

Palliative Care

**A Guide to Coping with Side Effects for
People with Cancer and Their Families from the
American Society of Clinical Oncology**



ASCO® Cancer.Net

ABOUT ASCO

Founded in 1964, the American Society of Clinical Oncology, Inc. (ASCO®) is committed to making a world of difference in cancer care. As the world's leading organization of its kind, ASCO represents nearly 45,000 oncology professionals who care for people living with cancer. Through research, education, and promotion of the highest-quality patient care, ASCO works to conquer cancer and create a world where cancer is prevented or cured, and every survivor is healthy.

ASCO furthers its mission through Cancer.Net and Conquer Cancer, the ASCO Foundation.

Cancer.Net (www.cancer.net) brings the expertise and resources of ASCO to people living with cancer and those who care for and about them. All the information and content on Cancer.Net is developed and approved by members of ASCO, making Cancer.Net an up-to-date and trusted resource for cancer information.

Conquer Cancer (www.conquer.org) funds research into every facet of cancer to benefit every patient, everywhere. Conquer Cancer helps turn science into a sigh of relief for patients around the world by supporting groundbreaking research and education across cancer's full continuum.

Learn more at www.ASCO.org. Follow us on Facebook, Twitter, LinkedIn, and YouTube.

MILLIONS OF PEOPLE RELY ON CANCER.NET FOR:

- Information on 120+ cancer types
- Information on navigating cancer care
- Coping and survivorship resources

GET YOUR CANCER INFORMATION IN THE FORMAT YOU WANT:

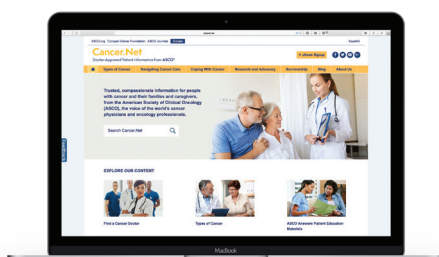
Download the app



Watch videos



Browse the website



Listen to podcasts



ASCO patient education programs are supported by:

CONQUER CANCER®
THE ASCO FOUNDATION

PALLIATIVE CARE

Introduction	2	Talking About Your Care	20
What Is Palliative Care?	3	Getting the care you want	21
How palliative care differs from hospice care	3	Questions to ask	24
When and where palliative care is given	4	Resources	26
Who provides palliative care?	5	Palliative Care Dictionary	28
How do I get palliative care?	7		
The Goals of Palliative Care	9		
Managing symptoms and side effects	9		
Helping with practical concerns	16		
Addressing spiritual questions or concerns	18		
Providing support to caregivers, family, and friends	18		

ASCO ANSWERS is a collection of oncologist-approved patient education materials developed by ASCO for people with cancer and their caregivers.

This booklet was developed by and is ©2020 American Society of Clinical Oncology, Inc. (ASCO). All rights reserved worldwide. No sponsor was involved in the development of the content. The mention of any company, product, service, or therapy does not constitute an endorsement of any kind by ASCO or Conquer Cancer®, the ASCO Foundation. It is the responsibility of the treating physician or other health care provider, relying on independent experience and knowledge of the patient, to determine drug dosages and the best treatment for the patient. ASCO assumes no responsibility for any injury or damage to persons or property arising out of or related to any use of the booklet or any errors or omissions. Information in ASCO's patient education materials is not intended as medical advice or as a substitute for medical advice. Patients with health care-related questions should call or see their physician or other health care provider promptly and should not disregard professional medical advice, or delay seeking it, because of information encountered here. ASCO believes that all treatment decisions should be made between patients and their doctors. Advances in the diagnosis, treatment, and prevention of cancer occur regularly. For more information, visit Cancer.Net (www.cancer.net).

INTRODUCTION

Cancer and its treatment may cause discomfort that affects how you are able to live your life. However, a specialized area of medicine called palliative care focuses on preventing, managing, and relieving the symptoms of cancer and any side effects caused by treatment. It also provides comprehensive support to people living with cancer and their families. Any person, regardless of age or type and stage of cancer, may receive palliative care before, during, and after treatment. Palliative care is also called supportive care.

This booklet is designed to help people with cancer, their families, and their caregivers understand how palliative care can improve quality of life throughout treatment, discuss their options, clarify their expectations, and find support. By starting palliative care as early in the treatment process as needed, your health care team will be able to better prevent and manage the potential challenges of cancer. As a result, you will have a cancer care plan that makes you more comfortable throughout all stages of your illness.



WHAT IS PALLIATIVE CARE?

Cancer often causes symptoms, and any treatment for cancer may cause side effects. An important part of your cancer care, regardless of diagnosis, is preventing or relieving these symptoms and side effects. Doing this helps keep you as comfortable as possible while maintaining the best possible quality of life from diagnosis through treatment and beyond. This is called palliative care.

In addition to treating physical issues, such as pain, nausea, and fatigue, palliative care also focuses on supporting your emotional, spiritual, and practical needs. It also supports the needs of your family and caregivers. You can receive palliative care at any age and at any stage of illness.



Receiving palliative care does not mean that you will no longer receive treatment for the disease. People often receive treatment to slow, stop, or eliminate cancer in addition to treatment to ease discomfort. In fact, research shows that people who receive both types of treatment often have less severe symptoms, a better quality of life, and report they are more satisfied with treatment.

How palliative care differs from hospice care

Although you may hear “palliative care” and “hospice care” used in similar ways, they are not the same. Palliative care is given at every step of the treatment process. It provides an extra layer of support for people with any stage of cancer. Hospice care is a specific type of palliative care. It is only provided to people with advanced cancer who are expected to live six months or less.

If you have advanced disease, your doctor may suggest treatments to improve symptoms or treatments directed at the cancer. If you choose to stop treatment for cancer, such as chemotherapy, this does not mean you have stopped “fighting” the disease. It also does not

mean that your health care team has abandoned you or given up. Instead, the focus may be on relieving symptoms and allowing for additional support in all areas of your life. If a person decides to begin hospice care, a member of the palliative care team will help with the transition and address the physical and emotional issues that come with that choice.

For more information about advanced cancer care planning, visit www.cancer.net/advancedcancer.

When and where palliative care is given



Ideally, palliative care should start as early as needed in the cancer treatment process and continue throughout all stages of the disease. This could mean as early as diagnosis, or if there are new symptoms or side effects, or if there are symptoms that need further supportive care. You may receive palliative care in a doctor's office, hospital, cancer center, long-term care facility, or your home, depending on the treatments that have been recommended and the available resources. Talk with your doctor, nurse, or oncology social worker about your options.

ASCO recommends that all patients with advanced cancer receive palliative care early on and along with cancer treatment. For those newly diagnosed with advanced cancer, the recommendation is that palliative care should be offered within 8 weeks after diagnosis. ASCO also recommends that patients ask about which palliative care services are available to them and to meet with a dedicated palliative care team, which can provide a range of services.

Who provides palliative care?

Because palliative care focuses on providing patients and families with physical, emotional, social, practical, and spiritual support, a number of health care professionals may be involved. Your oncologist, oncology nurse, and other members of your health care team are always concerned about your comfort and well-being, so palliative care is often provided by the same team that



oversees your disease-directed treatment. Sometimes an oncologist may recommend seeing a palliative care specialist. Palliative care specialists are extensively trained to help patients, families, and caregivers cope with a life-threatening illness.

If you are referred to a palliative care specialist, he or she will not replace your oncologist. These clinicians will work together to develop a care plan that meets your specific needs and individual goals. Your health care team will continue to adjust this plan as your needs and wishes change. They will also bring other specialists and health care professionals into your team as needed. Members of the palliative care team may include:

Oncologist. An oncologist is a doctor who specializes in treating cancer. Often, your oncologist serves as the leader of your health care team. He or she is in charge of designing your treatment plan and deciding on medicines and dosing. He or she may talk with other health care professionals to create your palliative care plan. These could include a palliative medicine physician or pain specialist.

Palliative medicine physician. This is a doctor who specializes in both palliative care and hospice care. He or she works with the health care team to relieve symptoms and side effects. A palliative medicine physician will also talk with a patient to make sure the treatment plan is aligned with his or her goals and values.

Nurses and advanced practice nurses. The nurses on your team help manage pain and other symptoms. They also act as the main contact for the rest of your health care team. If you receive palliative care at home, nurses may visit you regularly to monitor your care and ensure your needs are met.

Social worker. A social worker provides counseling for you and your family and arranges family meetings. A social worker may also help with practical issues like transportation and can connect you with local resources. Social workers also help with discharge from the hospital and finding in-home help or, if it becomes necessary, hospice care.

Pain specialist. Pain specialists, or pain medicine doctors, are experts at finding the cause of pain and treating it. They may prescribe medication, recommend a rehabilitation program, and/or perform pain-relieving procedures. An oncologist or palliative medicine physician may be able to control your pain without referring you to a pain specialist.

Chaplain. A chaplain is usually a member of a specific religion. He or she is trained to listen to patients' and family members' concerns, especially about death and dying. Chaplains are also available to discuss other faith-related and spiritual matters. A chaplain's support can be helpful when a person has a serious illness.

Dietitian. A dietitian can help address nutritional challenges, such as nausea or appetite loss. Dietitians may also provide advice about nutritional supplements and help create specialized eating plans.



Physical and occupational therapists. A physical therapist helps maintain mobility and improve how well a person moves. Physical therapists also develop exercise programs to maintain or improve your physical strength during and after treatment. Occupational therapists typically focus on daily tasks and functioning, especially upper body movement, to help sustain independence.

Child life specialist. These trained professionals specialize in helping children and their families understand a child's serious illness. They also assist siblings through the experience.

Volunteers. Many palliative care programs have trained volunteers who visit with patients who want companionship and emotional support. Volunteers often perform simple tasks, such as reading out loud or writing notes, or can simply sit and talk. Volunteers often provide respite for caregivers.

Grief and bereavement coordinator. A grief coordinator counsels family members who are facing or have suffered the loss of a loved one. They have specialized training in social work or psychology.

How do I get palliative care?

If you would like to receive palliative care, ask your oncologist about the palliative care services available to you. You can bring this booklet with you to start the discussion. This can help you explain why you think palliative care is important for you and your family. You may also want to ask for a referral to a palliative care specialist. Health care professionals typically welcome the support and information palliative care specialists provide and can connect you with these resources. This kind of self-advocacy, or advocacy on your behalf by a friend or family member, can help ensure that you are connected with the resources you need, including palliative care, at all phases of treatment and recovery.



KATE'S STORY

Kate, a 39-year-old mother of two, thought her shortness of breath and wheezing were caused by allergies. Instead, her doctor told her she had lung cancer and recommended disease-directed treatment and palliative care. During this conversation, the doctor asked Kate and her husband, Steve, what their greatest fear about treatment was. Both were concerned that Kate, who would be taking chemotherapy at home, would be often alone during the day because Steve, a pilot, travelled frequently.

Kate and Steve were introduced to a nurse who explained the side effects that Kate might experience from the chemotherapy. A social worker provided information on a reliable in-home nursing company. Kate decided that she felt comfortable being at home without extra help, but the social worker called the nursing company and confirmed that, if needed, a visiting nurse could be quickly sent to Kate, which reassured Steve. The social worker also connected them to a counselor who specialized in working with families dealing with serious illness. This counselor helped Kate and Steve talk about the diagnosis with their children.

"Being diagnosed with cancer was a huge shock, and I felt like life was spiraling out of control," Kate explained. "My health care team gave me some of that control back instantly by helping me make proactive decisions before treatment even began. I felt stronger because of it, and so did my family."

THE GOALS OF PALLIATIVE CARE

The goal of palliative care is to improve your quality of life. This means allowing you to live the way you want during and after treatment and equipping your family and caregivers to support you while taking care of themselves. Palliative care can accomplish this by addressing a number of different cancer-related challenges.

Managing symptoms and side effects

Cancer can cause physical and emotional symptoms, and cancer treatment, such as chemotherapy, radiation therapy, and surgery, often causes side effects. The specific symptoms and side effects you may experience and their level of severity depends on a number of factors, including the type and stage of the cancer, its location, your treatment plan, and your overall health. Palliative care aims to prevent, manage, and/or relieve cancer-related discomfort no matter the cause and regardless of whether the discomfort is mild, moderate, or severe.

■ Physical

Physical symptoms of cancer, such as pain, fatigue, breathlessness, insomnia, and weight changes, vary widely from person to person. Your health care team will work with you to find the best way to control your physical symptoms, as well as prevent or ease treatment-related side effects, such as nausea and vomiting, diarrhea, and appetite loss.



Before starting treatment, a member of your health care team can help you understand which side effects are most likely to occur and put a personalized plan in place to prevent or manage them. A combination of therapies is often used to relieve physical symptoms and side effects. These may include:

Medication. Many types of medications are used to manage symptoms and side effects. For example, antiemetics are drugs that help prevent vomiting. Pain is mostly managed with medication. Your palliative care specialist or oncologist may recommend non-opioid

medications, including acetaminophen (such as Tylenol) and ibuprofen (such as Advil and Motrin). Opioids may be recommended for moderate to severe pain. They are only given with a prescription. See page 12 for more information about managing pain.

Occupational therapy. The physical challenges that sometimes accompany cancer treatment may affect a person's ability to perform daily tasks. An occupational therapist may be able to help improve your ability to perform such tasks and/or modify your environment to support your needs.

Physical therapy. Cancer treatment can cause muscle weakness, muscle imbalances, changes in posture, and mobility issues that a specialized strengthening program helps correct.

Nutritional counseling. Dietitians can help you find ways to stay hydrated and maintain or lose weight; provide suggestions to reduce nausea and vomiting; address changes in appetite and taste; recommend foods, vitamins, and other supplements that may be missing from your diet; and suggest other forms of nutritional support when necessary.

Relaxation techniques. Relaxation can increase your energy levels and ease pain by loosening your muscles. Different types of relaxation techniques include deep breathing, meditation, and guided imagery, which combines breathing with meditating on a mental image.

Massage. Studies suggest that massage, which is the gentle moving and rubbing of muscles and soft tissue, may help decrease pain and fatigue in people with cancer. Some massage therapists specialize in working with people who have complex health issues, such as cancer.



Acupuncture. During acupuncture, a trained practitioner stimulates specific areas of the body, known as acupuncture points, usually with small needles. It can sometimes be used to control symptoms and side effects such as pain, fatigue, nausea, vomiting, weight loss, insomnia, dry mouth, hot flashes, and nerve problems.

Exercise programs. Physical activity, such as walking and yoga, can help boost your energy and help you cope with the demands of treatment. Some people will need to exercise while being watched by a health care professional, while others will be able to exercise on their own.

You may also receive palliative treatments similar to those used to eliminate the cancer, such as surgery or radiation therapy. A member of your health care team will help you understand the goal of each treatment and ensure you receive it in the way that is best for you. For example, if you have trouble swallowing pain medication, the team can explore other options with you, such as injections or pain patches that are worn on the skin.

Be sure to tell a member of your health care team if you are experiencing a problem so it can be addressed as quickly as possible. Easing physical discomfort will help you complete your treatment plan, maintain your independence, and have a higher quality of life.

SAM'S STORY

Sam had been living with prostate cancer for 14 years when he found out that the cancer had spread to his right hip and spine. His oncologist prescribed a combination of medications and physical therapy that brought him limited pain relief. Concerned by Sam's increasing discomfort, his doctor referred him to a pain specialist.

When Sam met with the specialist, he explained he was most frustrated by the fact that he could no longer sit up or stand for more than a few minutes because of the pain. He also discussed the severe dizziness that his medications were causing. Sam wanted to be able to walk to the mailbox alone and drive his grandson to baseball practice. Independence was as important to him as pain management.

After reviewing his medical file, the pain specialist recommended a surgically implanted pump that would deliver pain medication directly into his spinal cord. After the surgery, Sam was able to stop taking all but one of his prescription medications, and he is much more active than before.

MANAGING PAIN

Pain is a common symptom for people with cancer. However, it may help to know that up to 95% of cancer-related pain can be successfully treated or managed. Unfortunately, not all people with cancer benefit from pain-relief strategies because they don't talk about their pain with their health care team. Untreated pain can make other aspects of cancer seem worse, such as fatigue, weakness, shortness of breath, nausea, constipation, sleep disturbances, depression, anxiety, and mental confusion.

Your doctor or another member of your health care team can help you find the most effective pain-relief strategy. Often, this involves taking pain-relieving medications called analgesics at scheduled times. Non-opioid medications, including acetaminophen and ibuprofen, are used to treat mild or moderate pain. They are sometimes used along with prescription pain medicines, called opioids, to treat more severe pain. Opioids, also called narcotics, include hydrocodone, fentanyl, hydromorphone, methadone, morphine, oxycodone, and oxymorphone. Because these are such strong pain relievers, extra care and caution must be taken to ensure opioids are correctly taken and stored.

In general, it is easier to prevent pain from developing or getting worse than it is to take it away. If you have had pain, taking your medication regularly can keep it from coming back. If you take your pain medications as prescribed and the pain continues, talk with a member of your health care team. You may need extra doses of the medication.

Taking medication is not the only option for controlling pain. Some cancer therapies also help relieve pain. For example, radiation therapy may be used to treat pain caused by cancer that has spread to the bone. Other non-medication options include acupuncture, biofeedback, breathing exercises/meditation, counseling, distraction techniques, using heat and cold, imagery and visualization, massage, nutrition support, and physical or occupational therapy. Effective pain control usually combines several methods, and these methods may change as your health changes.

To learn more about managing cancer-related pain, visit www.cancer.net/pain.

■ Emotional

In addition to physical side effects, the diagnosis and treatment of cancer often trigger difficult emotions that can affect your daily life. Palliative care specialists and other members of your health care team not only have a wealth of experience and knowledge about cancer, cancer treatment, and side effects, but they can also provide and connect you with emotional and social support resources. These resources will help you develop effective coping strategies for common issues.

Fear of treatment-related side effects. As you prepare to start cancer treatment, it is normal to fear treatment-related side effects. However, your health care team is focused on preventing and controlling your side effects. Don't be afraid to talk with your doctor, nurse, or pharmacist about possible side effects and how you can manage them. This information can ease your mind and prepare you for what lies ahead.

Depression. People with cancer may experience depression, which is a treatable mood disorder. Depression may make it harder to cope with cancer treatment. It may also interfere with your ability to make choices about your care. As a result, identifying and managing depression are important parts of cancer treatment. Talk with your doctor if you experience the symptoms of depression, especially if they last two weeks or longer. The symptoms of depression may include feeling numb or hopeless, loss of motivation, or loss of interest in things you used to enjoy. They may appear shortly after diagnosis or anytime during or after treatment and can range from mild to severe. Severe depression interferes with a person's relationships and day-to-day activities and responsibilities. Although depression is not uncommon for people with cancer, it does not have to be part of living with cancer.



Anxiety. Anxiety may be described as feeling nervous, on edge, or worried. It is a normal emotion, but intense or prolonged anxiety can interfere with your daily activities and relationships. You may be anxious about treatment or treatment-related side effects, having the cancer return or spread after treatment, losing independence, having relationships change, and the possibility of dying. Anxiety may make it harder to cope with treatment. It may also interfere with your ability to make choices about your care. As a result, identifying and managing anxiety are important parts of cancer treatment.

Anger. Anger is often among the first emotional reactions a person has to a cancer diagnosis, but it can develop any time throughout treatment and survivorship. If not managed, anger can lead to depression. When expressed in a safe, positive way, anger can help you change things for the better.

Stress. A disease such as cancer can be one of the most stressful experiences of a person's life. Coping with cancer can be more challenging with added stress from family, work, and financial concerns. Long-lasting stress may weaken the immune system, causing other health problems and decreasing your feelings of well-being.



Guilt. Many people living with cancer experience guilt. Guilt is a feeling of blame and regret that is usually hard to acknowledge and express. People with cancer may feel guilt because they did not notice symptoms earlier, feel like they are a burden on their caregivers, or survived cancer while others did not. Although feelings of guilt are common, it is not healthy to dwell on them. Letting go of guilt can help improve your well-being and your ability to cope.

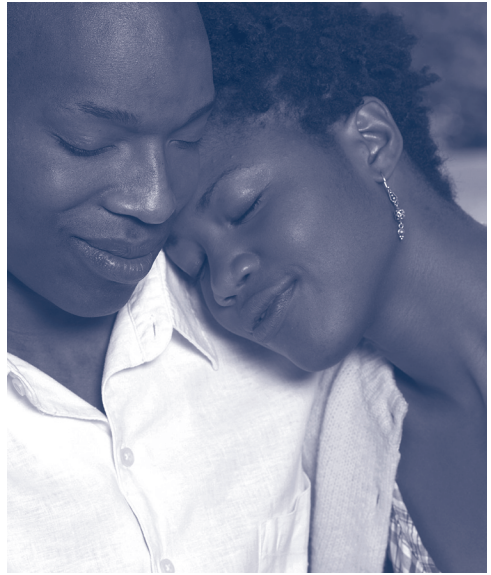
Physical changes. Both cancer and its treatment may change how you look. How you feel about your appearance is called body image. Many people with cancer feel self-conscious about changes to their bodies. Some of the more common physical changes of cancer include hair loss, weight changes, surgery scars, rashes, fatigue, the need for an ostomy, and loss of an organ, limb, or breast.

Uncertainty about your future. Many people with cancer may feel a lack of certainty about what the future holds. You may feel that your life is less secure or predictable than it once was. Uncertainty can lead to other feelings, such as a sense of loss, anxiety, anger, sadness, or fear, that can interfere with your ability to live life fully. You may experience feelings of grief for the life you lived before cancer. It is important to ask for support when you are feeling this way. There are many resources to help you.

Research has shown that sharing fears and anxieties with family, friends, counselors, clergy, or support groups helps strengthen people emotionally and perhaps even physically. A member of your health care team can connect you with these resources or teach you how to express your feelings privately through activities such as journaling or meditating. Several of the therapies used to treat physical side effects, including massage, relaxation techniques, and acupuncture, often help with some emotional concerns.

■ Sexual

The physical and emotional challenges you may experience during and after cancer treatment can affect your desire and ability to have sex. Even if treatment does not directly affect your reproductive organs, it can affect your mood, energy levels, and overall sense of well-being. Although it may seem difficult or awkward, it is important to talk openly with your doctor, nurse, or another member of your health care team about your sexual health and intimacy concerns. There are several ways you, as well as your partner or spouse, can get support for these concerns, including talking with social workers, support groups, or specialists in sexual medicine.



Physical sexual problems. Sexual issues may develop during treatment, directly after treatment, or years later. Relieving the physical side effects that influence your ability to have and enjoy sex is an important part of your care. Your health care team can work with you to diagnose sexual problems and give you information on management tools, such as medications and devices.

Changes in intimacy and desire. Sexual health is not just affected by changes to the body. The emotions surrounding a diagnosis of cancer and its treatment may influence your ability to feel close to your partner (intimacy) and may extend beyond active treatment. Medications may also affect your sexual desire. A member of your health care team can work with you to address physical and emotional challenges, such as depression, fear of recurrence, and changes in your appearance.

Fertility concerns. An inability to have children is a common side effect of many cancer treatments, and this infertility may be temporary or permanent. People who are concerned about their ability to have children should talk with their oncologist or another member of their health care team before treatment begins, when most fertility-preserving procedures need to be done. They can help you understand how your recommended treatment plan may affect your fertility and provide information about your options for preserving it.

For more information about managing side effects, visit www.cancer.net/sideeffects.



Helping with practical concerns

Costs of cancer care. The financial impact of a cancer diagnosis is often a major source of stress and anxiety for people with cancer and their families. For some, cost is a major reason why they do not follow or complete their cancer treatment plan. However, not following your treatment plan for any reason can put your health at risk and lead to even higher costs in the future. The members of your health care team can help you figure out what costs to expect and for how long, as well as show you how to address your financial concerns.

It is important to know that palliative care is often covered by private health insurance plans, and it may be paid for by Medicaid and Medicare, depending on the situation. Medicaid is a health insurance program administered by each state that covers older adults, people with lower incomes, people with disabilities, and certain people in families with dependent children. Medicare is health insurance provided by the federal government for those 65 and older, as well as for some disabled Americans. If you have a long-term care policy, it may also provide some palliative care coverage benefits.

Your health care team can help you find resources that assist with costs related to your treatment, doctor appointments, and medications, as well as help you think through and address other expenses that might be added to your budget due to the treatment schedule, such as childcare, gasoline, and parking fees.

Transportation and travel. It is important to consider how you will get to and from the doctor's office and/or treatment facility, whether by car, bus, train, or airplane. Depending on where you decide to receive treatment, you may also need to find a hotel, apartment, or other place to stay.

Family and living expenses. There are a number of extra costs related to running your household and caring for your family during cancer treatment that you need to consider and plan for, such as childcare, elder care, or coping support.

Caregiving, at-home care, and long-term care. Some people with cancer need additional care, such as hiring a person to fix meals or drive them to each medical appointment. Some people may also need extended nursing care at a specialized facility or the assistance of a home health aide.



Employment, legal, and financial issues. Some people find they need professional guidance on employment, legal, or financial issues related to a cancer diagnosis. This may involve addressing lost wages, learning about employment rights under the law, figuring out medical expenses during income tax filing, or writing a will or advance directive (see "Getting the care you want" on page 21).

To learn more about managing the cost of cancer care, visit www.cancer.net/managingcostofcare.

Addressing spiritual questions or concerns

Many people struggle with questions of why they have cancer and what it means for them moving forward. For some, organized religion plays a central role in their lives, and the support of faith and clergy members is a significant source of comfort. For others, spiritual comfort may lie in a sense of connection to nature or people.

A member of your health care team can refer you to resources that will help you explore your spiritual views or beliefs as you try to make sense of your experience and find new meaning in life. Many hospitals and cancer centers have chaplains who can give support to people of all faiths, as well as those who do not consider themselves religious at all. In addition, your health care team can connect you and your family to other spiritual and religious resources in the community that have experience helping people diagnosed with cancer.



Providing support to caregivers, family, and friends

The complex feelings and lifestyle changes caused by cancer and its treatment can become as overwhelming for family caregivers, other family members, and friends as they are for you. Several studies have shown that caregivers are at an increased risk for depression. Palliative care specialists are trained to meet the needs of caregivers and help them cope with their own distress and emotional pain.

Research suggests that when palliative care services are introduced to caregivers earlier, they will be able to cope better with the caregiving experience. Your health care team can provide support to caregivers by:

- ▶ Explaining your illness, treatments, and medications
- ▶ Teaching them ways to manage care problems using creativity, optimism, and planning
- ▶ Promoting self-care, including healthy eating, exercise, and relaxation
- ▶ Helping them develop an effective caregiving partnership with you
- ▶ Providing a network of support and ways to grow it
- ▶ Teaching decision making and giving decision support
- ▶ Connecting them to counseling and respite care
- ▶ Offering practical and financial assistance
- ▶ Helping with advanced care planning

ALFONSO'S STORY

Alfonso, a single father, was struggling to work two part-time jobs and take care of his 8-year-old son, Matias, who had been diagnosed with leukemia at age 2. The disease had been in remission, but then Matias needed a bone marrow transplant. The oncologist said that after Matias left the hospital, he would need to stay home, as isolated as possible, for at least three months. Alfonso knew he could not afford to take that much time off work to provide the care Matias needed, so the palliative care team stepped in.

First, a social worker helped Alfonso arrange a schedule that had his sister staying with his son three days a week. Then she connected him to a local charity that provided him with the funds to hire a health aide for two additional days. Next, an oncology nurse came to his home and taught Alfonso and his sister how to wash their hands, sanitize the house, and wear masks and gloves when interacting with Matias. The nurse also explained how and when to give him his medication and how to look for symptoms of infection.

Noticing that Alfonso looked tired and thin, the nurse asked if she could speak with him in the kitchen. He was terrified his son would get worse while he was at work, and he had not slept for more than a few hours at a time in months. At the nurse's suggestion, he began attending a local support group for parents of children with cancer and received medication and counseling for anxiety. Today, Matias remains in remission, and Alfonso is at a full-time job that gives him a more flexible schedule.

"I couldn't take care of myself and my son alone," Alfonso said. "Without the extra care, I don't know how we would have made it through. I'm so grateful for all the help we received."

TALKING ABOUT YOUR CARE

Talking about cancer, cancer treatment, and your needs is an important part of palliative care. These conversations help clarify your goals and expectations. This could mean wanting to continue cancer treatment as long as possible, regardless of the difficulty of treatment, or it could mean maintaining a specific quality of life, even if that means stopping treatment at some point. The best palliative care occurs when patients and their families work together with the health care team.

Don't be afraid to ask your health care team questions or express your opinions, preferences, and concerns. Tell the members of your health care team if you experience any pain, discomfort, or other side effects, such as mouth sores, nausea, vomiting, and constipation, even if you feel they are not serious. There are usually several options for relieving these symptoms, but doctors and nurses need to know you are in pain or discomfort in order to help you feel better. If you are confused about your options, tell them. They can provide more information and guide you through the decision-making process so you are able to make informed choices about your care. (See "Tips for talking with your health care team" on page 23.)

If you have been referred to a palliative care specialist, your palliative care team can help you and your caregivers understand your diagnosis, treatment plan, and prognosis, which is the chance of recovery. These may change throughout the course of your illness, so continue to have open and honest discussions with your oncologist and palliative care team.



JAN'S STORY

After being diagnosed with breast cancer, Jan's oncologist recommended she have chemotherapy before surgery to remove the tumor in her left breast. A few hours after each treatment, she became extremely nauseated and began vomiting. This occurred each time she received a treatment and lasted for several hours.

A few weeks into her treatment, Jan's doctor asked how she was feeling. Jan told him about the nausea and vomiting, but said she understood that they were "just a part of chemotherapy." The doctor explained that while these side effects are common, there are a number of ways to control them using palliative care.

After that, Jan began receiving a different anti-nausea drug by vein at the outpatient clinic 30 minutes before her chemotherapy began. The doctor also prescribed an anti-nausea drug that she could take at home three times a day. A nurse recommended other tips, such as eating ginger and sitting up after eating. Jan's nausea improved, but the drug she took at home made her so drowsy she was unable to stay awake for more than a few hours at a time. The doctor switched her to a skin patch that provided a different type of medication, and both the nausea and drowsiness were almost completely gone.

"I thought that being sick from chemotherapy was just part of having cancer treatment," Jan said. "I learned that with all the new medications out there today, I didn't have to suffer. I was able to finish chemotherapy and have a successful surgery."

Getting the care you want

Although talking about your wishes with your caregiver, other loved ones, and health care team is often enough, there are also legally binding documents that explain the types of medical treatment you do and do not want if you become unable to make these decisions for yourself. Many people think about these types of documents as being useful only at the end of life; however, no matter what stage of disease you have been diagnosed with, they are important to have.

■ Advance directives

By putting your wishes in writing, you retain control of the decisions about your health, even if you cannot speak for yourself. It also gives your family members peace of mind that you will receive the care that you want.

An advance directive is a legal document. The first part of an advance directive is called a Durable Power of Attorney for Health Care. In this part you can name one or more people you trust to make decisions about your care. The people you name become your health care representatives. The second part, called a living will, says what treatments you think you would want if you were seriously ill. It also includes what treatments you think you would NOT want.

■ **Do not resuscitate forms**

A “do not resuscitate” order is another way to say what kind of care you want. You can create it along with an advance directive. Or, you can have one by itself. A “do not resuscitate” order is also called a DNR.

If your heart or breathing stops, health care providers will try to start it again. The medical term for this is “resuscitation.” It is also called “cardiopulmonary resuscitation,” or CPR. The law says health care providers must do it unless you have a medical order about it. A DNR is this type of medical order. It says what you do want and what you don’t. A DNR order says you do not want CPR if your heart stops beating.



■ **Physician orders for life-sustaining treatment forms**

“Physician orders for life-sustaining treatment,” or POLST, are medical orders. A POLST form addresses plans to use or not use CPR in an emergency. Therefore, POLST forms can include DNR orders, but they can also state that you want and must be given CPR if your heart stops beating. Besides CPR, POLST forms can include your wishes on having antibiotics for certain types of illnesses or having a breathing or feeding tube.

You may change these forms if you change your mind. You will need to notify your entire health care team, including your oncologist, palliative care team, and any other health care providers if you make any changes. You will also want to make sure that you and any other people involved in decisions about your health care have up-to-date copies that are easy to access. Copies should also be on file anywhere you receive treatment or care, such as a hospital, doctor’s office, or nursing home. To make changes to a DNR or POLST, tell a member of your health care team that you want to change it.

TIPS FOR TALKING WITH YOUR HEALTH CARE TEAM

- ▶ Ask the doctor to explain your diagnosis, treatment plan, and prognosis. Prognosis is the chance of recovery. These may change over time, so continue to have open, honest discussions with your doctor.
- ▶ Write your questions down before appointments or home visits. This can lower your stress level and help make the most of your time with your health care team.
- ▶ Make a list of your physical, emotional, and practical concerns so you can share them at your next appointment. Addressing social, emotional, functional, and spiritual needs is just as important as issues with physical health.
- ▶ Ask your health care team to explain if you don't understand an explanation, description, or unfamiliar medical word.
- ▶ Tell members of your health care team about any pain, discomfort, or other side effects, even if you feel they are not serious.
- ▶ Bring a family member or friend to your appointments so they can write down or record information for you. This will allow you to focus on the conversation and then read or listen to the information again later.
- ▶ Keep track of your symptoms and side effects. Write down what they are, how often they occur, and how severe they are. This will help the doctor identify the causes and find solutions.
- ▶ Learn more about your type of cancer and its treatment from reliable websites, such as Cancer.Net, www.cancer.net, and the National Cancer Institute, www.cancer.gov, so it is easier for you to ask questions.
- ▶ Take advantage of new technologies that allow patients to connect with their health care team, such as patient portals, or to track their care, such as health care apps.

Questions to ask

It is important to talk with your health care team soon after cancer has been diagnosed so you understand your prognosis, the goals of treatment, and your options for managing symptoms and side effects. Planning for all possibilities, including the need for palliative care, will help you, your caregivers, and other family and friends better cope with whatever lies ahead.

■ Questions to ask about your diagnosis

- ▶ What type of cancer do I have?
- ▶ Does my cancer have a subtype or any other characteristics that will be helpful to know?
- ▶ Where exactly is it located?
- ▶ What is the stage? What does this mean?
- ▶ What is my prognosis? Is it possible for me to fully recover from this type of cancer?
- ▶ Where can I find more information about this type of cancer?

■ Questions to ask about symptoms

- ▶ What are some common symptoms of this type of cancer?
- ▶ How can they be prevented or managed?
- ▶ What are the treatment options for my symptoms?
- ▶ Will certain activities make my symptoms worse?

■ Questions to ask about treatment

- ▶ What are my treatment options?
- ▶ Which treatments or combination of treatments do you recommend? Why?
- ▶ What is the goal of each treatment? Is it to eliminate the cancer, help me feel better, or both?
- ▶ Who will be part of my cancer care team, and what does each member do?
- ▶ What clinical trials are available for me? Where are they located, and how do I find out more about them?
- ▶ How will this treatment affect my daily life? Will I be able to work, exercise, and perform my usual activities?

■ **Questions to ask about treatment side effects**

- ▶ What are the potential short- and long-term side effects of each treatment option?
- ▶ Are there ways I can prepare for treatment to reduce the chance of experiencing side effects?
- ▶ What can be done to manage any side effects I may experience?
- ▶ Should I track the symptoms or side effects I have? If so, how?
- ▶ If I develop a new symptom or side effect or an existing one gets worse, what should I do?
- ▶ How can I keep myself as healthy as possible during treatment?
- ▶ What lifestyle changes—such as diet, exercise, and rest—should I make to be healthy before and after treatment?
- ▶ Could any of my treatments affect my sex life? If so, how and for how long?
- ▶ Will this treatment affect my ability to become pregnant or have children? If so, can I talk with a fertility specialist before cancer treatment begins?
- ▶ What long-term side effects or late effects are possible based on my cancer treatment?

■ **Questions to ask about support**

- ▶ What type of support services does palliative care provide?
- ▶ Can you recommend someone who specializes in palliative care?
- ▶ Where can I receive palliative care services?
- ▶ What other support services are available to me? To my family?
- ▶ If I am worried about managing the practical concerns of cancer treatment, who can help me?
- ▶ If I'm worried about managing the costs of cancer care, who can help me?

■ **Questions to ask your palliative care team**

- ▶ Who will be a part of my palliative care team? What are their roles?
- ▶ How often will I be in contact with or see the palliative care team?
- ▶ When and how should I contact the palliative care team?
- ▶ Who should I contact after hours or for an emergency?
- ▶ How will you coordinate care with my oncologist and other health care providers?
- ▶ If I have a concern, should I reach out to the palliative care team or my oncology team first?

RESOURCES

You can find additional information about cancer treatment, side effects, and palliative care and links to patient support and resource organizations on Cancer.Net (www.cancer.net). The following national organizations also provide resources about palliative care, hospice care, medical decision making, and other topics addressed in this booklet. Because programs and services continually change, visit www.cancer.net/support to find the most current information.

American Academy of Hospice and Palliative Medicine

www.palliativedoctors.org

American Cancer Society

www.cancer.org

800-227-2345

CancerCare

www.cancercare.org

800-813-4673

Caregiver Action Network

www.caregiveraction.org

202-454-3970

Center to Advance

Palliative Care

www.getpalliativecare.org

International Association for Hospice & Palliative Care

www.hospicecare.com

866-374-2472

Jack & Jill Late Stage Cancer Foundation

www.jajf.org

404-537-5253

Medicaid

www.medicaid.gov

877-267-2323

Medicare

www.medicare.gov

800-633-4227

National Association for Home Care & Hospice

www.nahc.org

202-547-7424

National Cancer Institute (NCI)

www.cancer.gov

800-422-6237

National Center for Complementary and Integrative Health

www.nccih.nih.gov

888-644-6226

National Hospice and Palliative Care Organization

www.caringinfo.org

703-837-1500

www.polst.org
202-780-8352

<https://cam.cancer.gov>
800-422-6237

[illegible]

PALLIATIVE CARE DICTIONARY

Adjuvant therapy: Treatment given after the main treatment to reduce the chance of cancer coming back by destroying any remaining cancer cells. It usually refers to chemotherapy, radiation therapy, hormone therapy, and/or immunotherapy given after surgery.

Caregiver: A person who provides important physical, practical, and emotional support to a person with cancer. Caregivers are often family members or friends and may have a range of responsibilities on a daily or as-needed basis.

Chemotherapy: The use of drugs to destroy cancer cells.

Chronic: Refers to a disease or condition that persists, often slowly, over a long time.

Clinical trial: A research study that tests new treatments and/or prevention methods to find out whether they are safe, effective, and possibly better than the current standard of care, which is the best known treatment.

Complementary medicine: A diverse group of treatments, techniques, and products that are used in addition to standard cancer treatments.

Cure: To fully restore health. This term is sometimes used when a person's cancer has not returned for at least five years after treatment. However, the concept of "cure" is difficult to apply to cancer because undetected cancer cells can sometimes remain in the body after treatment, causing the cancer to return later. Recurrence after five years is still possible.

Fatigue: When related to cancer and/or its treatment, fatigue is a persistent feeling of physical, emotional, or mental tiredness or exhaustion. This type of fatigue is different from tiredness from not getting enough rest.

Hospice: Refers to a facility or program that provides palliative care to a person who has less than six months to live. Hospice care aims to reduce pain and discomfort so that a person approaches the end of life with peace, respect, and dignity.

Immunotherapy: A type of cancer treatment designed to boost the body's natural defenses to fight the cancer. It uses materials made either by the body or in a laboratory to improve, target, or restore immune system function. It may also be called biologic therapy.

Infertility: Inability to become pregnant or father children.

Integrative medicine: A combination of medical treatments for cancer and complementary therapies to help manage the symptoms and side effects of cancer.

Late effects: Side effects of cancer treatment that occur months or years after a diagnosis of cancer because of the related treatments, such as chemotherapy, radiation therapy, or surgery.

Long-term care insurance: A type of insurance that covers assistance with daily activities, such as bathing, dressing, or eating. This long-term care can be provided either at home or in a skilled nursing facility, such as a nursing home.

Metastasis: The spread of cancer from the place where the cancer began to another part of the body. Cancer cells can break away from the primary tumor and travel through the blood or the lymphatic system to the lymph nodes, brain, lungs, bones, liver, or other organs.

Nausea: The urge to vomit or throw up.

Oncologist: A doctor who specializes in treating cancer. The main types of oncologists are medical, surgical, radiation, gynecologic, and pediatric oncologists.

Oncology nurse: A nurse who specializes in caring for people with cancer.

Oncology nurse navigator: A nurse who specializes in helping patients and families navigate the challenges of cancer. Navigators promote communication between patients and health care team members and connect patients with resources to help them complete treatment and maintain their quality of life.

Palliative care: Any form of treatment that concentrates on reducing a person's symptoms or treatment-related side effects, improving quality of life, and supporting patients and their families. It may also be called supportive care.

Prognosis: Chance of recovery; a prediction of the outcome of a disease.

Psychologist/psychiatrist: Mental health professionals who work to address a person's emotional, psychological, and behavioral needs.

Quality of life: An overall sense of well-being and satisfaction with life.

Radiation therapy: The use of high-energy x-rays or other particles to destroy cancer cells. Also called radiotherapy.

Recurrence: Cancer that has returned after a period during which the cancer could not be detected. “Local recurrence” means that the cancer has come back to the same general area where the original cancer was located. “Regional recurrence” refers to cancer that has come back in the lymph nodes or other tissues near the original cancer site, usually by direct spread. “Distant recurrence” refers to cancer that has come back and has spread to other parts of the body, usually by traveling through the lymph system or bloodstream.

Rehabilitation: Services and resources that help a person with cancer obtain the best physical, social, psychological, and work-related functioning during and after cancer treatment.

Remission: The disappearance of the signs and symptoms of cancer but not necessarily the entire disease. The disappearance can be temporary or permanent.

Respite care: Short-term care that can provide caregivers with a few hours or days of rest.

Screening: The process of checking whether a person has a disease or has an increased chance of developing a disease when the person has no symptoms.

Side effect: An undesirable result of treatment, such as fatigue, nausea, or hair loss.

Stage: A way of describing where the cancer is located, if or where it has spread, and whether it is affecting other parts of the body.

Surgery: The removal of cancerous tissue from the body through an operation.

Survivorship: This term means different things to different people. Common definitions include having no disease after the completion of treatment and the process of living with, through, and beyond cancer.

Survivorship care plan: A personalized schedule of follow-up examinations and tests that the doctor recommends after a patient’s active treatment period ends. This may include regular physical examinations and/or medical tests to monitor the patient’s recovery for the coming months and years. It may also be called a follow-up care plan.

Symptom: A change in the body or mind that indicates that a disease is present.

Targeted therapy: Treatment that targets specific genes, proteins, or other molecules that contribute to cancer growth and survival.

Treatment summary: A written summary of the therapies that the patient had during the active treatment period. This is often used in conjunction with a survivorship care plan to help monitor a survivor's long-term health.

For more definitions of common cancer related terms, visit www.cancer.net/cancerterms.

NOTES

This image shows a blank sheet of white paper with horizontal blue ruling lines. The lines are evenly spaced and run across the width of the page. There are no margins, text, or other markings on the paper.

NOTES

[illegible]

Looking for Other Patient Information Resources?

ASCO ANSWERS GUIDES

ASCO Answers Guides feature comprehensive information about the diagnosis, treatment, side effects, and psychosocial effects of a specific cancer type, as well as practical information for patients and families. Guides on survivorship and caregiving are also available.

ASCO ANSWERS FACT SHEETS

ASCO Answers Fact Sheets provide a one-page (front and back) introduction to a specific type of cancer or cancer-related topic. Each includes an overview, illustration, words to know, and questions to ask the health care team. Cancer.Net has more than 65 fact sheets available (including some in Spanish), covering different cancer types, diagnosis and treatment, and side effects.

ASCO ANSWERS BOOKLETS

ASCO Answers Booklets provide in-depth, practical guidance on specific topics in cancer care, including advanced cancer care planning, pain, cost of care, managing weight, palliative care, and stopping tobacco use.

For Patients and Caregivers: If you are interested in additional educational materials, visit www.cancer.net/ascoanswers to find all of our available materials in electronic format.

For Oncology Professionals: Bulk quantities of high-quality print materials are available for purchase. Visit www.cancer.net/estore or call 1-888-273-3508 to place your order.

To request free promotional materials for your practice, please send an email to contactus@cancer.net.

Cancer.Net

Doctor-Approved Patient Information from ASCO®

WE WANT TO HEAR FROM YOU

If you found this material helpful or if you have comments or suggestions about how it could be better, please let us know at contactus@cancer.net.



AMERICAN SOCIETY OF CLINICAL ONCOLOGY

AMERICAN SOCIETY OF CLINICAL ONCOLOGY

2318 Mill Road, Suite 800

Alexandria, VA 22314

Phone: 571-483-1300

Fax: 571 366-9530

www.asco.org | www.cancer.net

For more information about ASCO's patient information resources,
call toll-free 888-651 3038 or e-mail contactus@cancer.net.

To order more copies of this booklet,
call 888-273-3508 or visit www.cancer.net/estore.

© 2020 American Society of Clinical Oncology.

For permissions information, contact permissions@asco.org.

PC17