

Advisor

For Members of Heartland Alliance of America



Support for Serious Illness Palliative Care Is Here to Help

(NIH-News In Health) Being diagnosed with a serious illness is life-changing. Many decisions must be made, with many unknowns. But there are experts who can help you navigate the complicated landscape of a long-term, serious illness. Palliative care specialists focus on comfort care and improving your quality of life during a serious illness.

"Palliative care is a holistic approach to medicine and caregiving," explains Dr. Matthew DeCamp, a physician at University of Colorado, Anschutz Medical Campus. "It places the patient's quality of life and needs and values front and center."

Sometimes, palliative care is confused with hospice care. Both offer comfort care and symptom management. Hospice is a type of palliative care that's only offered at the end of life. It requires all treatments be stopped. But other types of palliative care can be offered alongside life-saving treatments.

"Embracing palliative care does not mean that you're giving up on treatment," says Dr. Alexis Bakos, an aging expert at NIH. "Ideally, palliative care should be offered at the very beginning of a diagnosis of any serious illness."



work with you to make sure your advance care plan reflects your concerns and goals.

“Unfortunately, advance care planning conversations often don’t happen until too late,” Wiener says. “If you wait until you are experiencing a medical crisis or if you are at the end of your life, you don’t really have the time to contemplate what is most important to you.”

Wiener’s team studies ways to help children with cancer communicate their care wishes to their family and health care providers. They’ve created an advance care planning guide, called “Voicing My CHOICES.” It helps teens and young adults consider and document their values, hopes, and fears.

What makes an illness “serious?” A high risk of death or one that lowers your quality of life or ability to perform daily tasks. Examples include chronic heart and lung diseases, cancer, neurodegenerative diseases like dementia and Parkinson’s, and many others.

A palliative care team can assist with many aspects of a serious illness. They can help you find ways to cope with physical, psychological, emotional, or spiritual suffering. They can support you with symptom management and assist health care providers in coordinating your care.

The palliative team can also help you create an advance care plan. This describes your wishes for future medical treatments. It includes who you want to make your medical decisions if you’re not able to. The team can also support you with end-of-life care, hospice care, and bereavement if needed.

Making a Plan

“The goal of palliative care is to lessen symptoms and enhance quality of life,” says Dr. Lori Wiener, a palliative care expert for children with cancer at NIH. “And there’s good data to support that early palliative care integration improves health-related quality of life.”

But what makes a better quality of life can be different for everyone. “The palliative care provider will meet with you really early on. They’ll find out about your medical history and the symptoms that are most distressing to you,” says Wiener. “They will learn your preferences for care and communication.” Then, the provider can

The team also developed an electronic distress screening tool, called “Checking IN.” This tool assesses what’s most distressing to the child. It asks about symptoms that interfere with their life when they check in to their appointment. Then, it provides a report to the doctor ahead of time. Emotional and physical distress are often missed in children and teens with serious illnesses. Checking IN helps doctors learn about youths’ needs before their visit.

Gaining a Better Understanding

Planning for a serious illness can be complicated. “Patients and families often remain unaware of how their serious illness may progress,” says DeCamp. “They may not know how long they might be expected to live or how long or what types of symptoms they might have. Physicians, nurses, and other members of the care team are



also historically not very good at predicting the course of a disease.”

Artificial intelligence (AI) tools have become available to help predict the course of a person’s disease, or prognosis. “Understanding prognosis is one critical piece of information that people need for their future life and care plans,” DeCamp says. “The promise of AI-based tools is that we can make better predictions for clinicians, patients, and families to enable them to get care that’s most consistent with their wishes.”

DeCamp is studying ethical issues around using an AI tool that calculates a “mortality score.” This score estimates a patient’s chance of survival over the next six to 12 months.

Sometimes these scores are automatically included in medical records, DeCamp says. So a patient may accidentally see it when they don’t want to know their chances of survival. Or health care staff may be able to view the scores, despite the families not wanting them to.

Knowing the mortality score has the potential to change how a patient is treated. “If we become overly focused on that number, it could affect how we talk to patients,” DeCamp explains. “It could also affect the way patients and families make decisions versus what palliative care is really about, which is providing care across all of physical, social, psychological, and spiritual needs.”

The accuracy of AI predictions depends on many factors. These include whether the AI was trained using data from people with backgrounds and health conditions like the patient’s. DeCamp’s team is hoping to help address these types of ethical issues as AI tools become more available.

Getting the Help You Need

If you’ve been diagnosed with a serious illness, ask your doctor about palliative care. Some providers may not offer it to you early on. Others may not offer it at all. But your provider may be able to refer you to a palliative care specialist.

“Earlier NIH research was focused on making sure that primary care clinicians were aware of palliative care,” Bakos explains. Now, NIH is looking at how to involve more specialists in palliative care conversations, such as emergency department physicians, neurologists, and intensive care unit providers.

Palliative care can help you improve your quality of life and understand your treatment options. It’s available as soon as you are diagnosed with a serious illness.

Discuss Advance Care Planning

Here are some tips for starting a conversation about advance care planning with your loved ones:

- **Start simple.** Ask about any concerns they may have, what decisions they may need to make, and who they trust to make decisions for them.
- **Share what’s important to you.** Your loved one may feel more comfortable discussing their preferences if you share, too.
- **Remind them why it’s important.** By documenting their wishes, they are more likely to get the care they want. It can also help loved ones feel less burden, guilt, and depression.
- **Try to be understanding.** After a recent diagnosis or health change, it can be overwhelming and difficult to discuss the future.
- **Keep the conversation going.** Listen carefully to what the person says and encourage them to continue sharing.
- **Provide information on [how to get started](#).**

NOTICE of ANNUAL MEETING of MEMBERS



The Annual Meeting of the Members of the Heartland Alliance of America will be held at 12444 Powerscourt Drive, Suite 500A, St. Louis, Missouri 63131 on Monday, September 15, 2025 at 10:00 a.m. CST for election of Directors and for the transaction of such other business as may properly come before the meeting or any adjournment thereof.

The above notice is given pursuant to the By-Laws of the Association.

PROXY **Heartland Alliance of America** **September 15, 2025 Annual Meeting of Members** **THIS PROXY IS SOLICITED ON BEHALF OF** **THE HEARTLAND ALLIANCE OF AMERICA**

The undersigned Member of the Heartland Alliance of America does hereby constitute and appoint the President of the Heartland Alliance of America, the true and lawful attorney(s) of the undersigned with full power of substitution, to appear and act as the proxy or proxies of the undersigned at the Annual Meeting of the Members of the Heartland Alliance of America and at any and all adjournments thereof, and to vote for and in the name, place and stead of the undersigned, as fully as the undersigned might or could do if personally present, as set forth below:

1. () FOR, or to () WITHHOLD AUTHORITY to vote for the following nominees for the Board of Directors for the terms of office as set forth below:
 - a. John Marshall
 - b. Samuel Reeves
2. In their discretion, the proxies are authorized to vote upon such other business as may properly come before the Meeting.

DATED: _____, 2025

Signature _____

Name (please print) _____

Please date and sign and return promptly to 12444 Powerscourt Drive, Suite 500A, St. Louis, MO 63131 whether or not you expect to attend this meeting. The Proxy is revocable and will not affect your right to vote in person in the event that you attend the meeting.

St. Louis, Missouri

Date: August 15, 2025

(over)

HEARTLAND ALLIANCE OF AMERICA IS AN ASSOCIATION—NOT INSURANCE.

The Heartland Alliance of America (“Heartland”) will be nominating two directors to its Board of Directors at its annual meeting on September 15, 2025. Heartland’s Board of Directors has appointed a Nominations Committee to nominate successor directors. Heartland members may also propose nominations for the Board of Directors. Heartland members may nominate individuals to the Board of Directors through a written petition. The petition must identify the individual being nominated and must be signed by at least 30 current active Heartland members. All nominations for Directors, including nominations by petition, must be submitted to Heartland no later than September 1, 2025. A sample petition is printed below for your review.

Petition for Nomination to the Heartland Board of Directors

Individual being Nominated: _____

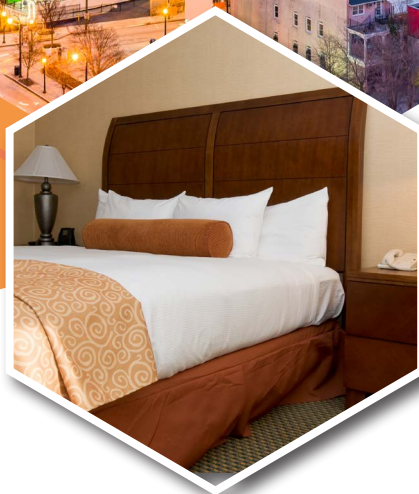
Heartland Member Name:

This image shows a blank sheet of white paper with horizontal ruling lines. The lines are evenly spaced and run across the width of the page. There are no margins, text, or other markings on the paper.

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