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# THE SILENT PANDEMIC: HEART DISEASE

**Dear Caring Family,**

Heart Disease is present in every American family. It affects one in three adults and kills one in of four—more than any other disease.

COVID-19 has increased premature death of heart patients because many have not sought essential treatment for fear of contracting the virus.

No one with advanced heart failure need suffer alone or die prematurely due to lack of care. That is where we come in—The National Partnership for Healthcare and Hospice Innovation (NPHI). NPHI numbers 80 not-for-profit community based advanced illness and hospice care providers. Beginning in April of 2021, our national network launched a nationwide campaign—ADVANCED CARDIAC CARE.



**Tom Koutsoumpas, CEO, NPHI**

Now families with loved ones suffering from advanced heart failure can receive the full support of NPHI member home-based cardiac care including hospice when necessary. We can prevent endless trips to the ER, and endless stress for patients and their families. More importantly, we can provide weeks, even months of quality time at home rather than a loved one suffering and dying in a hospital, isolated and alone.

No family should go without in-home care for heart disease. And we turn no one away—even if they have no means to pay.

To learn more visit [www.hospiceinnovations.org](http://www.hospiceinnovations.org) and download a complimentary copy of our new *Advanced Cardiac Care Patient and Caregiver Handbook*. Or call **844-GET NPHI** (438-6744) to receive a copy from your local NPHI member.

**No one with heart failure should ever suffer alone. Ever.**

**Tom Koutsoumpas, CEO, National Partnership for Healthcare and Hospice Innovation (NPHI)**

The National Partnership for Healthcare and Hospice Innovation (NPHI) member programs are patient, family and community-focused advanced illness and hospice care providers with expertise and passion for the mission of the highest quality, person and family centered, mission oriented end-of-life care.

[hospiceinnovations.org](http://hospiceinnovations.org)



**National Partnership for  
Healthcare and  
Hospice Innovation**

*The not-for-profit voice for advanced illness,  
hospice, and palliative care*





## QUESTIONS TO ASK

If you have a terminal illness and are approaching the end of your life, it's a good time to start thinking about in-home hospice care. Your doctor can help you to understand your options and refer you to hospice providers in your area. Here are some good questions to ask:

+ How much time do you think I have?

+ Do you recommend hospice?

+ How will hospice change my care?

+ What other benefits can I receive?

+ What will hospice offer my family or other caregivers?

+ What if I change my mind?

where they live, and more than half of hospice patients die at home. Whatever your condition may be, the goal of hospice is the same: to keep you comfortable and allow you to focus your energy on what matters most to you at the end of your life.

# CONDITIONS THAT COULD LEAD TO IN-HOME HOSPICE CARE

## WATCH OUT FOR THESE COMMON DIAGNOSES

By Kendall K. Morgan

Reviewed by Neha Pathak, MD, WebMD Medical Editor

Any condition that leads two doctors—for example, your primary doctor and a hospice doctor—to certify that your expected life span is 6 months or less could lead you to in-home hospice care. Many patients in hospice actually have multiple conditions that might qualify them. Your principal diagnosis will be the one that your doctor determines is most responsible for your terminal status.

“It can be any terminal condition, but there are some common conditions that we see,” says Lori Bishop, a health care nurse executive and vice president of Palliative and Advanced Care at National Hospice and Palliative Care Organization (NHPCO) in Alexandria, VA. “In the elderly population and as people are living longer, many have multiple serious illnesses. It's not unusual to have dementia and heart disease.”

About a third of hospice patients in recent years have an advanced cancer that no longer is responding well to treatment. Other common diagnoses that lead to hospice include:

- Advanced heart failure or other heart disease
- Alzheimer's or dementia
- End-stage (or advanced) lung disease, such as chronic obstructive pulmonary disease (COPD)
- Severe stroke
- HIV
- Amyotrophic lateral sclerosis (ALS)
- Parkinson's disease

“Dementia can be very tricky because it really depends on the type of dementia you have,” Bishop says. “Some progress more quickly and others are slower.”

Hospice care will depend on the type of dementia and the expected prognosis. In some cases, a person with dementia or another condition may worsen for a time and then level out or even improve. The good news is that it's possible to enter and leave hospice multiple times if your condition, circumstances, or wishes change.

The vast majority of people receive hospice care at home or in a nursing or assisted living facility

# COUNSELING FOR CAREGIVERS AND FAMILIES

## HOW TO FIND SUPPORT AS YOU NAVIGATE HOSPICE WITH YOUR LOVED ONE

By Rachel Reiff Ellis

Reviewed by Neha Pathak, MD, WebMD Medical Editor

### BY THE NUMBERS

#### Facts about caregiving and mental health.

**40% to 70%**

Amount of family caregivers with clinically significant symptoms of depression.

**4 out of 10**

Number of family members who find caregiving highly stressful.

**14.5%**

Amount of caregivers who report 14 or more mentally unhealthy days in a month.

Hospice is more than just care for a loved one at the end of life. The process of hospice focuses on the physical, emotional, and spiritual well-being of both the dying person and their entire family.

“Cicely Saunders, the physician who founded hospice in England in 1967, based it specifically on addressing caregivers’ needs,” says Judy Bartel, nurse and chief clinical officer for Hospice of the Western Reserve in Cleveland, OH. “It’s intended to be a unit of care, supporting both the patient and the family.”

### WHERE TO TURN

Hospice teams are made up of many members who are trained to counsel and support caregivers. “It’s the entire team’s responsibility to actively listen, to take care of the total care of the patient and family,” Bartel says.

These include:

- **Bereavement counselors.** These

trained professionals can help you talk about what it’s like to have a loved one die. They are familiar with the grief process and can help normalize your emotions.

- **Chaplains.** Even if you aren’t religious, you and your loved one may grapple with issues surrounding the meaning of life. “Chaplains provide spiritual care, not necessarily religious care,” says the Rev. Jill M. Joyner, hospice chaplain in Atlanta. A hospice chaplain can help guide you through questions about purpose, impact, and other big end-of-life questions.
- **Social workers.** In addition to emotional support, social workers can help guide you through the logistics of hospice such as finances, transportation, and insurance.



## COMMON GRIEF NEEDS

Hospice expert Judy Bartel lists emotional and psychosocial areas that research shows can help usher in a “good death” for all involved.

- + **Anticipatory grief.** Dealing with the weight and pain of loss you feel as you come to understand your loved one will die.
- + **Helplessness.** Sorting through feelings of being out of control and helping your loved one find purpose and meaning as they deal with the same issue.
- + **Closure.** Working on saying thank you, goodbye, and/or “I forgive you,” with words or actions.
- + **Gratitude.** Learning how to tap into thankfulness for your loved one and express this to them or yourself.

“All of these people are licensed counselors, or if they do spiritual care, they have had mandatory continuing education credits related to pastoral care,” Bartel says. “Most hospices have music and art therapists that are licensed counselors as well.”

Even bedside aides who spend the most time physically present with your loved one can provide the family with active listening and emotional support, even if they aren’t formally licensed as counselors.

Also good to know: Hospices are required by Medicare to provide bereavement services to family members and friends for at least a year after the hospice patient dies.

“We do grief support, we do art therapy, we do music therapy,” Joyner says. “I’ve even had a standing once-a-month lunch date with a widow who was having a really hard time with her husband’s death. Support is there to serve as a safety

net for grieving families.”

### HOW COUNSELING CAN HELP

Your well-being matters, even as you’re focused on the end of a loved one’s life. What’s more, finding care and support can actually help you give better care.

“Often, when caregivers are able to gain more of a sense of emotional control, it helps the patient have less angst and feel less unsettled,” Bartel says.

When you tap into your own resources for emotional and spiritual support, it can help you deal with the wide array of emotions that can come with caring for a dying loved one, such as:

- **Burnout.** Caregiving at the end-of-life can be lonely and exhausting. Counselors can be a source of respite for you to vent as well as learn strategies to avoid becoming overwhelmed.
- **Anger.** You may find yourself feeling

overly irritable and angry as you come to terms with the fact that your loved one is going to die. Often, anger can lead to guilt. A counselor can help you deal with these intense feelings and find healthier outlets for your frustration.

- **Fear.** Being in charge of someone’s care, even with the help of hospice, can feel daunting. Thinking about your loved one going through the death process itself may also make you anxious. Professionals who deal with death often can help you understand what’s to come so you know what to expect.
- **Decision-making.** Though counselors can’t tell you what to do, they can support you and help you talk through the sometimes hard choices you and your loved one will need to make as death nears.



# UNDERSTANDING ADVANCE DIRECTIVES

## KNOW THE BASICS ABOUT END-OF-LIFE CARE BEFORE YOU GET THERE

By Kendall K. Morgan

Reviewed by Neha Pathak, MD, WebMD Medical Editor

Advance directives are legal documents that state your wishes in the event that you can't make your own health care decisions. Silvia Perez-Protto, MD, director of the Center for End of Life Care at the Cleveland Clinic in Ohio, says that perhaps the most important is a medical power of attorney.

The medical power of attorney allows you to assign who will make health care decisions for you. You can choose three members of your family or friends, listed in order of priority. Without this document, these decisions will be made by your spouse or family members according to the laws in your state.

"If you don't have a health care power of attorney, a family member per state hierarchy will still make decisions," Perez-Protto says. "But if you are estranged from family, we don't have a surrogate. If something happens, let's say that a person is married but separated, the law in the state of Ohio says you have to go through that person to make decisions. If a person has been living with someone for 20 years but is not married, they will have no say because they are not related by blood or marriage. The advanced directive helps you to choose who should make decisions for you if you do not have capacity to make your own decisions."

Advance directives also include the living will. The living will outlines which medical treatments or procedures you want (or don't want) to keep you alive if you can't make decisions or if you are permanently unconscious. A living will

tells your doctor if you want to die naturally with only comfort care. It may cover medical decisions related to:

- Cardiopulmonary resuscitation (CPR)
- Mechanical ventilation
- Tube feeding
- Dialysis
- Antibiotics
- Comfort or palliative care
- Organ donation

As important as these documents are, Perez-Protto says, they aren't enough. "It's important to have conversations [with loved ones] about your goals and what you want if something happens. It's difficult to have these conversations, but we have to have them." She recommends online resources such as "The Conversation Project" to guide you.

If you have a terminal illness or are nearing the end of your life, advance directives are especially key. But Perez-Protto says it's never too soon to put these documents in place. Make sure they are signed by witnesses or notarized, and ask your health care providers to put them into your medical chart where they will be readily available if the need arises. You'll need to revisit these documents over time as circumstances or your wishes change.

"I recommend that every adult have advance directives independent of their health," Perez-Protto says. "Anyone can have an accident or stroke anytime and become incapacitated. Having this document in the medical record helps the medical teams to know your wishes and reach the right person, who you want to make decisions."



GETTY IMAGES



# WHAT CAN IN-HOME HOSPICE CARE DO?

## LEARN ABOUT THE BENEFITS AVAILABLE TO YOU

By Kendall K. Morgan

Reviewed by Neha Pathak, MD, WebMD Medical Editor

When it's clear that treatment isn't working and you or a loved one is approaching the end of life, it's time to think about hospice care. The goal of hospice is to live as well as you can with treatment focused on comfort and quality of life. In most cases, hospice care happens at home.

"A lot of times people wait too late and then wish they would have accessed hospice care sooner," says Lori Bishop, vice president of Palliative and Advanced Care at National Hospice and Palliative Care Organization in Alexandria, VA. "I call it the Cadillac of health care benefits. I don't know of another benefit that's as comprehensive."

If your doctors certify that you are expected to live for 6 months or less, in-home hospice care will cover:

- Treatment for symptoms such as pain
- Medical, nursing, and social services
- Home health aides and volunteers
- Physical, occupational, and speech therapy

- Medical equipment and supplies
- Spiritual and grief counseling

"Hospice covers visits by an interdisciplinary team," explains Bishop, a health care nurse executive who led hospice and palliative care programs for many years. "It's not just a nurse, but also hospice physicians and nurse practitioners. You're also getting a social worker to not only help you as an individual who is ill, but the whole family. That's often a concern of individuals [at the end of their life]. They don't want to be a burden to the family. Hospice is a way for the family to get support, too."

Hospice doesn't include treatment to cure your illness, and you'll need to have a primary caregiver. This is usually a spouse, other family member, or friend, who will work with your hospice team. Depending on your needs, hospice nurses or others on the team will make regular visits. They're also available by phone at any time, day

## EXPOSING HOSPICE MYTHS

There are many misconceptions about hospice care and what it means to enroll.

"A lot of people think hospice means imminent death, that you have hours to days to live," says Lori Bishop, a hospice and palliative care expert.

But, she says, it's often best to take advantage of hospice care for weeks if not months to get the most benefit. The duration of hospice care isn't limited, nor will hospice care hasten your death. Bishop says that many people who access hospice sooner actually live longer, in part because of the comfort care and other services they receive.

If your condition improves or a new treatment option becomes available, it's also possible to leave hospice and start it up again later, if you wish.

or night. Hospice aides and trained volunteers can give your family caregiver(s) some needed relief along with about a year's worth of bereavement care and support after your death.

"Hospice is as much about living as it is about the end of life," Bishop says. "It's about how you want to spend your time and deal with symptoms or emotions that might be burdensome to help you live the best life for the days that you have left."



# THE GREATEST PANDEMIC IN AMERICA IS **HEART DISEASE.**

## IT AFFECTS ONE OF THREE ADULTS AND KILLS ONE OUT OF FOUR.



**Dr. Cameron Muir** (pictured) and his colleagues – members of The National Partnership for Healthcare and Hospice Innovation (NPHI), are committed to dramatically improved care for heart failure patients.

**THOSE WITH  
ADVANCED HEART  
FAILURE NEED  
NOT SUFFER  
ALONE ANYMORE!**

**Question:** Dr. Muir, why are NPHI members addressing heart failure during the COVID-19 pandemic?

**Dr. Muir:** COVID-19 has increased the risk of premature death because many heart patients are not seeking essential treatment for fear of contracting the virus. We provide heart failure care including hospice care wherever people call home. We come to you and maintain rigorous infection prevention protocols to ensure the highest level of safety to avoid COVID transmission.

**Question:** You are launching a new comprehensive heart care initiative – what's it called and what do you hope to achieve?

**Dr. Muir:** This aggressive focus on heart disease is called Advanced Cardiac Care. Two major reasons.

- 1** Very few families with loved ones suffering from advanced heart failure seek the full support of home-based care and hospice which is a tragedy. A tragedy, because we can prevent needless pain, endless stress for patient and family members, and provide weeks and even months of quality time vs the patient suffering and then dying in a hospital bed isolated and alone.
- 2** Among minority families and the LGBTQ+ population very few receive proper advanced cardiac care. We will work proactively to establish trust, increase access to high quality care, and reduce their need to seek extremely stressful ER treatments often entailing countless trips to the hospital.

**Question:** What can folks do right now to find out more about Advanced Cardiac Care?

**Dr. Muir:** They can go to [www.hospiceinnovations.org](http://www.hospiceinnovations.org) to print a copy of our brand new Advanced Cardiac Care Patient and Caregiver Handbook. Or call **844-GET NPHI (438-6744)** to receive a copy from their local not-for-profit NPHI member.

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