

PALLIATIVE CARE

The Relief You Need When You Have a Serious Illness







PALLIATIVE CARE:

Improving quality of life when you're seriously ill.



Dealing with any serious illness can be difficult. However, care is available to make you more comfortable right now. It's called palliative (pal-lee-uh-tiv) care. You receive palliative care at the same time that you're receiving treatments for your illness. Its primary purpose is to relieve your pain and other symptoms and improve your quality of life.

Palliative care is a central part of treatment for serious or life-threatening illnesses. The information in this brochure will help you understand how you or someone close to you can benefit from this type of care.

What is palliative care?

Palliative care is comprehensive treatment of the discomfort, symptoms, and stress of serious illness. It does not replace your primary treatment; palliative care works together with the primary treatment you're receiving. The goal is to prevent and ease suffering and improve your quality of life.

If you need palliative care, does that mean you're dying? The purpose of palliative care is to address symptoms such as pain, breathing difficulties, or nausea, among others. Receiving palliative care does not necessarily mean you're dying.

Palliative care gives you a chance to live your life more comfortably.

Palliative care provides relief from symptoms including pain, shortness of breath, fatigue, constipation, nausea, loss of appetite, problems with sleep, and many other symptoms. It can also help you deal with the side effects of the medical treatments you're receiving. Perhaps most important, palliative care can help improve your quality of life and provide help to your family as well.

Palliative care is different from hospice care.

Palliative care is available to you at any time during your illness. Remember that you can receive palliative care at the same time you receive other treatments for your illness. Its availability does not depend upon whether your condition can be cured. The goal is to make you as comfortable as possible and improve your quality of life.

You don't have to be in hospice or at the end of life to receive palliative care. People in hospice always receive palliative care. Hospice focuses on a person's final months of life. To qualify for some hospice programs, patients must no longer be receiving treatments to cure their illness.

Palliative care also provides support for you and your family and can improve communication between you and your health care providers.

Palliative care strives to provide you with:

- Expert treatment of pain and other symptoms so you can get the best relief possible.
- Open discussion about treatment choices, including treatment for your disease and management of your symptoms.
- Coordination of your care with all of your health care providers.
- Emotional support for you and your family.

Palliative care can be very effective.

Researchers have studied the positive effects palliative care has on patients and their families. Recent studies show that patients who receive palliative care report improvement in:

- Pain, nausea, and shortness of breath.
- Communication with their health care providers and family members.
- · Emotional support.

Other studies also show that starting palliative care early in the course of an illness:

- Ensures that care is more in line with patients' wishes.
- Decreases stress and increases confidence in making decisions surrounding a loved one's care.
- Meets the emotional and spiritual needs of patients and their families.

PALLIATIVE CARE

is designed especially for your needs.



Palliative care can improve your quality of life in a variety of ways.

Together with your primary health care provider, your palliative care team provides pain and symptom control with every part of your treatment. Team members spend as much time as it takes with you and your family to help you fully understand your condition, care options, and other needs. They also help you make smooth transitions between all the settings where you may receive care (the hospital, nursing facilities, or home care).

This results in well-planned, complete treatment for all of your symptoms throughout your illness—treatment that takes care of you in your present condition and anticipates your future needs.

Palliative care is a team approach to patient-centered care.

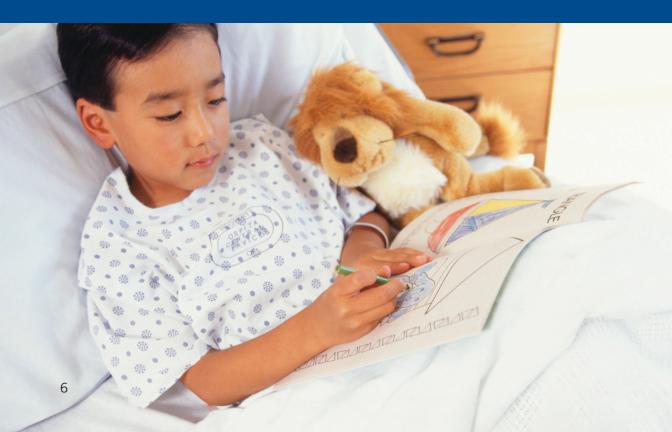
Every palliative care team is different. Your palliative care team may include:

- doctors
- nurses
- social workers
- religious or spiritual advisors
- pharmacists
- nutritionists
- counselors and others



CARE THAT SUPPORTS

you and your wishes.



Palliative care supports you and those who love you by making you comfortable. It also helps you set goals for the future that lead to a meaningful, enjoyable life while you get treatment for your illness.

How do you know if you need palliative care?

Many adults and children living with serious illnesses such as cancer, heart disease, lung disease, kidney failure, multiple sclerosis, AIDS, and cystic fibrosis, among others, experience physical symptoms and emotional distress related to their diseases. Sometimes these symptoms are due to the medical treatments they are receiving.

You may want to consider palliative care if you or your loved one:

- Suffers from pain or other symptoms due to ANY serious illness.
- Has physical or emotional pain that is NOT under control.
- Needs help understanding their illness and discussing treatment.

Start palliative care as soon as you find out that you have a serious illness.

It's never too early to start palliative care. In fact, palliative care occurs at the same time as all other treatments for your illness and does not depend upon the course of your disease.

There is no reason to wait. Palliative care teams understand that pain and other symptoms affect your quality of life and can leave you lacking the energy or motivation to pursue the things you enjoy. They also know that the stress of what you're going through can have a big impact on your family. And they can assist you and your loved ones as you cope with the experience of living with a serious illness.

Palliative care involves working together as a team.

Patients who may want palliative care often wonder how it will affect their relationships with their current health care providers. Some of their questions include:

- Will I have to give up my primary health care provider?
- Who do I ask for palliative care?
- Will I offend my health care provider if I ask questions?

Most important, you do NOT give up your own health care provider to get palliative care. The palliative care team and your health care provider work together.

Most clinicians appreciate the extra time and information the palliative care team provides to their patients. You may have to ask your health care provider for a referral to get palliative care services. Tell your health care provider you are thinking about palliative care and ask how to access palliative care in your area.



Where is palliative care provided?

Palliative care can be provided in the hospital, at outpatient clinics, or at home. The process begins when either your health care provider refers you to the palliative care team or you ask your health care provider for a referral. Palliative care is provided by a team of professionals, including medical and nursing specialists, social workers, pharmacists, nutritionists, religious or spiritual advisors, and others.

Who pays for palliative care?

Most insurance plans cover at least part of the palliative care services, just as they would other medical services. Medicare and Medicaid also typically cover palliative care. If you have concerns about the cost of palliative care, a social worker, care manager, or financial advisor at your hospital or clinic can help you.

How does palliative care address pain?

If you have an illness causing you pain that is not relieved by drugs such as acetaminophen or ibuprofen, the palliative care team may recommend trying stronger medicines.

As always, if you have concerns about taking medications, talk to your palliative care team. They can tell you about how various medications work, what their side effects are, and how to get the most effective pain relief.





Don't wait to get the help you deserve. Ask for palliative care and start feeling better now.

If you think you need palliative care, ask for it now. Tell your health care provider that you'd like to add palliative care to your treatment and ask to meet with the palliative care team or ask for a referral for palliative care.

If you want to find palliative care in your area, go to **www.getpalliativecare.org** to search by state and city.



www.ninr.nih.gov







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