



ASCOanswers

Palliative Care

**Improving Quality of Life for Patients
and Families**

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Doctor-Approved Patient Information from ASCO®



ABOUT ASCO

Founded in 1964, the American Society of Clinical Oncology (ASCO) is the world's leading professional organization representing physicians who care for people with cancer. With more than 35,000 members, ASCO is committed to improving cancer care through scientific meetings, educational programs, and peer-reviewed journals. ASCO is supported by its affiliate organization, the Conquer Cancer Foundation, which funds groundbreaking research and programs that make a tangible difference in the lives of people with cancer.



ABOUT CANCER.NET

The best cancer care starts with the best cancer information. Well-informed patients are their own best advocates and invaluable partners for physicians. Cancer.Net (www.cancer.net) brings the expertise and resources of the American Society of Clinical Oncology (ASCO), the voice of the world's cancer physicians, to people living with cancer and those who care for and care about them. All the information and content on Cancer.Net was developed and approved by the cancer doctors who are members of ASCO, making Cancer.Net an up-to-date and trusted resource for cancer information on the Internet. Cancer.Net is supported by the Conquer Cancer Foundation, which provides funding for breakthrough cancer research, professional education, and patient and family support.

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Palliative Care

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

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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 both 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.

This booklet is designed to help people with cancer, their families, and their caregivers understand how palliative care improves 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 the treatments 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 you be as comfortable as possible and maintain your 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, as well as 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 disease-directed treatment. 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 fewer symptoms, maintain a better quality of life, and report they are more satisfied with their treatment plan.

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 as an extra layer of support for people with any stage of cancer. Hospice care is a specific type of palliative care provided to people with later-stage disease who are expected to live six months or less.

If you have later-stage disease, your doctor may suggest at some point during your illness that the main focus of your treatment transition primarily into palliative care. Choosing to stop disease-directed treatment, such as chemotherapy, and continuing to receive only palliative care does not mean you have stopped “fighting” the disease or that your health care team has abandoned you or given up. Instead, it gives you the chance to get relief from burdensome symptoms and receive additional support in all areas of your life. If a person decides to begin hospice care, palliative care specialists 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. 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.

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 specially 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 doctors will work together to develop a care plan that meets your specific needs. Your health care team will continue to adjust this plan as your needs and wishes change. They will also introduce other specialists and health care professionals into your team as needed. These new team members may include:

Palliative care nurses. Palliative care nurses provide general care and help you manage pain and other symptoms. They often act as the main point of contact for the rest of your palliative care team and your other health care providers, including your oncologist. If you receive palliative care at home, nurses may visit you regularly to ensure you receive the care you need.

Social worker. A social worker provides counseling for you and your family, helps with financial issues and finding transportation, arranges family meetings, and can connect you and your family to local resources. Social workers also help with discharge from the hospital to a person's home and finding in-home help, or, if necessary, hospice care.



Pain specialist. Pain specialists, or pain medicine doctors, are experts at finding the cause of pain and treating it. They may do this by working with the palliative care specialist and prescribing medication, recommending a rehabilitation program, and/or performing pain-relieving procedures. In many palliative care teams, the palliative care specialist is also an expert in pain management.

Chaplain. A chaplain is a person usually affiliated with a specific religion who is trained to listen to patients and family members who have concerns or interests in discussing faith-related and spiritual matters, especially when a person has a serious illness.

Dietitian. A dietitian can help address nutritional challenges, such as nausea or appetite loss; provide practical tips for nutritional supplements; and develop specialized eating plans.



Physical and occupational therapists. If needed, a physical therapist helps you maintain mobility and improve how well you move. A physical therapist can also develop an exercise program to maintain or improve your physical strength during and after treatment. Occupational therapists typically focus on daily tasks and functioning, especially upper body movement, while physical therapists specialize in overall movement.

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

Child life specialists. These trained professionals specialize in helping children and their families understand a child's serious illness as well as assisting siblings through the experience.

Grief and bereavement coordinator. This is a professional with specialized training in social work or psychology who counsels family members who are facing or have suffered the loss of a loved one.



How Do I Get Palliative Care?

If you think you would benefit from palliative care and your oncologist does not mention it, ask about the palliative care services available to you. You can bring this booklet with you to start the discussion. Then you can 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.

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, and 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, who 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

Unlike disease-directed treatment, which aims to slow, stop, or eliminate the cancer, the goal of palliative care is to improve 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 is able to do 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 what the cause and regardless of whether that discomfort is mild, moderate, or severe.



PHYSICAL

Physical symptoms of cancer, such as pain, fatigue, difficulty breathing, and weight loss, 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. Often a combination of therapies is 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, anti-emetics are drugs that help prevent vomiting. Pain is also largely controlled 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, which must be prescribed by a doctor, may be recommended for moderate to severe pain. See page 13 for more information about managing pain.

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 nutrition 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 is a combination of breathing and meditation.



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 improve your ability to tolerate treatment. Some people will need to exercise under supervision, while others will be able to exercise independently.

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 a way that is most beneficial to you. For example, if you have trouble swallowing pain medication, the team can explore other options with you, such as pain patches that are worn on the skin or injections.

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 prescription drugs 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, as well as the severe dizziness 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. Usually 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 also are sometimes used along with other prescription pain medicines, called opioids, to treat more severe pain. Opioids, also called narcotics, include hydrocodone, fentanyl, hydromorphone, methadone, morphine, oxycodone, and oxymorphone. Because they are such strong pain relievers, extra care and caution must be taken to ensure opioids are taken and stored correctly.

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 pain occurs in spite of taking your regularly scheduled pain medication, your doctor may recommend extra doses.

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 options include physical therapy, distraction techniques, acupuncture, imagery and visualization, biofeedback, and massage. The most complete and potentially successful approach to pain control usually combines several methods, and these methods may change as your health changes.

EMOTIONAL

In addition to physical side effects, the diagnosis and treatment of cancer often trigger difficult emotions that can affect your daily life. Oncology and palliative care nurses 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, such as:

Fear of treatment-related side effects. As you prepare to start cancer treatment, it is normal to fear the unexpected and worry that treatment will be difficult. Getting accurate information about your diagnosis and treatment plan can go a long way toward easing your mind and helping you prepare for what lies ahead.



Depression. Depression is characterized by feeling down, depressed, or sad; having little interest in or receiving little pleasure from doing things; and feeling hopeless. Depression may appear shortly after a cancer diagnosis or anytime during or after treatment. Depression lowers a person's quality of life and may interfere with a person's ability to make choices about cancer treatments. Although depression is common for people with cancer, it is not considered a normal part of living with cancer.

Anxiety. Anxiety causes people to feel nervous, on edge, or worried much of the time and may interfere with your daily activities and relationships. You may be anxious about the possibility of dying, having the cancer return or spread after treatment, receiving treatment or experiencing treatment-related side effects, losing control over future life decisions, becoming dependent on others, and possible changes in your relationships with family and friends. A person's symptoms of anxiety may worsen the physical side effects caused by cancer. For example, anxiety may increase the fatigue caused by cancer treatment.

Anger. Anger is often one of the first emotional reactions a person has to a cancer diagnosis, but it can develop any time during and after treatment. If not managed, anger can lead to depression. By learning to express anger in a safe, positive way, it can become a source of power to help change things for the better.

Stress. A disease such as cancer can be one of the most stressful experiences of a person's life. Feelings of stress can be increased by 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. People living with cancer often believe they have done something wrong, either to cause the disease or at some other point during the treatment or survivorship process. Letting go of guilt can help improve your well-being and your ability to cope.

Physical changes. Physical changes that occur during cancer and cancer treatment, such as weight gain, weight loss, surgical scars, or hair loss, as well as changes other people cannot see, such as infertility, can make you uncomfortable and self-conscious.

Uncertainty about your future. Many people with cancer face uncertainty. You may feel that your life is less secure or predictable than it once was or that you do not know what the future holds. Uncertainty can lead to other feelings, such as anxiety, anger, sadness, or fear that can interfere with your ability to live life fully.

Research has shown that sharing fears and anxieties with family, friends, counselors, clergy, or support groups helps strengthen patients emotionally and perhaps even physically. Your nurse or social worker 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, also 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 sexuality 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 such as impotence 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. Sexuality is not just affected by changes to the body; mental health plays a key role. 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. A member of your health care team can work with you to address 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 infertility may be temporary or permanent. People who are concerned about their ability to have children can 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 options for preserving it.

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

Helping with Practical Concerns

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 so you get the best possible care.

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 lower-income people, the elderly, 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 benefits.



Your health care team can help you find resources that assist with costs related to treatment, doctor appointments, and medications, as well as help you think through and address other expenses that might be added to your budget, such as childcare, gasoline, and parking fees. Social workers, oncology nurse navigators, and other members of your health care team can also help you address additional practical concerns, including:

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, and 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 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.

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 cancer patients and survivors.

Providing Support to Family, Friends, and Caregivers

The complex feelings and lifestyle changes caused by cancer and its treatment can become as overwhelming for family, friends, and caregivers 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 family caregivers and help them cope with their own distress and emotional pain.



Research suggests that the earlier palliative care services are introduced to caregivers, the better they will be able to cope with the caregiving experience. Palliative care experts 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, which is short-term care that can provide them with a few hours or days of rest
- Offering practical and financial assistance
- Assisting 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 stem cell 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 because it helps clarify your goals and expectations. This could mean wanting to continue disease-directed 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.

Never be afraid to ask your health care team questions or express your opinions, preferences, and concerns. Tell the doctors and nurses about any pain, discomfort, or other side effects, such as mouth sores, nausea, vomiting, and constipation you experience, even if you feel they are not serious. Often there are many options for relieving these symptoms, but doctors and nurses need to know you are in pain or discomfort 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.

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 honest discussions with both your oncologist and your 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 intravenously 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 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 family, caregiver, and health care team is often enough, there are also legally binding documents you can sign, known as advance directives, that explain the types of medical treatment you want and do not want if you become unable to make these decisions for yourself. Many people think about these types of documents being useful only at the end of life; however, they are important to have in your file no matter what stage of disease you have been diagnosed with.

By putting your wishes in writing, you keep control of decisions about your health, even if you cannot speak for yourself. It also relieves your family members of the guilt and anxiety associated with trying to assume or guess what specific interventions and approach to your care you would want.



Once you make an advance directive, you may change it if needed. Changes are allowed as long as you still have or regain your ability to make decisions. You will need to notify your oncology team, 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.

TIPS FOR TALKING WITH YOUR HEALTH CARE TEAM

- Write your questions down before appointments or home visits. This can lower your level of stress and help make the most of your time with the doctor.
- Make a list of your physical, emotional, and practical concerns so you can share them with your doctor, nurse, or another member of your health care team.
- Tell the team member you are talking with if you are having trouble understanding an explanation, description, or unfamiliar medical words.
- 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 (what they are, how often they occur, and how severe they are) to help the doctor identify the causes and find solutions.
- Learn more about your type of cancer 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.

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 family, and caregivers better cope with whatever lies ahead.

QUESTIONS TO ASK ABOUT YOUR DIAGNOSIS

- What type of cancer do I have?
- Where exactly is it located?
- What is the stage? What does this mean?
- Is this type of cancer caused by genetic factors? Are other members of my family at risk?
- What is my prognosis? Is it possible for me to fully recover from 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 and stage of cancer?
- How will these symptoms change during or after disease-directed treatment?
- Besides treating the cancer, what else can be done to relieve or manage my symptoms?

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 treatment team, and what does each member do?
- Are there other options I should consider, such as clinical trials?
- 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 in my treatment plan?
- Are there ways I can prepare for treatment to decrease the chance of experiencing side effects?

- What can be done to manage any side effects I may experience?
- 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?
- How will this treatment affect my sex life?
- Will this treatment affect my ability to become pregnant or have children? If so, what can be done to preserve my fertility?
- What other long-term side effects may be associated with 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 cost of treatment, finding transportation, or taking care of other practical concerns, 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?
- Whom should I contact after hours or for emergencies?
- 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?

NOTES

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

847-375-4712

American Cancer Society

www.cancer.org

800-227-2345

CancerCare

www.cancercare.org

800-813-4673

Caregiver Action Network

www.caregiveraction.org

202-772-5050

Caring Connections from the National Hospice and Palliative Care Organization

www.caringinfo.org

800-658-8898

Center to Advance Palliative Care

www.getpalliativecare.org

Hospice and Palliative Nurses Association

www.hpna.org

412-787-9301

International Association for Hospice & Palliative Care (IAHPC)

www.hospicecare.com

866-374-2472

Jack and Jill Late Stage Cancer Foundation

www.jajf.org

404-537-5253

Medicaid

www.medicaid.gov

Medicare

www.medicare.gov

800-633-4227

Palliative Care Dictionary

Anxiety: Feelings of nervousness, fear, apprehension, and worry.

Chemotherapy: The use of drugs to destroy cancer cells.

Clinical trial: A research study that involves volunteers. Many clinical trials test 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.

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.

Depression: Defined as having a low mood and/or feeling numb consistently for more than two weeks, every day and much of the day.

Disease-directed treatment: Treatment designed to slow, stop, or eliminate cancer. Disease-directed treatment may include surgery, chemotherapy, radiation therapy, targeted therapy, or immunotherapy.

Fatigue: A persistent feeling of physical, emotional, or mental tiredness or exhaustion related to cancer and/or its treatment.

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.

Infertility: Inability to become pregnant or father children.

Learning resource center: A location in a hospital or cancer center where patients and families can get information about health-related topics and learn about support resources. Also called a health or hospital library.

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.

Nausea: The urge to vomit or throw up.

Oncologist: A doctor who specializes in treating cancer. The five main types 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.

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.

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.

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

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

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

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.

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