

**Aging Well SIG**  
**Bethesda Metro Area Village**

## **Hospice Care**

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February 26, 2023

Former President Jimmy Carter has entered hospice, so this is an appropriate time to learn more about this end-of-life option.

Most of us in the U.S. will die of chronic diseases in old age, and many illnesses cause a slow decline toward death over months or years.

As life winds down, we need to rely more on gentler medical interventions, or just comfort care with little intervention, to support a good quality of life.

Unfortunately, medical interventions usually rise as the end of life draws closer. For example, 20 percent of patients undergo life-sustaining interventions such as intubation and CPR in the last six months of life.

We are overdue for a change in our thinking about end-of-life care. Like President Carter, we will benefit by accepting the inevitability of death and finding ways to experience less suffering and more compassion during our final days.

When done well, hospice care can help patients live fully until they die. It can help them have the best quality of life possible for the time they have left.

### **Hospice Care**

Hospice care is delivered to patients with six months or less of life expectancy. By this time, trying to cure the disease is no longer an option, so efforts to cure are replaced by comfort care only.

Hospice care is designed to relieve suffering, optimize quality of life, and help patients live well until they die. It can help people live longer with less stress and more comfort.

Unfortunately, some doctors believe that hospice means they have failed, and to some patients, hospice represents giving up. Both beliefs are mistaken.

Hospice is not a fast track to death. The patient is not giving up on life. They are simply choosing a smoother, gentler ride for the journey and living the best life possible until they die.

Moreover, selecting hospice care over continuing curative care can sometimes extend the patient's life.

Studies show that older patients in hospice live longer than similar patients who select surgery and other medical interventions in an attempt to prolong life and postpone death.

### **Hospice Is a Type of Care, Not a Place**

In the U.S., hospice does not refer to a place but to a type of care reimbursed by Medicare or health insurance and carried out primarily in people's homes.

Hospice helps patients—and their loved ones and caregivers—not just physically but emotionally and spiritually, too.

This is possible because a hospice team includes doctors, nurses, social workers, home health aides, interfaith chaplains, trained volunteers, bereavement counselors, and complementary therapists. Together, they offer a wide range of services.

Those services include medical supplies and equipment, nursing care, respite services (relief for the caregiver), medications to manage symptoms like pain, and spiritual support.

The supplies and medical equipment include an adjustable hospital bed, a wheelchair, a bedside toilet, and needed drugs and medications. Volunteer visits are also often offered, along with 24/7 telephone support.

Many hospices, especially nonprofit ones, offer complementary or non-pharmacological interventions (as an adjunct to conventional treatment), including touch (such as hand massages with lavender), music therapy, art therapy, pet companionship, and aromatherapy.

Hospice focuses on doing everything possible to improve the quality of life while the terminal disease takes its natural course. As a result, it increases the chances of a peaceful death.

### **Hospice Doesn't Do Everything**

Hospice does not provide home care 24/7. So when you get hospice care, you don't suddenly get a nursing care team to take over. Some people are surprised to learn this.

Hospice team members provide house calls lasting one or two hours but are not with the patient for hours on end.

Bathing, feeding, changing soiled diapers, and giving medication must be provided by loved ones or by aides hired and paid for by the family.

While hospice teams are impressive, the fact remains that patients in hospice are on their own most of the time, so there is an abundance of work left for friends and loved ones to do.

The hospice nurse will teach caregivers how to administer, for example, morphine if it is needed, but actually administering morphine and other medications, keeping the patient clean, changing

bed sheets, shifting the patient's body so they don't get bed sores, and a range of other menial, tedious, and burdensome tasks are left for the family to do.

If you can afford it, it probably makes sense to hire nursing aides or home health aides to help reduce the daily work burden on the caregivers.

### **The Benefits of Hospice Care**

The benefits of hospice care include living longer, living with a higher quality of life, the comfort of receiving care at home, dying more gently and peacefully, having fewer emergency room visits and non-beneficial treatments, support for loved ones by a team of professionals, and decreased cost.

Research shows that patients at the end of life seek out hospice far too late and consequently fail to receive all its benefits, missing out on months of helpful care and quality time.

Once enrolled in hospice care, loved ones should always call the hospice before calling 911 because, with hospice, the aim is to treat agitation or other problems at home if possible and avoid getting overmedicalized in hospital.

### **Death Doulas**

Death doulas are an excellent supplement to hospice care because they provide the one thing hospice has a limited supply of, and that is spending virtually unlimited time with the families and patients.

But they come with a price tag that some families may not be able to afford.

In contrast to hospice, Medicare and insurance carriers do not reimburse the cost of death doulas. Instead, the dying patient or their family pays the death doula.

### **Finding a Hospice**

You or your loved ones must choose a hospice that respects your priorities, values, and beliefs and will honor your end-of-life choices.

You want to find out answers ahead of time to questions like how often a hospice team member will visit and how long most visits will last. Another critical question is how your medical care will change when you enter hospice. All curative treatments for the terminal disease will stop, and comfort care will be paramount.

The people on your hospice team will play a vital role in the last months and days of your life, and each hospice has a different set of policies. You want to select a hospice that will provide the care you want.