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# **Palliative Care**

Palliative care is focused on improving the quality of life for people living with a serious illness like cancer. People with cancer may receive palliative care at any time from the point of diagnosis, throughout treatment, and beyond. The information here will help you learn more about palliative care.

#### **Understanding Palliative Care**

Palliative care helps patients and caregivers manage the symptoms of cancer and side effects of cancer treatment. Learn more about palliative care in this guide.

- What Is Palliative Care?
- Who Should Get Palliative Care and Why?
- How and Where Is Palliative Care Provided and How Is It Paid For?
- Finding a Palliative Care Program
- Questions to Ask About Palliative Care
- Palliative Care Videos

### **Managing Treatments and Side Effects**

Find information about dealing with the side effects of cancer and cancer treatment, as well as what to consider if a treatment isn't working.

- Side Effects
- Coping and Living Well During Cancer Treatment
- Complementary and Integrative Medicine
- If Cancer Treatments Stop Working

#### **More Palliative Care Resources**

- Palliative Care Resources from ACS CAN
- GetPalliativeCare.org
- Center to Advance Palliative Care

## What Is Palliative Care?

Palliative care is a special approach to caring for anyone with serious illness, such as cancer. Palliative care focuses on improving the quality of life by helping patients and caregivers manage the symptoms of a serious illness and side effects of treatment. It's designed to work with the health care team to help people with a serious illness live as well as they can for as long as they can.

Palliative care is appropriate for people of any age and at any stage in any serious illness. Palliative care should be used whenever the person has symptoms that need to be controlled.

- Palliative care and cancer
- What's the difference between palliative care and hospice care?

#### Palliative care and cancer

Palliative care is recommended as a standard part of care given to people with cancer. Palliative care does not treat the cancer itself, but can be provided at any time during the cancer experience. Often, palliative care is offered as soon as cancer is diagnosed, provided at the same time as cancer treatment, and continued after treatment is complete. One of its goals is to prevent or treat symptoms and side effects as early as possible.

Palliative care looks at how the cancer experience is affecting the whole person by helping to relieve symptoms, pain, and stress. It gives patients options and allows them and their caregivers to take part in planning their care. It's about making sure that all their care needs are addressed. The specialized professionals who are part of the palliative care team can help look for and manage mental, physical, emotional, social, and spiritual issues that may come up.

Palliative care may also be called supportive care, symptom management, or comfort

care. And it's often a part of <a href="https://example.com/hospice-care">hospice care</a>¹ if cancer is no longer being treated because it has worsened. No matter what it's called, palliative care has long been recognized as an important part of cancer care and treatment.

## What's the difference between palliative care and hospice care?

#### How they are alike

- The goal of both palliative care and hospice care is to provide better quality of life and relief from symptoms and side effects for people with a serious illness.
- Both have special care teams for a person's physical, emotional, mental, social, and spiritual needs.
- Hospice care often includes palliative care.

#### How they are different

When care is given:

- Palliative care can be offered and provided at any stage of a serious illness.
- Hospice care is offered and provided for patients during their last phase of an incurable illness or near the end of life, such as for some people with <u>advanced or</u> metastatic cancer<sup>2</sup>.

#### What other care can be given:

- Palliative care can be provided while the patient is getting active treatment. In other words, it can be given at the same time as chemo, radiation, or immunotherapy for cancer.
- Hospice care is provided when there is no active or curative treatment being given for the serious illness. "Treatment" during hospice care means only managing symptoms and side effects.

#### What the care team does:

- A palliative care team is separate from the medical care team that's giving and managing treatment for the illness, but communicates with the medical care team.
- A hospice care team coordinates the majority of care for a patient, and

communicates with the patient's medical care team.

To learn more, see How and where is hospice care provided and how is it paid for?<sup>3</sup>

## **Hyperlinks**

- 1. www.cancer.org/cancer/end-of-life-care/hospice-care.html
- 2. www.cancer.org/cancer/managing-cancer/advanced-cancer.html
- 3. www.cancer.org/cancer/end-of-life-care/hospice-care/who-provides-hospice-care.html
- 4. www.getpalliativecare.org/
- 5. www.caringinfo.org
- 6. palliativedoctors.org/
- 7. palliativedoctors.org/creating-a-plan/useful-resources
- 8. prc.coh.org/

#### Additional resources

Along with the American Cancer Society, other sources of information on palliative care include:

GetPalliativeCare.org Website: www.getpalliativecare.org4

Has information on palliative care for patients and home caregivers, including a
directory for palliative care providers. CaringInfo Website: <a href="www.caringinfo.org">www.caringinfo.org</a>5Has
information on hospice and palliative care, caregiving, advance care planning, grief
and loss. PalliativeDoctors Website: <a href="mailto:palliativedoctors.org">palliativedoctors.org</a>67Has a helpful list of
resources for people living with serious illness and for their caregivers and loved
ones

### **City of Hope Pain/Palliative Care Resource Center**

Website: <a href="http://prc.coh.org">http://prc.coh.org</a>

 Web-based clearinghouse of information and resources to help patients and families to improve the quality of pain management and palliative care

#### References

American Society of Clinical Oncology (ASCO). *Palliative care in oncology*. Accessed at https://www.asco.org/practice-guidelines/cancer-care-initiatives/palliative-care-oncology on April 2, 2019.

Doyle C. Concurrent palliative care: Recommendations from the ASCO clinical practice guideline. 2017. Accessed at https://www.ascopost.com/issues/december-10-2017/concurrent-palliative-care-recommendations-from-the-asco-clinical-practice-guideline/ on April 2, 2019.

Ferrell BR, Temel JS, Temin S, Smith TJ. Integration of palliative care into standard oncology care: ASCO clinical practice guideline update summary. *Journal of Oncology Practice*. 2017; 13(2):119-121.

Krouse RS, Kamal AH. Interdisciplinary care for patients with advanced cancer. In DeVita VT, Lawrence TS, Rosenberg SA, eds. *DeVita, Hellman, and Rosenberg's Cancer: Principles and Practice of Oncology.* 11<sup>th</sup> ed. Philadelphia, PA: Lippincott Williams & Wilkins; 2019:2242-2247.

Marrelli TM. *Hospice and Palliative Care Handbook.* Indianapolis, IN: Sigma Theta Tau International; 2018.

Nabati L, Abrahm JL. Caring for patients at the end of life. In Niederhuber JE, Armitage JO, Kastan MB, Doroshow JH, Tepper JE, eds. *Abeloff's Clinical Oncology*. 6<sup>th</sup> ed. Philadelphia, PA: Elsevier; 2020:751-763.

National Cancer Institute (NCI). *Palliative care in cancer*. Accessed at https://www.cancer.gov/about-cancer/advanced-cancer/care-choices/palliative-carefact-sheet on April 2, 2019.

National Comprehensive Cancer Network (NCCN). *Palliative care.* Version 1.2019. Accessed at www.nccn.org on April 2, 2019.

National Institutes of Health (NIH) National Institute on Aging (NIA). What are palliative care and hospice care? Accessed at https://www.nia.nih.gov/health/what-are-palliative-care-and-hospice-care on April 2, 2019.

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# Who Should Get Palliative Care and Why?

Any person diagnosed with a serious illness who is having symptoms should get palliative care. People with complex medical problems, for instance, someone who is diagnosed with and being treated for heart failure, kidney disease, diabetes, or cancer, should get palliative care. These serious illnesses often lead to physical, <a href="mailto:emotional">emotional</a>1, spiritual, and social problems that go beyond what the medical team can provide.

- Why palliative care is important in cancer care
- Benefits of palliative care

## Why palliative care is important in cancer care

For cancer patients, it's important to remember that the effects of cancer and its treatment can be very different from person to person. A palliative care team includes a group of specialists who look at each person's situation and work together to help the patient and caregiver with various types of needs. The palliative care team can help by:

- Controlling physical symptoms and side effects<sup>2</sup>
- Managing <u>emotions</u><sup>3</sup> that come with a cancer diagnosis and treatment
- Showing the family ways to coping<sup>4</sup> with life and family changes
- Understanding any spiritual concerns
- Supporting needs of caregivers<sup>5</sup>
- · Assisting with financial, work, and insurance issues
- $\bullet$  Helping fill out  $\underline{\text{advance directives}}^6$  and other forms
- Transitioning to <a href="hospice care">hospice care</a> if treatment stops working or if cancer worsens

Palliative care should be offered and be available from the time of diagnosis until it's no

longer needed – at any stage and in any care setting.

## Benefits of palliative care

There are many studies that show the benefits of palliative care on the well-being of patients and their families or caregivers. For example, studies have shown that patients who have palliative care visits while in the hospital spend less time in intensive care units and are less likely to visit the emergency room or to be re-admitted to the hospital after they go home. Studies have also shown that people with chronic illnesses, like cancer, who get palliative care have less severe symptoms. They have better quality of life, less pain, less shortness of breath, less depression, and less nausea.

Research has also shown that cancer patients receiving palliative care have better emotional health. This may be because their medical care tends to better align with their values, goals, and preferences. Their families also feel more satisfied with the patient's care.

Some studies have also suggested that starting palliative care soon after a cancer diagnosis may also extend survival.

## **Hyperlinks**

- 1. <u>www.cancer.org/cancer/managing-cancer/side-effects/changes-in-mood-or-thinking.html</u>
- 2. www.cancer.org/cancer/managing-cancer/side-effects.html
- 3. <u>www.cancer.org/cancer/managing-cancer/side-effects/changes-in-mood-or-thinking.html</u>
- 4. www.cancer.org/cancer/survivorship/coping.html
- 5. www.cancer.org/cancer/caregivers.html
- 6. <u>www.cancer.org/cancer/managing-cancer/making-treatment-decisions/advance-directives.html</u>
- 7. www.cancer.org/cancer/end-of-life-care/hospice-care.html
- 8. www.getpalliativecare.org/
- 9. prc.coh.org/

#### Additional resources

Along with the American Cancer Society, other sources of information on palliative care

#### include:

GetPalliativeCare.org Website: www.getpalliativecare.org8

 Has information on palliative care for patients and home caregivers, including where to find palliative care programs in your state

City of Hope Pain/Palliative Care Resource Center Website: http://prc.coh.org9

 Web-based clearinghouse of information and resources to help patients and families to improve the quality of pain management and palliative care

#### References

Dunn GP, Pruskowski J, Simonian LK. Palliative care for cancer and treatment-related changes for inpatients. In Hopewood P, Milroy MJ, eds. *Quality Cancer Care: Survivorship Before, During, and After Treatment*. New York, NY: Springer Publishing Company; 2018:199-216.

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# How and Where Is Palliative Care Provided and How Is It Paid For?

- Who provides palliative care?
- Where palliative care is given
- How palliative care is paid for

## Who provides palliative care?

Palliative care is most often offered and started by the cancer care team who is giving your treatment. The doctors and nurses you see during your treatment visits may provide some palliative care themselves, such as helping to <a href="mailto:managesymptoms">managesymptoms</a><sup>1</sup> and side effects like nausea or pain. And they will continue to help control those problems while you are getting treatment. But they will often refer patients to a team of palliative care specialists.

This palliative care "team" typically includes a palliative care doctor (who may be board-certified in Hospice and Palliative Medicine), a palliative care nurse, social worker, dietitian, patient navigator, and maybe a person with a spiritual role such as a pastoral counselor or chaplain.

Many hospitals and oncology clinics have these teams as part of the services they provide. With many types of professionals, the palliative care team can better help with symptoms and problems that are harder to manage, like severe pain, family distress, insurance issues, or complex medical problems.

## Where palliative care is given

Palliative care is most often given to the patient in the home as an outpatient, or during a short-term hospital admission. Even though the palliative care team is often based in a hospital or clinic, it's becoming more common for it to be based in the outpatient setting.

The palliative care team also can see patients, family, and caregivers in intensive care units, emergency rooms, treatment centers, or hospital units.

Most actual palliative care happens at home. At home, you may take medicines and use other methods prescribed by the team, or your family members and loved ones might need support as they help care for your needs. The team provides support to the patient as well as to the home caregivers.

You can read more about caregiving in What a Cancer Caregiver Does<sup>2</sup>.

## How palliative care is paid for

Palliative care can be covered by both government and private insurance plans, but it may be part of **chronic care** or **long-term care** coverage. Sometimes it's included in the <u>hospice care</u><sup>3</sup> part of coverage depending on how the health plan describes what palliative care is.

It's important to check and see if your insurance coverage has certain limits on palliative care, such as a list of what types of serious illnesses are covered, or other situations that may or may not be eligible for palliative care services.

There can also be limits on where palliative care is provided. Coverage may differ if you are getting palliative care in the hospital, rehab, or a skilled nursing or hospice facility instead of getting it at home. Sometimes nursing visits, social work, and spiritual care are covered, in addition to the care and medicines that help control symptoms. It's best to check with your health insurance company for details about what is covered and what is not.

## **Hyperlinks**

- 1. <u>www.cancer.org/cancer/managing-cancer/side-effects.html</u>
- 2. www.cancer.org/cancer/caregivers/what-a-caregiver-does.html
- 3. www.cancer.org/cancer/end-of-life-care/hospice-care.html

- 4. www.getpalliativecare.org/
- 5. prc.coh.org/

#### Additional resources

Along with the American Cancer Society, other sources of information on palliative care include:

GetPalliativeCare.org Website: www.getpalliativecare.org4

 Has information on palliative care for patients and home caregivers, including where to find palliative care programs in your state

City of Hope Pain/Palliative Care Resource Center Website: http://prc.coh.org5

 Web-based clearinghouse of information and resources to help patients and families to improve the quality of pain management and palliative care

#### References

Center for Medicare and Medicaid Services (CMS). *Medicare hospice benefits*.Accessed at https://www.medicare.gov/pubs/pdf/02154-medicare-hospice-benefits.pdf on April 2, 2019.

Dunn GP, Pruskowski J, Simonian LK. Palliative care for cancer and treatment-related changes for inpatients. In Hopewood P, Milroy MJ, eds. *Quality Cancer Care: Survivorship Before, During, and After Treatment*. New York, NY: Springer Publishing Company; 2018:199-216.

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# Finding a Palliative Care Program

In most cases, your doctor or cancer care team can offer and start palliative care services. But if palliative care is not offered or available (or for some other reason), they can refer you to a specialized palliative care provider or palliative care team.

Maybe you want to learn more, or would like to talk to more than one provider who offers palliative care. In these cases, there are organizations that keep lists to help you find a palliative care team or palliative care provider. You may also find palliative care information and referral services through the American Cancer Society by searching Find Support Programs and Services in Your Area<sup>1</sup>

You will also need to contact your insurance company to check if you are eligible and to get a list of palliative care providers, teams, or centers.

The following organizations have listings of palliative care providers:

- Get Palliative Care<sup>2</sup>
- National Hospice and Palliative Care Organization<sup>3</sup>

## **Hyperlinks**

- 1. www.cancer.org/support-programs-and-services.html
- 2. getpalliativecare.org/provider-directory/
- 3. <a href="https://www.nhpco.org/find-a-care-provider/">www.nhpco.org/find-a-care-provider/</a>
- 4. www.getpalliativecare.org/
- 5. prc.coh.org/

#### **Additional resources**

Along with the American Cancer Society, other sources of information on palliative care include:

GetPalliativeCare.org Website: www.getpalliativecare.org4

 Has information on palliative care for patients and home caregivers, including where to find palliative care programs in your state

City of Hope Pain/Palliative Care Resource Center Website: <a href="http://prc.coh.org">http://prc.coh.org</a>

 Web-based clearinghouse of information and resources to help patients and families to improve the quality of pain management and palliative care

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# **Questions to Ask About Palliative Care**

If your health care team has mentioned palliative care, you should understand its benefits and limitations. Consider asking your oncologist or oncology nurse these questions to learn as much as you can about your care options.

- Are you recommending palliative care for me? Why?
- How do I find out if I'm eligible?
- What is included in palliative care that's different from the care you can give me?
- Who will be part of my palliative care team?
- Where will I receive palliative care?
- Do I need to check with my insurance company about coverage for palliative care?
- How long will my palliative care last?
- What will the palliative care team do if my symptoms get worse? What if my symptoms get better?
- How will you communicate with the palliative care team and my other doctors?
- How are my family and friends involved in palliative care?
- What decisions do I need to make? Can you be involved in those decisions with me?

## **Hyperlinks**

- 1. www.getpalliativecare.org/
- 2. prc.coh.org/

#### Additional resources

Along with the American Cancer Society, other sources of information on palliative care include:

GetPalliativeCare.org Website: www.getpalliativecare.org1

 Has information on palliative care for patients and home caregivers, including where to find palliative care programs in your state

City of Hope Pain/Palliative Care Resource Center Website: http://prc.coh.org2

 Web-based clearinghouse of information and resources to help patients and families to improve the quality of pain management and palliative care

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