

SpeakUP™



What you need to know about your serious illness and palliative care was developed in collaboration with

American Academy of Hospice and Palliative Medicine
www.aahpm.org

Association of Professional Chaplains
www.professionalchaplains.org

Center to Advance Palliative Care
www.capc.org

Hospice and Palliative Nurses Association
www.hpna.org

Lance Armstrong Foundation
www.livestrong.org

National Association of Social Workers
www.socialworkers.org

National Hospice and Palliative Care Organization
www.nhpco.org

What you need to know about your serious illness and palliative care

The Joint Commission is the largest health care accrediting body in the United States that promotes quality and safety.

Helping health care organizations help patients

When you have a serious illness or health problem, you may need palliative care. Palliative care is special health care that can ease pain and other symptoms and side effects from your illness or treatment. It can help you and your family cope with your illness, as well as emotional, practical and spiritual concerns. Palliative care can help you feel better and assist you in dealing with:

- Breathing problems
- Constipation
- Depression
- Exhaustion
- Loss of appetite
- Nausea
- Pain
- Sleeping problems or fatigue
- Spiritual and emotional support

It can also help with:

- Decision making
- Managing your health care
- Planning the future
- Recommending financial resources
- Supporting family members

This brochure will help you and your family talk about palliative care. It will also help you better understand how palliative care can help you.

How do you get palliative care?

Ask your doctor to put you in touch with a palliative care team. A palliative care team includes a doctor, nurse, social worker and chaplain with special training. The team works with you and all your health care providers to give you extra help during your illness. The team can also help you get the palliative care and services that are best for you.

Who can be helped by palliative care?

Palliative care is for anyone with a serious illness or health problem. Even kids can be helped by palliative care.

When can you get palliative care?

You can get palliative care as soon as you are told about your serious illness or health problem. These illnesses can include heart, lung, kidney or liver failure, cancer, and some memory problems.

Palliative care can be given at the same time you are being treated to cure your illness.

Is palliative care the same as hospice care?

Hospice care is a type of palliative care. Hospice care begins in the final months of life. Hospice care also provides a team of care providers to help the patient and support the family. Many hospitals, nursing homes and hospices offer both palliative and hospice care. You can receive palliative care for many years.

Can a family member or friend help with your care?

Yes. You have the right to have a personal representative, or advocate with you when you get treatment and services. Tell your palliative care providers who your advocate is. Also tell them what information you would like shared with your advocate.

Are services and support offered to your family or friends?

Yes. Your palliative care team can teach your family and friends how to help care for you. They can also provide emotional support to your family and friends throughout your illness.

What questions may the palliative care providers ask you?

- Do you have questions about your illness or health problem?
- Do you know what your treatment choices are? Do you need to have the choices explained?
- What are your needs and wishes for care?
- How do you want to make decisions about your care?
- Do you have any symptoms that are bothering you right now?
- What can we do to make you more comfortable?
- What gives meaning to your life?
- How would you like to spend your time among work, school, family, hobbies and other activities?
- How can we help you and your family cope with the changes caused by your illness? Do you and your family need emotional support?

- Do you have a health care power of attorney? If you do not have one, a palliative care provider can help you write down your wishes.
- Would you like to receive spiritual help? Many people find that speaking with a chaplain helps them cope with their illness.

What questions should you ask your palliative care providers?

- What services do they provide? What are the costs of the services?
- Are they certified or licensed?
- Is staff available 24 hours a day, seven days a week?
- Who is the main contact person on the team? How do you reach that person? How often will you talk with them?
- How will they create your palliative care treatment plan? Do they welcome ideas from you and your family about the plan?
- How do they work with your regular doctor and other care providers?
- What can they do to help make your daily life easier? For example, can they recommend a support group or help with transportation? Can they visit you at home?
- Can they provide pain medicines that you cannot get over-the-counter?
- Can they provide an interpreter?
- Do they offer treatments such as massage or music therapy?
- How will your personal, religious or cultural beliefs be addressed?
- Can someone from your faith work with the palliative care chaplain to make sure your spiritual needs are met?

Where can you get palliative care?

Palliative care can be provided in hospitals, clinics, hospices, nursing homes, and your home. Ask:

- Where are palliative care services provided in your area?
- Can you get palliative care services in a place that is convenient for you?
- What happens if you have to move from your home to the hospital, nursing home or other location?

How will you pay for palliative care?

Palliative care is often covered by insurance and government programs. Ask:

- Can they help you find out what services and medicines are covered?
- Can they help you manage paperwork from health care providers, such as bills?
- Can they help you find a way to pay for care?

Where can you find more information?

- Doctors who specialize in palliative care – www.palliativedoctors.org
- Hospitals that offer palliative care – www.getpalliativecare.org/providers
- Information about coping – www.helpstartshere.org
- Palliative care providers and hospices – www.caringinfo.org
- Joint Commission certified palliative care programs – www.qualitycheck.org/help_certified_orgs.aspx