



PALLIATIVE CARE 101:

COMFORT IN ALL PHASES OF ILLNESS

IT IS A MEDICAL ILLUSION THAT treating a disease can be separated from caring for the person who is suffering. When doctors and other clinicians focus only on curing an illness — instead of holistically responding to a patient's pain, symptoms and personal needs — they miss the opportunity to provide the broadest spectrum of comfort and quality of life.

Palliative care is a powerful antidote to that disease-specific approach to care, providing specialized expertise in the relief of the pain, symptoms and stress of serious illness. The goal of palliative care is to anticipate, prevent and relieve suffering, creating the best possible quality of life at any stage of an illness. Palliative care is generally low-tech and high touch. It's also a highly complementary approach to care provided at the same time as curative treatment.

Palliative care relieves symptoms such as pain, shortness of breath, fatigue, constipation, nausea, loss of appetite and difficulty sleeping. It helps patients gain the strength to carry on with daily life. It improves their ability to tolerate medical treatments and it helps them better understand their choices for care. It's important to remember that palliative care is not the same as hospice. While hospice programs always provide palliative services, they focus on people who are no longer seeking curative treatments.

Palliative care is not a one-size-fits-all approach. Because patients have a range of diseases and respond differently to treatment options, a key benefit of palliative care is that it customizes treatment to meet individual needs. Palliative care can also provide an opportunity for family and friends to gather information about how an illness is likely to progress and to begin planning for long-term-care needs.

Doctors, nurses and social workers work with chaplains, therapists, pharmacists, nutritionists and others to create a palliative care team. Palliative care focuses on the entire person, not just his or her illness. The team members caring for you will address any social, psychological, emotional or spiritual needs you may have. Collaborating with your primary doctor, your palliative care team provides:

- » Expert treatment of pain and other symptoms
- » Close, clear communication
- » Help navigating the health care system
- » Guidance with difficult and complex treatment choices
- » Detailed practical information and assistance

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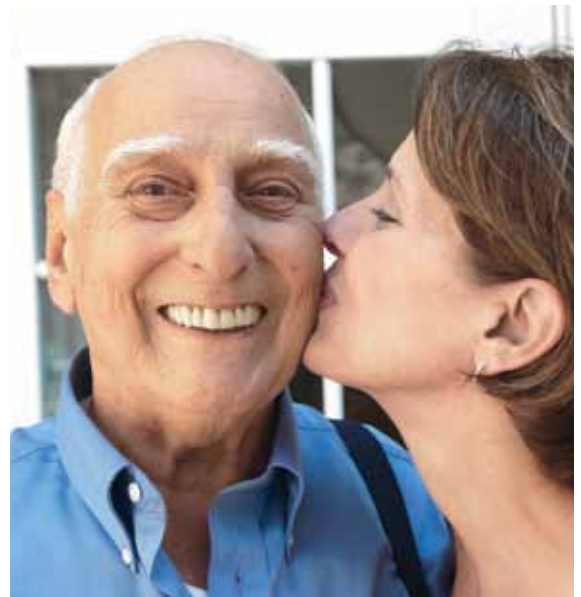
- » Emotional and spiritual support for you and your family

If you are suffering with pain and other symptoms, the first step is to talk to your own doctor about palliative care. Here are some tips on how to start that conversation:

- » Tell your doctor you are considering palliative care and ask what palliative services are available in your area.
- » Ask your doctor to explain your illness as well as past, current and future recommended treatments and procedures.
- » Explain to your doctor what quality of life means to you. This may include being able to spend time with loved ones, aggressively treating pain and other distressing symptoms, the ability to make your own decisions for care and where you prefer to receive treatment.
- » Be sure your doctor is aware of any personal, religious or cultural beliefs, values or practices that are important to consider in your care and treatment.

- » Explain what curative treatments you may or may not want, such as resuscitation if your heart were to stop, being placed on a mechanical ventilator if your lungs were to fail, undergoing dialysis if your kidneys were to fail and artificial nutrition by a feeding tube if you were unable to eat.

- » If you have completed a living will or health care proxy, be sure to inform your doctor and provide him or her with a copy. 📄



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* Expanding Palliative Services

The expansion of palliative medicine has been a critical step in addressing the unmet needs of patients with serious illness and their families. According to the *Journal of Palliative Medicine*, from 2001 to 2003 the number of hospital-based palliative care

programs grew by more than 60 percent. Now, one in four U.S. hospitals has a palliative care program, and all U.S. medical schools must provide training in palliative medicine.



Get Informed: Five Questions to Ask about Serious Illness

No one likes to receive bad news, especially when it is about your health. Being diagnosed with a serious illness is one of the scariest and most upsetting things that can happen to you or a loved one. It is not uncommon to have a mixture of many emotions — fear, anger, sadness, anxiety, guilt. Also, if a person has had symptoms for a long period of time or has undergone many tests, finally “knowing the answer” to what is wrong may in some ways even be a relief.

Studies show that when given bad news about an illness, it is rare for patients and families to be able to remember everything they are told during the appointment. You may have to be told the information several times, and in different ways, before you are able to absorb or understand it. In addition, it can be very hard to think clearly in such a situation, so try not to be preoccupied with asking all of the “right” questions immediately. Below are some questions you should ask your physician when you or a loved one is diagnosed with a serious illness.

Can you tell me that again?

When being told bad news, it is completely normal to not be able to take in everything that you are told. Whether it is at the same appointment or at the next one, it can be helpful to ask this question to make sure you understand what your doctor is telling you.

Can I say that back to you so I know that I correctly understand what you are telling me?

Studies show that in many cases physicians believe they are clearly and fully explaining a diagnosis, while in reality the patient has left the discussion with only a partial or incorrect understanding of the information. Ask your physician if you can tell him/her your understanding of the conversation in

your own words to make sure you fully comprehend what has been said.

What do we do next?

While it takes a while to adjust to bad news, knowing what comes next can often relieve anxiety and help focus your mind on positive activities. Work with your doctor to get a sense of the plan so you can better understand what comes next. When are you seeing the doctor next? Are there more tests that need to be done before the next visit?

How serious is this?

This is probably the scariest question of all. Many times there are very good treatments that can cure your disease, and your doctor can tell you about them. Remember that not everyone wants to know the answer to this question — so doctors may not always tell you this without your asking. Also remember that if you are a family member who hears the diagnosis with a loved one, he or she may not want to know the answer (and vice-versa). So sometimes it is important to first ask your loved one, “How much more do you want to know now?”

What else should I be asking at this point?

This kind of open-ended question allows your doctor to give you information that you might not think to ask. Many times the shock of hearing bad news makes it difficult to think, and so you may need help with asking the next question.

Once you understand your illness, the likely progression and potential treatments, you can consider all your options — including palliative care.

From the Center to Advance Palliative Care at www.getpalliativecare.org

Palliative Care Questions and Answers

Is palliative care the same as hospice?

No. While many palliative techniques are used in hospice care, palliative programs are in no way limited to people at the end-of-life. Palliative care empowers patients while they manage the course of any chronic illness, enhancing their quality of life by anticipating, preventing and treating their suffering.

So, how exactly are palliative and hospice programs different?

Like hospice, palliative care addresses a person's physical, social and spiritual needs and supports patient autonomy by strengthening access to information and respecting a patient's choices and wishes. Unlike hospice, palliative care supports the patient's and family's goals for curative treatment or longevity and is not limited to the last phases of life.

How do I know if palliative care is right for me?

Palliative care can be used at any stage of illness and along with curative treatments. It may be right for you if you suffer from pain and other symptoms due to a serious illness or injury.

What can I expect from palliative care?

You can expect a comfortable and supportive atmosphere that reduces anxiety and stress. You can also expect relief from symptoms such as pain, shortness of breath, fatigue, constipation, nausea, loss of appetite and difficulty sleeping.

Does my insurance pay for palliative care?

Most insurance plans cover all or part of the palliative care treatment you receive in the hospital, as with other hospital and medical services. This is also true of Medicare and Medicaid. Drugs, medical supplies and equipment may also be covered. If costs concern you, a social worker or financial consultant from the palliative care team can help you with payment options.

What role does my doctor play?

The hallmark of palliative care is a team approach to patient care. Your primary doctor will continue to direct your care and play an active part in your treatment. The palliative care team provides support to and works in partnership with your primary doctor.

How do I start getting palliative care?

Start by talking with your doctor or nurse, discussing your treatment plan and asking for a referral. Tell your family, friends and caregivers that you want palliative care and why it is important to you.

Aren't palliative programs an added expense to the health care system?

Research consistently demonstrates that palliative programs can reduce costs without shortening life. In the largest study of its kind, the Center to Advance Palliative Care and the National Palliative Care Research Center examined expenses and quality of care for hospitalized patients with chronic conditions. According to this study of eight different hospitals with palliative care programs:

- » Hospitals saved from \$279 to \$374 per day per palliative care patient.
- » Hospitals saved \$1,700 to \$4,900 on each admission of a palliative care patient.
- » Savings included significant reductions in pharmacy, laboratory and intensive care costs. This meant savings of more than \$1.3 million for a 300-bed community hospital and more than \$2.5 million for the average academic medical center.

"Cost of Savings Associated with U.S. Hospital Palliative Care Consultation Programs." *Archives of Internal Medicine*, Vol. 168, No. 16, September 8, 2008.

Questions?

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