



Support for Serious Illness Palliative Care Is Here to Help

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.”

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.

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 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.

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Definitions

Neurodegenerative Diseases

Diseases in which nerve cells stop working or die.

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

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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 informa-

tion 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. Learn more at go.nih.gov/NIHNiHJun25Palliative. ■



Wise Choices

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.** Visit go.nih.gov/NIHNiHJun25CarePlan.

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Web Links

For more about palliative care, see “Find More Information” in the online article: newsinhealth.nih.gov/2025/07/support-serious-illness

Wonderous Worms

Unearthing New Insights Into Health

Worms tend to be long, skinny, wiggly creatures. Their simple bodies lack limbs and a backbone. Most have no eyes. It's hard to imagine a creature more strikingly different from people. Yet studies of worms have given scientists surprising insights into the basic biology of human life and health.

A tiny worm called *Caenorhabditis elegans*, or *C. elegans*, is a favorite among biologists. Unlike worms used for fishing, *C. elegans* are best viewed with a microscope. Scientists have been studying this simple animal for over 70 years.

"We've seen over and over again that these worms can lead to major findings relevant to human health and disease," says Dr. Ann Rougvie, an expert in *C. elegans* biology at the University of Minnesota.

Research on these common worms helped lay the foundation for at least four Nobel Prizes. One study revealed how genes can control organ development and cell death. This gave insights into Alzheimer's disease, AIDS, and more. Another study led to a new class of drugs to treat cancer and other disorders.

C. elegans was also the first animal to have all of its DNA sequenced, every cell named and tracked, and all of its nerve cells mapped.

Like humans, *C. elegans* has a brain, muscles, digestive system, and more. But the simplicity of worms makes them easier to study. The worm's entire nervous system, including the brain, is made of just 302 cells.

"This is in contrast to the human brain, which has billions and billions of cells," Rougvie explains. Yet people and worms have many of the same molecules that carry signals in the brain and nervous system.

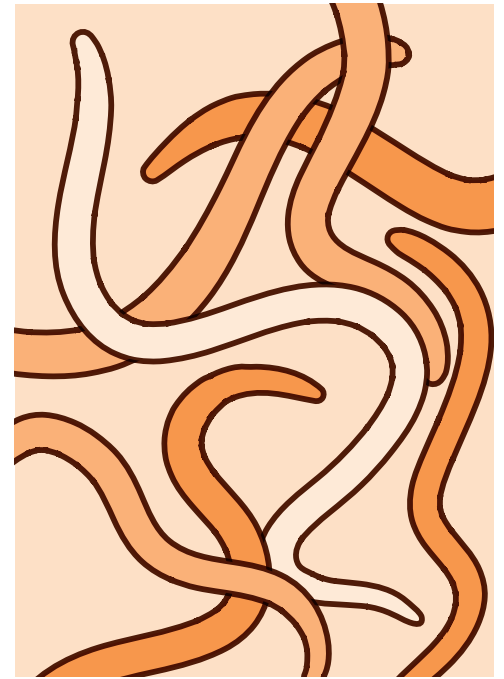
By altering specific genes, researchers have created worms that have conditions similar to humans. Examples include dementia, stroke, or heart disease.

"About 50% of the genes in these worms have counterparts in humans," Rougvie says. By comparing genetic sequences across different animals, scientists can figure out how genes function. And they can learn how genetic glitches can affect health and disease.

In early development, cells follow similar patterns when forming body parts in people and worms. But, *C. elegans* is transparent, so you can see exactly what's happening inside.

"The adult worm always has 959 body cells. With a microscope, you can watch development happen from the fertilized egg to the adult," Rougvie says. "The cells divide in essentially the same pattern in every *C. elegans*." So researchers can predict which cells will become muscle, nerve, or other cells. That, plus the worms' two-to-three week lifespan, has helped shed light on processes like development and aging.

Rougvie manages the NIH-sup-



ported *Caenorhabditis* Genetics Center. It houses over 26,000 genetically unique strains of *C. elegans*. Some strains are short and fat. Others can glow. Some age faster than others. Scientists around the world can order specific strains of worms for their own research. And they can contribute new strains to the center.

"If everyone gets their worms from us, that means everybody's using the same strains of worms. And that enhances consistency and reproducibility of research findings," Rougvie says.

"I'm a strong believer in basic research, which is asking fundamental questions about how life works," she says. Such basic research in *C. elegans* more than 30 years ago led to discovery of a new type of molecule, called microRNAs.

"Scientists have since learned that microRNAs are present in all animals. And they're extremely important to human health and disease," Rougvie says. "This type of curiosity-driven science helps us learn how life works in general." The researchers who discovered these molecules received a Nobel Prize last year. ■



Wise Choices

Why Scientists Choose *C. elegans*

- **Simple.** Basic discoveries in the worm can shed light on activities in more complex creatures.
- **Small.** Their tiny size makes them inexpensive and easy to house.
- **Freezer-friendly.** Living worms can be stored in the freezer for decades, then thawed and revived for future study.
- **Glow worms.** *C. elegans* cells can be modified to produce glowing proteins, which lets scientists track the proteins. This research use led to a Nobel prize in 2008.



Web Links

For more about basic research models, see "Find More Information" in the online article: newsinhealth.nih.gov/2025/07/wonderous-worms



Health Capsules

For links to more information, please visit our website and see these stories online.

Baby With Rare Disease Gets Personalized Gene Therapy

Scientists have found ways to fix faulty genes for some common genetic disorders. These include sickle cell disease, various blood disorders, and a severe skin condition. But treating rarer genetic conditions has been more challenging. A new NIH-funded study used a personalized gene-editing approach in a baby born with a rare, often deadly disorder.

The baby had a disease called CPS1 deficiency. People with this disease don't have the enzyme that removes harmful ammonia from the body. About half of babies with

CPS1 deficiency die as infants. The research team had spent years creating personalized therapies for people with similar disorders. So they were ready when the newborn showed symptoms of CPS1 deficiency.

The team quickly crafted an experimental gene therapy. The baby received two treatments around the time he was six months old. A few weeks later, he needed less medication to keep ammonia levels in check. And his diet could include more protein. Protein intake can lead to ammonia buildup in kids

with untreated CPS1 deficiency.

No serious side effects were seen. But follow-up will be needed to be sure the therapy remains safe and effective. With further study, this type of personalized gene therapy could help to treat a variety of disorders.

"Years and years of progress in gene editing and collaboration between researchers and clinicians made this moment possible," says Dr. Rebecca Ahrens-Nicklas of the Children's Hospital of Philadelphia, who helped lead this study. ■

Grinding Your Teeth?

Do you often find that you're clenching your jaw or rubbing your teeth together? Do you tend to wake up with a sore jaw, ear pain, or headache? If so, you may have a condition called bruxism. That's the medical term for clenching your jaw or teeth or grinding your teeth.

Mild or occasional tooth grinding or clenching may not cause problems. But frequent or severe bruxism can lead to jaw pain, fatigue, and headaches. It can damage your teeth

and make them crack, loosen, or even fall out.

Bruxism is more common in children than adults. Many people with bruxism don't realize they have it, especially if it occurs during sleep. The causes of bruxism are not fully understood. But the condition has been linked to stress, depression, smoking, alcohol, caffeine, certain medications, and other factors.

If you think you may be grinding or clenching your teeth, talk to a

health care provider. They might suggest ways to reduce stress, relieve depression, or improve sleep. They can also suggest how to protect your teeth and break the habit of tooth grinding.

Visit your dentist regularly. They can check for signs of bruxism, such as tooth wear and jaw muscle tenderness. Learn more about bruxism at www.nidcr.nih.gov/health-info/bruxism. ■



Featured Website

Risky Drinking Can Put a Chill on Your Summer Fun

go.nih.gov/NIHNIHJul25RiskyDrinking

Drinking alcohol in the heat can mean trouble. Heat plus alcohol can raise the risk for sunburn, dehydration, and drowning.

Be smart this summer. Think before you drink. Stay safe and stay healthy. Get tips at this NIH website.



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