



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, 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.