NATIONAL INSTITUTE OF NURSING RESEARCH

PALLIATIVE CARE

The Relief You Need When You're Experiencing the Symptoms of Serious Illness

PALLIATIVE CARE:

Improving quality of life when you're seriously ill.

Dealing with the symptoms of any painful or serious illness is difficult. However, special 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 the pain and other symptoms you are experiencing 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 distressing 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 distressing 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.

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 treatments that are meant to cure your illness. Its availability does not depend upon whether or not 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, but 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. Recent studies show that patients who receive palliative care report improvement in:

- Pain and other distressing symptoms, such as nausea or shortness of breath.
- Communication with their health care providers and family members.
- Emotional support.

Other studies also show that palliative care:

- Ensures that care is more in line with patients' wishes.
- Meets the emotional and spiritual needs of patients.

PALLIATIVE CARE

is comprehensive care 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 combines vigorous pain and symptom control into every part of your treatment. Team members spend as much time with you and your family as it takes to help you fully understand your condition, care options and other needs. They also make sure you experience a smooth transition between the hospital and other services, such as home care or nursing facilities.

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.

A team approach to patient-centered care.

Palliative care is provided by a team of specialists that may include:

- palliative care doctors
- palliative care nurses
- social workers
- chaplains
- pharmacists
- nutritionists
- counselors and others

SPECIAL CARE

that supports you and your wishes.

Palliative care supports you and those who love you by maximizing your comfort. 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 illnesses such as cancer, heart disease, lung disease, kidney failure, AIDS and cystic fibrosis, among others, experience physical symptoms and emotional distress related to their diseases. Sometimes these symptoms are related 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.
- Experiences physical or emotional pain that is NOT under control.
- Needs help understanding your situation and coordinating your care.

Start palliative care as soon as you need it.

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. Serious illnesses and their treatments can cause exhaustion, anxiety and depression. 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 difficult experience.

Working together as a team.

Patients who are considering 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?
- What do I say if there is resistance to referring me for palliative care services?
- Will I offend my health care provider if I ask questions?

Most important, you do NOT give up your own health care provider in order 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. Occasionally a clinician may not refer a patient for palliative care services. If this happens to you, ask for an explanation. Let your health care provider know why you think palliative care could help you.

Getting palliative care is as easy as asking for it.

In most cases, palliative care is provided in the hospital. 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. In the hospital, palliative care is provided by a team of professionals, including medical and nursing specialists, social workers, pharmacists, nutritionists, clergy and others.

Insurance pays for palliative care.

Most insurance plans cover all or part of the palliative care treatment you receive in the hospital, just as they would other services. Medicare and Medicaid also typically cover palliative care. If you have concerns about the cost of palliative care treatment, a social worker from the palliative care team can help you.

What happens when you leave the hospital?

When you leave the hospital, your palliative care team will help you make a successful move to your home, hospice or other health care setting.

If morphine is prescribed, will it be dangerous?

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 such as morphine.

Simply stated, morphine is an opiate – a strong medicine for treating pain. Like other similar opiate medicines (hydrocodone, oxycodone), it provides safe and effective pain treatment. In fact, almost all pain can be relieved with morphine and similar strong drugs that are available today. So no one should suffer because they or their health care provider have concerns about morphine or other drugs in the opiate family.

If I take morphine, will I become addicted?

In fact, very few people who use opiates for pain relief ever become addicted or dependent on these medicines. However, it is important to be aware that anyone taking opiates for more than two weeks should not stop doing so abruptly. You should ask your health care provider about gradually reducing your dose so that your body is able to adjust.

There is no reason to wait until your pain is unbearable before you begin taking morphine. As your pain increases, your morphine dose can be safely increased to provide the relief you need over time.

All opiates can cause nausea, drowsiness and constipation. However, as your body adjusts to the medicine, side effects will generally decrease. Also, side effects such as constipation can easily be managed.

As always, if you have concerns about taking these or any 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 specialists to your treatment team and request a consultation.

If you want to find a hospital in your area that offers a palliative care program, you can go to the Palliative Care Provider Directory of Hospitals at **www.getpalliativecare.org** to search by state and city.

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National Institute of Nursing Research
National Institutes of Health
31 Center Drive, Room 5B10
Bethesda, Maryland 20892-2178

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