



THE IMPORTANCE OF HOSPICE

Compassion & Choices of Washington(C&C) 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 can help patients 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. A patient's prognosis must be six months or less, and a referral from a doctor is required. Hospice services are provided in the home or long term care facility. For patients who require more intensive nursing care, residential hospice facilities may be available. Residential 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. On hospice, family, friends, and other loved ones are considered the patient's primary caregivers and are generally asked to help with feeding, bathing, turning 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 patient'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 round-the-clock 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?
- Can you continue to see your own doctor?
- 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's position on resuscitation, hydration, and antibiotics? Is this consistent with yours?
- 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 Organization, 1.888.459.0438, or go to www.wshpco.org, and click on "Find a Provider".
- Call C&C, 206.256.1636, or toll-free 1.877.222.2816.

Who pays for hospice care and what is included?

Medicare and Medicaid covers hospice for patients who have a prognosis of six months or less. However, if patients live longer, they are usually not discharged from hospice. This benefit covers services, medications, and equipment related to the illness. These 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 up to one year after the patient's death.

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

Once you choose a hospice:

A nurse or social worker will come to your home to do an intake interview. This visit may take an hour or two. 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 assigned to you, call hospice and ask to speak to the nursing supervisor. Request a different nurse. 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. It may be necessary to sedate the patient to unconsciousness in order to control pain- this is your right. If your pain or symptoms continue, report your pain level higher on a level of 1-10 to the nursing staff or physician and be vigilant in your efforts to seek relief. Never ask staff to end your life or use the word suicide. You run the risk of closer scrutiny and tighter control over all 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.

The Death With Dignity Act

Although, hospice has no legal role in the Death With Dignity Act (DWDA), some hospices have more patient-centered policies than others. However, no hospice will deny care to a patient choosing the DWDA. If finding a hospice provider that will honor your choice is important to you, contact C&C for a referral. If your only option is to use a provider who won't honor your choice, it may be best not to request or share information about the DWDA. For more information about hospice, please contact C&C.