

palliative

complete
care
everyone
deserves

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what is palliative care?

It is active, total care for people with advanced medical illness, especially chronic and progressive life-limiting conditions. The

primary goal of palliative care is to help patients and their families live as fully and comfortably as possible and have the best possible quality of life.

AS A RULE, GOOD PALLIATIVE CARE:

Treats the whole person; meets people's medical, emotional, spiritual, or other physical needs.

Involves family and friends; people closest to the patient such as yourself need to be aware of the patient's wishes—in case you are needed to provide care or speak on their behalf.

Plans for the future; helps patients understand the future course of their illness and think ahead about the choices they are likely to face. Such advance planning allows changes in treatment or living arrangements to be made smoothly and according to a patient's wishes. And planning tells the care team what types

of care are important to a patient. For instance, a person may want to stay at home as long as possible, even if it means risking a fall. Another might prefer to enter a nursing home sooner, so that immediate help is always available.

Is flexible; allows patients to pick and choose among all the possible treatments and therapies available for their condition. For instance, a person may want to avoid unpleasant or not-very-promising treatments in favor of care that will improve the quality of their remaining life (such as pain relief or help with breathing problems).

Can take place in many different settings: in the home, or in nursing homes, assisted-living facilities, hospitals, or hospice. A home-care service or hospital might have staff trained in palliative care. Or a nursing home might have a special palliative care unit.

Is not the same as hospice, which is palliative care for patients nearing death who have decided to forego cure and, instead, focuses strictly on remaining comfortable. Palliative care can be offered alongside treatments that are meant to cure.

Involves a team of family, friends and professional caregivers from different disciplines; spouses, brothers, sisters, adult children, friends, doctors, nurses, acupuncturists, chiropractors, massage therapists, nutritionists, herbalists, social workers, spiritual advisors and psychologists can all play a crucial role in giving a person the care that will make living as comfortable and rewarding as possible.

who needs palliative care?

HERE ARE SOME EXAMPLES:

Selma is a 75-year-old woman with early congestive heart failure who needs therapy to avoid the stress and anxiety that can worsen her breathing problems.

Carlos is a 28-year-old man with severe brain damage due to a job-related accident. He needs round-the-clock care to help him manage nearly every aspect of his life. His family needs help to find all the supports both he and they need.

Frank is getting good medical care but often seems listless and “down.” With nurses’ encouragement, family members find ways to laugh together over favorite jokes and funny movies, to focus on good memories and, in this way, offer their own “symptom relief.”

Chun is a 61-year-old man with esophageal cancer who needs help resting comfortably, relief from his dry mouth, and relief from his severe pain.

elements of good palliative care

Good palliative care means making sure that a variety of needs are being attended to—these needs differ for each individual. Careful

and open planning sessions that include the patient whenever possible are the best way to start deciding on a course of good palliative care.

advance care planning

As a family caregiver, it is important to plan in advance for various situations. Such situations may include: changes in your friend or family member's medical condition; psychological or spiritual issues such as coping with illness and grief; or decisions on whether to pursue a certain therapy or treatment.

SOME QUESTIONS THAT SHOULD BE CONSIDERED AHEAD OF TIME ARE:

What should doctors know about patients' pain? Are there some situations in which patients would tolerate some pain in favor of

increased alertness, or do they want to do everything possible to relieve all pain? Let the doctor know your questions about pain. Find out the options in your case and communicate your preferences to the doctor.

Who should speak for patients if they are unable to do so themselves?

Can all care be given in the home?

Will the time come when assisted living services or a nursing home are needed?

Are there some treatments or kinds of care that patients want even if it would cause unpleasant side effects?

Do patients want to know about all options, including invasive or experimental treatment, even as the illness worsens?

When are the benefits worth the downsides?

What circumstances will offer patients the most ease and comfort?

Do they want company or do they prefer to be alone?

Do they want to be touched or massaged?

Do they want to be surrounded by music?

Do they want to try alternative medical treatments such as acupuncture or chiropractic to improve how they feel?

What type of emotional and/or supportive counseling (if any) will be needed?

What is the best way to meet patients' spiritual needs? Will family and friends also need counseling or support?

Be specific and let the care team know.

The more specific a care plan is—the more the professional staff knows—the better the care and consideration for the patient and the family are likely to be.

care coordination

You may want guidance in anticipating the patient's care needs and in making plans to meet these needs. **You may also need help to identify and coordinate all the services that everyone will need over time.**

Typically, a nurse will be the care coordinator on a palliative care team. If the patient is not in a palliative care program, a social worker or geriatric care manager can help you piece together the elements of a palliative care plan.

who needs
palliative
care?

Li's nursing home has a contract with a palliative care program at a nearby hospital but it does not offer the Chinese massage that helped her in the past. Her daughter, who is willing to pay separately for the massage, works with the hospital social worker to identify a practitioner willing to go to the nursing home and with the nursing home social worker to make arrangements for regular sessions.

Care managers can explain medical information and treatment options.

They can help you keep track of all the types of care and treatment the patient is receiving. And they can assist with handling different institutions such as doctor offices, hospitals, and insurance plans including Medicaid and Medicare.

Programs and facilities that offer palliative care will include a care manager on the professional care team. If you are not part of a program, **you can also find a social worker or nurse through a home health care agency** or a program like the Alzheimer’s Association. (For more information, see the RESOURCES section on p. 14.)

Care managers are also helpful in locating other community resources if some needs are not met by palliative care providers (alternative-therapy providers, disease-specific support groups for the patient or family, or elder-law attorneys, for example).

pain management

Nobody has to be in pain! The doctor, nurse, care provider, or even social worker should be told if the patient reports or seems to be suffering any pain. If this does not get the patient the attention they deserve, you can either request or directly contact a

Patricia is a 62-year-old woman with advanced Parkinson’s disease who cannot walk or feed herself. She needs an assistant at night as well as massage therapy and pain management for severe muscle cramps in her legs and back.

pain-management specialist. Today, there are many effective approaches to managing pain—**nobody should suffer needlessly.** (For more information on locating Pain Management experts, see the RESOURCES section on p. 14.)

Earlene is a 50-year-old woman with multiple sclerosis. In addition to her physical needs, she and her family members need emotional counseling to help them cope with the stress and sadness they're experiencing as her condition advances

who needs palliative care?

psychological aspects & counseling

Often times, the patient and the family need help in dealing with painful feelings and issues that are difficult to talk

about even between people who are very close. Counselors can help all involved feel as positive and supported as possible.

spiritual needs

For some people, religion and/or spirituality are extremely important aspects of life. Good palliative care offers pastoral care from clergy as well as other kinds of spiritual help, depending on the patient's spiritual or religious beliefs. Such guidance should be available to the patient and to involved relatives and friends.

flexibility

Whether it is care that cures, care that comforts, or some combination of the two, good palliative care provides services that meet the patient and/or the family's definition of comfort, dignity, and quality of life.

how to get palliative care

It starts with conversations among family and/or close friends about the kind of care the patient needs and wants. In order to find

palliative care, you or the patient must tell someone it is wanted.

Start asking for help from the providers the patient is already in contact with, or is most comfortable with. This may be a doctor, a nurse from a home health agency, or a social worker from a nursing home or hospital.

The patient will benefit most if the doctor is fully committed to giving the best palliative care and symptom relief. Ultimately, the doctor must be told about the type of palliative care the patient wants. Why? Because **doctors often need to approve any services that insurance will cover.**

Speak up and be persistent! Whether in a hospital, nursing home, home health care agency, or doctor's office—do not stop asking questions until you get the information and help you need.

**working with
nursing
homes
& other facilities**

During the course of long-term care, situations can arise that cause you to question whether your friend or relative is getting the best possible care.

The patient may appear sluggish; want to do more of his or her own personal care; be overly groggy from medication; seem agitated or feel depressed and lonely; be in pain; or be losing a lot of weight.

It is your right to find out if the facility is doing all it can to make the patient feel comfortable—physically, socially, and emotionally—and engaged in life.

HERE ARE WAYS FAMILY CAREGIVERS CAN HELP:

Learn the rules of a facility and learn who really makes the decisions there. Long-term care institutions are similar to bureaucracies with specific chains of command.

Develop relationships and make allies with key staff, such as the social worker, head nurse, recreation director, or aides who will help with bathing and dressing the patient. Visit often. Cooperate with and support staff efforts, and

let them know you are monitoring the care quality your relative receives. **Remember the old saying: The squeaky wheel gets the grease.**

Suggest creative solutions. A person may feel frustrated because he or she cannot talk on the phone. Bring in a message recorder so he or she can listen to familiar voices. Suggest that the staff play the message tape every day.

After his grandfather went into a nursing home, Jim found that starting a family council and asking for a palliative care program for all residents got palliative care for his grandfather and other residents.

**who needs
palliative
care?**

Participate in the family council if there is one. Start one if such a group does not exist.

Sometimes the patient is not the only one experiencing a particular problem. Listen to the grievances and concerns of other family members while you are visiting. If action is needed, it can be taken collectively.

Know your rights so you can get the care your relative needs and is entitled to.

For instance, services should be customized to residents' needs and spelled out in their daily care plan. Know how flexible the care plan can be. Residents can, for example, have services tailored to meet their schedules, as opposed to the convenience of the staff. Family caregivers can and should attend treatment plan meetings. Check with Medicare, Medicaid or other insurance to see if the cost of palliative care is covered.

Remember that change takes time.

Be patient. Be persistent. Be assertive.

ALS Association

Provides education, advocacy, and information about amyotrophic lateral sclerosis (Lou Gehrig's disease). **800-782-4747**
www.alsa.org

Alzheimer's Association

Provides resources for families and caregivers of those suffering from Alzheimer's disease.
800-272-3900 www.alz.org

Children of Aging Parents

Provides publications on a variety of caregiver issues. Also provides support groups in some areas. **800-227-7294**
www.caps4caregivers.org

The Center for Family Caregivers

Provides online support and educational materials to family caregivers.
www.familycaregivers.org

Eldercare Locator

This free, federally-funded service provides information about local services by zip code. **800-677-1116**
www.eldercare.gov

Family Caregiver Alliance

The FCA Web site offers research, publications, statistics, fact sheets, public policy news and information on a variety of long-term care concerns. **415-434-3388**
www.caregiver.org

Friends and Relatives of Institutionalized Aged

Provides information, support and advocacy for New York nursing home residents and their family caregivers. **212-732-4455**
www.fria.org

healthfinder.gov

A free guide to reliable health information developed by the U.S. Department of Health and Human Services.
www.healthfinder.gov

Medicare.gov

The official U.S. government site for people with Medicare.
www.medicare.gov

National Alliance for Caregiving

Provides caregiving tips and guides and an Internet clearinghouse of 1,000 reviewed and rated resources for caregivers.
www.caregiving.org

National Family Caregivers Association

Offers caregiving tips and on-line resources including a support network and resource guides. **800-896-3650**
www.nfcacares.org

National Hospice and Palliative Care Organization

Offers information on hospice and palliative care and advocacy on end-of-life issues.
703-837-1500 www.nhpco.org

National Multiple Sclerosis Society

Provides advocacy, research and information about living with MS and lists of local resources.
800-344-4867 www.nmss.org

Stoppain.org

This award-winning Web site from the Department of Pain Medicine and Palliative Care at Beth Israel Medical Center provides a wealth of information on palliative care.
www.stoppain.org

Well Spouse Foundation

Offers a bimonthly newsletter and support groups in many areas.
800-838-0879
www.wellspouse.org

At left are resources you may want to turn to for help in understanding and finding the kinds of palliative care services your friend or relative wants.

resources



**National Alliance
for Caregiving**

**4720 Montgomery Lane
Bethesda, MD 20814**

www.caregiving.org

FRIA

**Friends and Relatives of
the Institutionalized Aged**

**11 John Street
Suite 601**

New York, NY 10038

www.fria.org

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