

## Advance Planning: End of Life Treatment Options

Doctors should provide counseling on treatment options at the end of your life if you request it. You are entitled to receive information and counseling about all of your end-of-life options including: refusing or directing the withdrawal of life prolonging care (such as a ventilator, feeding tube, cardiac device, medication, etc.), voluntary stopping of eating and drinking (VSED), palliative care, aggressive pain and symptom management, and aid in dying. As of January 2016, counseling sessions with your provider are reimbursed by Medicare.

### Choosing Care: Palliative Care and Hospice Care

#### What is palliative care?

Palliative care is specialized medical care for people with serious illnesses. Palliative care can be an option regardless of whether your condition is considered terminal. It focuses on relieving symptoms of serious illnesses. It is often provided alongside treatment aimed to cure your illness. Palliative care is provided by a team of doctors, nurses, and other health specialists who work together with the patient's primary doctor to provide more support for the patient. Palliative care is available at hospitals, outpatient clinics, long-term care facilities, hospices, or in your home, and can include: pain and symptom control, communication and coordination services, emotional support, and family/caregiver support.

#### Do I have to pay for palliative care?

Most insurance plans, including Medicare and Medicaid, cover all or part of palliative care treatment, just as they would cover other hospital and medical services.

#### What is hospice care?

If your prognosis is six months or less, you are eligible for hospice care. Hospice is typically provided in your home, although some residential in-patient hospices are available. Under the direction of a physician, a team of health care workers provides medical care to control pain and symptoms to help patients live as fully and comfortably as possible. Hospice offers medical, emotional, psychological, and spiritual support to the patient and family.

Some hospices offer specialized programs for children, people with specific diseases, "pre-hospice" care for those not yet medically-ready for hospice care and other extra services that may help your family.

*Where can I receive hospice care?*

You can receive hospice care in your home, nursing home, or assisted living facility. If you have a preferred hospital or know that you may need to go to a nursing home, it is important to find out which ones the hospice has contracts with so they can continue to provide your hospice services in the different location.

*Do I have to pay for hospice care?*

Hospice care is covered by Medicare, most Medicaid programs, and most private insurance. The following services might be available to you with limited cost-sharing, depending on your health care coverage:

- Routine care
- General inpatient care
- Continuous care
- Respite care
- Medications
- Equipment and supplies
- 24-hour-on-call access to hospice staff
- Grief support, complementary therapies

*How can I get hospice services?*

You can ask your doctor to refer you to a hospice program for an evaluation, or you can call any hospice program and ask that you be evaluated for hospice care. Check with your insurance providers about recommended hospice programs and providers. Be aware that many hospices have a religious foundation which may influence the care provided. If this is significant to you, choose a hospice from the faith tradition you hold, or one that is not religiously based.

**End of Life Rights/Options**

*What if I stop breathing and do not want doctors to help me breathe again?*

Good advance planning will include addressing what sort of treatment you want in emergencies, and documenting your wishes in an advance directive. You can, for example, include a Do-Not-Resuscitate (DNR) order, notifying caregivers that you do not want to be resuscitated in the event that your heart stops beating or you stop breathing. All states allow you to include instructions in your advance health care directive. You can also request an out-of hospital DNR order if you do not wish to be resuscitated if you have problems at home or anywhere outside of a medical facility. Your advance directive can specify if you want aggressive pain and symptom management, so any suffering or distress is minimized.

*What if I do not wish to be fed artificial food and water?*

An adult may choose not to take food or water, by mouth or through a tube. This is sometimes referred to as VSED (voluntary stopping of eating and drinking). Patients in every state have the right to stop taking food or water. You will need to record this wish in your advance directive. Appropriate supportive care should be arranged for in advance to minimize any discomfort.

*What if I want to stay on or get off of life support?*

You can always direct your own medical decisions while you are conscious and capable, including refusing or directing the withdrawal of any sort of life prolonging intervention. Appropriate supportive care should be arranged for in advance to minimize any discomfort. If you want life support to be withheld or withdrawn if you are not conscious and capable, make this clear in your advance planning documents and to anyone who will speak on your behalf. Your wishes can also be reflected in the form of a physician's order in a document commonly called a POLST.

*What is palliative sedation?*

Also referred to as terminal sedation, sedation to unconsciousness, or total sedation, this is the continuous administration of medication to relieve severe, uncontrollable symptoms. This treatment causes the patient to become fully unconscious, thus unaware of suffering or distressing symptoms. You will be maintained in this state until death occurs. Patients in every state have the right to request palliative sedation.

*What if I want a doctor to prescribe me medication so that I can achieve a peaceful death*

Aid in dying, sometimes inaccurately referred to as "physician-assisted suicide," gives mentally competent terminal patients the option to precipitate death by ingesting medication specifically prescribed for that purpose. Aid in dying is openly available in the following states: Oregon, Washington, Montana, Vermont, and New Mexico, and will be authorized in California in 2016. There are ongoing efforts to expand aid in dying to many other states, so contact the CLRC for additional information, especially if this option is of interest to you.

## **Resources**

### **California Hospice Foundation**

[http://cahospicefoundation.com/learn\\_about\\_hospice/tips.php](http://cahospicefoundation.com/learn_about_hospice/tips.php)

(California Hospice Foundation provides information on how to request hospice care and things to consider in choosing hospice care)

### **Get Palliative Care**

<http://getpalliativecare.org/whatis/>

(Get Palliative Care provides information and insight on palliative care and how to obtain it)

### **Compassion and Choices**

PO Box 101810

Denver, CO 80250-1810

800-247-7421

<https://www.compassionandchoices.org/>

(Provides advocacy, education and support at end-of-life)

### **Caring Info**

<http://www.caringinfo.org/>

(CaringInfo, a program of the National Hospice and Palliative Care Organization, provides free resources to help people make decisions about end-of-life care and services before a crisis)

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