THE WASHINGTON DEATH WITH DIGNITY ACT**

There are many dignified ways to die. People considering the option of Death with Dignity (DWD) should also be aware of other end-of-life options.

### **NOT STARTING OR STOPPING TREATMENT**

For some terminally ill people, further aggressive treatment may not be helpful and may prolong the dying process without improving the quality of life. Under certain circumstances, it can also increase suffering, ruin a person's remaining quality of life, or even shorten life.

Many people are unaware that stopping treatment can result in a peaceful death. For example, people on dialysis for kidney failure may be able to die peacefully simply by stopping dialysis. However, stopping certain medical treatments may result in too much discomfort or increased suffering. Consulting with your physician and arranging for optimal palliative (comfort) care are essential before stopping treatment.

Stopping treatment can be combined with hospice and palliative care and/or voluntary stopping eating and drinking (see below) to shorten the dying process and reduce suffering.

### **HOSPICE AND PALLIATIVE (COMFORT) CARE**

Palliative care is treatment of the discomfort, symptoms, and stress of serious illness, with the goal of making you comfortable and improving your quality of life. It provides relief from distressing symptoms including pain, shortness of breath, nausea, problems with sleep, and side effects of medications. You can receive palliative care while receiving curative medical treatments. People usually receive palliative care at clinics or hospitals, but home visits may be possible.

Hospice is a form of palliative care that seeks to optimize the quality of life at the end of life, while neither hindering nor hastening the dying process. Hospice is not a place but rather medical care that enables a peaceful death for most, but not all, people. It is covered by Medicare, Medicaid, HMOs (such as Group Health), the Veterans Administration, and most private health insurers.

To qualify for hospice, a person must have six months or less to live and will generally be required to decline further curative treatments. A referral from a doctor, who usually remains your primary care physician while you are on hospice, is required. Hospice caregivers control pain and other symptoms and provide counseling, family support, and many other services. Additionally, hospice helps people remain in control and die at home, where most people would prefer to die. For those who cannot remain at home, inpatient hospice facilities may be available. Hospice can also be provided in long-term care facilities, such as nursing homes, and may be the best option for people who cannot make end-of-life decisions for themselves because of dementia or other medical conditions.

While hospice has no legal role in the Death with Dignity (DWD) process, some hospices – particularly those affiliated with religious organizations – are less supportive of DWD than others. If having your hospice provider’s support for your decision to pursue the option of DWD is important to you, you may want to question potential hospice providers about their policies. However, no hospice will deny care to patients who choose the option of DWD.

End of Life Washington believes that hospice is an essential component of end-of-life care and encourages all individuals who have received a terminal diagnosis to enroll in hospice. Hospice is essential for terminally ill people who choose to stop treatment and/or voluntarily stop eating and drinking, especially if they wish to remain in their homes.

For more information, request or see our handout, *The Importance of Hospice*, or go to the Washington State Hospice and Palliative Care Organization’s website, [wshpco.org](http://wshpco.org).

## **VOLUNTARY STOPPING EATING AND DRINKING (VSED)**

When people die naturally of diseases such as cancer, they often lose their appetites and eventually stop eating altogether. Some people hasten the dying process the same way, by VSED. If a person stops eating and drinking, death may come as early as a few days but more commonly one to three weeks. It is especially important to avoid sips of water or other fluids, as this may prolong the process. A person who begins VSED prior to its natural occurrence should expect hunger and thirst for a few days, so it is very important to have swabs for dry mouth and reliable access to medication to decrease or eliminate symptoms.

When done properly, VSED results in a peaceful, humane death, and many people have used this method successfully. End of Life Washington recommends that people choosing VSED discuss their decision with family members, caregivers, and involved medical providers so as to prevent them from undermining the process by offering or encouraging the intake of food or water. Make sure they are knowledgeable in helping people use VSED. End of Life Washington believes that hospice or palliative care is essential during VSED.

For more information, request or see our handout, *Voluntary Stopping Eating and Drinking*.

## **PALLIATIVE SEDATION**

Some dying people experience so much pain or unmanageable symptoms that they cannot get relief from medications unless the dose is high enough to make them unconscious. Palliative sedation provides enough medication to keep the patient continuously unconscious and free of pain and symptoms. All nutrition and hydration is stopped, and the patient usually dies within a few days.

People using palliative sedation should be monitored around the clock to be sure the sedation is adequate. While this intensive monitoring can sometimes be provided in the home, it is usually provided in a skilled nursing or inpatient hospice facility.

Unlike adequate pain and symptom management, however, palliative sedation is not necessarily a “right”. While it can be requested, it is up to the medical provider to determine if it is appropriate. Unfortunately, some physicians and hospices are reluctant or unwilling to authorize palliative sedation, even though it is an ethical, legal end-of-life option. If having the option of palliative sedation is important to you, discuss it with your hospice or other medical provider well before it becomes necessary.

**End of Life Washington provides advice and support to people considering all end-of-life decisions, including Death with Dignity. For more information about any of these end-of-life options and to request our free client support services, contact End of Life Washington.**



## THE IMPORTANCE OF HOSPICE

End of Life Washington believes that hospice is an essential component of end-of-life care and encourages all individuals who have received a terminal diagnosis to enroll when they become eligible. Hospice can help people remain in control and die at home. The goal of hospice is to improve quality of life in the patient's last months, focusing on comfort care, control of pain, and symptom management, as opposed to continuing curative treatments. To qualify for hospice, a person must have six months or less to live, and a referral from a doctor is required. Hospice services can be provided in the home or long-term care facility. For patients who require more intensive nursing care, residential hospice facilities may be available. Inpatient hospices are generally reserved for care at the very end of life.

In addition to caring for the patient, hospice also provides instruction, assistance, and support for the family. While on hospice, family, friends, and other loved ones are considered the patient's primary caregivers and are generally asked to help with feeding, bathing, and giving medications. They are not expected to perform skilled nursing tasks or any care they are uncomfortable with or not physically able to provide. Primary caregivers should also alert the hospice staff to any changes in the terminally ill person's condition. In times of crisis, some hospices also provide inpatient care or respite care, allowing family members' time away from their caregiving duties. Hospice does not provide 24-hour care in the home.

### WHEN SELECTING A HOSPICE, BE SURE TO ASK THE FOLLOWING:

- Does the hospice service your area?
- Is the hospice licensed and Medicare/Medicaid certified?
- What services does the hospice provide?
- Is there 24-hour phone coverage?
- What is expected from you and your caregiver support system?
- Does the hospice have a support program for caregivers?
- Where is inpatient or respite care service provided?
- Is the hospice affiliated with a religious institution? If it is, ask how that influences the care delivered and the end-of-life options.
- What is the hospice position on palliative sedation? Use words such as, "If Dad's pain or symptoms become unmanageable, would you be willing to sedate him to unconsciousness until death occurs?"
- Will your insurance plan cover hospice?
- What out-of-pocket expenses are anticipated?
- Is there a sliding scale payment plan for expenses not covered by insurance?

### FINDING A HOSPICE PROVIDER:

- Ask your physician.
- Call the Washington State Hospice and Palliative Care Organization, 888.459.0438, or go to [www.wshpco.org](http://www.wshpco.org), and click on "Find a Provider".
- Call End of Life Washington, 206.256.1636, or toll-free 877.222.2816.

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## WHO PAYS FOR HOSPICE CARE AND WHAT IS INCLUDED?

Medicare, Medicaid, managed care plans (HMOs), and most other health insurance providers include a hospice benefit. This benefit covers services, medications, and equipment related to the illness. Other covered services include intermittent nursing services; home health aids and homemakers; social workers; spiritual caregivers; physical, occupational, and speech therapists; medications for pain and symptom management; medical supplies and equipment; short-term inpatient care for crisis management and respite care; continuous home care in times of crisis; and bereavement services for the family after the patient's death.

Many hospice programs also have payment plans for those without insurance coverage, and some may even offer services free of charge to those who are uninsured or cannot afford it.

## AFTER YOU CHOOSE A HOSPICE

A nurse or social worker will come to your home to do an intake interview. Be sure involved family members or friends will be present. When you meet your nurse, clearly describe any special needs you have. If you want the visits more or less frequent, let the nurse know. Remember, you are in charge. If you do not like the nurse or social worker assigned to you, call hospice and ask to speak to the nursing supervisor. You have the right to request a different nurse or social worker. If your location is served by more than one hospice provider, and your hospice is not being responsive or helpful, you may discharge them and utilize a new hospice provider. This is rarely necessary, but it is your right.

Hospice is responsible for managing your pain and symptoms. It is important for patients to accurately and timely communicate their pain level and symptoms. Pain should never go unmanaged. If your pain or symptoms continue, report your pain level higher on a level of 1-10 to your hospice nurse, and be vigilant in your efforts to seek relief. If your pain and/or symptoms become unmanageable and unbearable, you have the right to palliative sedation, which is sedation to unconsciousness for the remainder of your life. Not all hospice providers can provide palliative sedation in the home, however. Asking hospice staff to help you end your life or to speed up your dying process may result in closer scrutiny and tighter control over pain or sedative medicines.

Read through the written materials your hospice gives you. Have everyone involved in your care read them. Make sure you and anyone staying in the home knows how to reach hospice. **In case of a medical emergency, call hospice, not 911.** Post the hospice phone number near every phone.

## HOSPICE AND THE DEATH WITH DIGNITY ACT

Although hospice has no legal role in the Death with Dignity Act, some hospices have more patient-centered policies about Death with Dignity than others. However, no hospice will deny care to a patient choosing the option of Death with Dignity. If finding a hospice provider that will honor your choice is important to you, contact End of Life Washington for a referral. If your only option is to use a provider who won't honor your choice or who may attempt to undermine it, it may be best not to request information about Death with Dignity or share information about your intention to use the law.

For more information about hospice, please contact End of Life Washington.



Your life. Your death. Your choice.

## THE WASHINGTON DEATH WITH DIGNITY ACT AN OVERVIEW FOR PATIENTS AND FAMILIES

An End of Life Washington volunteer can help you navigate this process, locate physicians who are willing to honor your choice, and be present at the time of death, should you request it. Please call End of Life Washington early in your terminal diagnosis so that you have time to complete this process.

### Eligibility:

- ◆ Must be an adult Washington State resident.
- ◆ Diagnosed by a physician as terminally ill, with disease or condition that will cause death within six months.
- ◆ Capable of making an informed decision, not impaired by mental illness, dementia, or depression.
- ◆ Able to self-administer the prescribed dose of life-ending medication.

### PROCEDURES FOR REQUESTING LIFE-ENDING MEDICATION:

1. Ask your primary care physician or specialist if he/she will support your decision to obtain life-ending medication and write the prescription. The physician who writes your prescription is called the "Attending Physician." If he/she declines, ask if he/she would be your Consulting Physician.
2. Make a first oral request for the Death with Dignity Act (DWDA) prescription. Ask your physician, even if he/she has declined to participate in DWDA, to document your first oral request in your medical record.
3. You must have two physicians: an Attending (prescribing) Physician and a Consulting Physician to confirm your diagnosis, prognosis, and mental capacity.
4. After you have seen both the Attending and Consulting Physicians, complete a *Written Request for Medication* form. This form must be signed by two qualified witnesses. One witness can be a family member; one can be an employee of your doctor; or both witnesses can be bystanders. When the form is completed, give it to your Attending Physician.
5. Make a second oral request to the Attending Physician, no sooner than 15 days after the first oral request, and ask your Attending Physician to document your request in the medical record.
6. As long as 48 hours have passed since you provided your *Written Request for Medication* to the Attending Physician, you may obtain the prescribed medication(s) from a pharmacy recommended by End of Life Washington. You or someone you designate may pick up the prescription. You can leave the prescription on file with the pharmacy for up to six months, until you are ready to fill it (check with the pharmacist).

### Recommendations to Clients:

- ◆ When you have a life expectancy of six months or less, request a referral to hospice from your physician.
- ◆ Complete your Will, Health Care Directive, Durable Power of Attorney for Health Care, and Physician Orders for Life-Sustaining Treatment (POLST) form.
- ◆ Talk to your loved ones about your decision.
- ◆ Keep your decision private and only share it with your inner circle of family and friends. If you do talk about it, please do not reveal the identities of participating physicians and pharmacists.