

ASCOanswers

Advanced Cancer Care Planning

**A Decision-Making Guide for Patients
and Families Facing Serious Illness**

Cancer.Net 

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 30,000 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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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

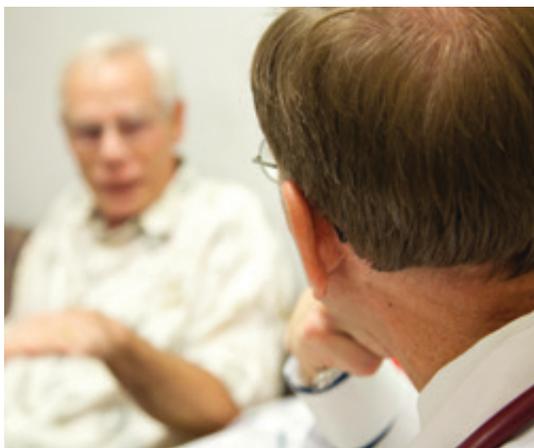
Despite major advances in the treatment of cancer during the past few decades, recovery from cancer is not always possible. If a cure or long-term remission (no signs of cancer) becomes unlikely or impossible, the disease may be called advanced, end-stage, or terminal cancer. However, incurable does not mean untreatable. People with advanced cancer continue to have treatment options and can maintain a good quality of life for months or even years.

This booklet is designed to help people with advanced cancer, their families, and their caregivers understand the treatment options available throughout the course of the illness, discuss these options, and find support. Clarifying what you value and hope for during this time, and then openly communicating these wishes with the members of your health care team, will not only help your doctors identify the best plan for your care, but also can give you a sense of power in a situation that may seem out of your control.



Care Options for Advanced Cancer

If you have been diagnosed with advanced cancer, a cure is no longer possible. However, you still have choices for care. At this time, it is helpful to talk with your doctor to understand your treatment options and the goals of each treatment. Some treatments may be used to shrink tumors to extend your life, while the main goal of other treatments may be to manage pain



JOHN ANDREW HUGHES

and relieve other symptoms so you can have a higher quality of life and/or maintain your independence. Because treatments like chemotherapy and radiation therapy are used to eliminate or control cancer, as well as treat symptoms, it is important to understand what you can expect your treatment plan to do for you in your situation.

There are a number of different types of treatment that may be suggested individually or in combination throughout the course of your illness: standard (disease-directed) treatment, clinical trials, palliative/supportive care, and hospice care. Each has a specific purpose, and your treatment plan may change based on the changing goals of your care.

Standard Treatment

Standard treatment is the most effective treatment currently available for your type and stage of cancer. This type of treatment focuses on directly controlling the disease. Although advanced cancer cannot be eliminated using standard treatment, some patients, families, and doctors may choose to start or continue treatments, such as surgery, chemotherapy, and/or radiation therapy, in the hope of slowing the cancer's growth. For some people with

some types of cancer, such as women with advanced breast or ovarian cancer, disease-directed treatment allows them to live for many years with a good quality of life. However, for patients with other types of advanced cancer, like advanced lung cancer, research has shown that continuing standard treatment often does not help improve the quality or length of a person's life. As a result, some people with advanced cancer choose to stop receiving disease-directed treatment, especially if it causes unpleasant or harmful side effects.

Before making a decision about whether to begin or continue disease-directed treatment, it is helpful to talk with your doctor about the chances that the cancer will respond to treatment, what the response may be (such as shrinking a tumor or slowing cancer growth), the risks of treatment (especially side effects), and the consequences of stopping standard treatment.

Clinical Trials

A clinical trial is a highly controlled research study involving volunteers. Many clinical trials test new drugs and treatments to find out whether they are safe, effective, and possibly better than the current (standard) treatment. Participating in a clinical trial may offer a person with advanced cancer the chance to help other people with cancer in the future; or, in some cases, the research may provide a personal benefit. Participating in a clinical trial is often a good option and should be considered throughout the course of treatment rather than as a last resort.

Palliative / Supportive Care

Palliative care is any treatment that focuses on reducing a person's symptoms, improving quality of life, and supporting patients and their families. Any person, regardless of age or type and stage of cancer, may receive palliative care. Ideally, palliative care is part of a person's treatment plan starting at diagnosis, and it can be given at the same time as disease-directed treatment or on its own.

The primary goal of palliative care is to help people living with a serious, chronic, and progressive disease, like cancer, by:

Managing the symptoms and side effects of the disease and its treatment. Medication, physical therapy, rehabilitation, nutritional advice, relaxation techniques, massage, and a wide range of other therapies are used to help manage pain, nausea, breathlessness, insomnia, and other physical symptoms.



Addressing a patient's practical needs. Patients receive additional help addressing financial and legal concerns, transportation issues, employment concerns, and more.

Focusing on a patient's emotional and social needs. Resources are provided to address concerns such as depression, anxiety, and fear and to help with family and other relationships.

Addressing a patient's spiritual needs or concerns. Palliative care experts help people explore their faith and beliefs as they work to accept the concept of completing their life. If needed, they can also connect patients and their families to a chaplain or other spiritual and religious resources in the community.

Providing support for the patient's family, friends, and caregivers. Family caregivers receive both emotional and practical support as they cope with the daily challenges of caregiving and the feelings that surround the eventual loss of a person with cancer.

WHEN AND WHERE PALLIATIVE CARE IS GIVEN

Palliative care starts as early as possible in the cancer treatment process and continues throughout all stages of the disease. At some point during your illness, though, your doctor may suggest 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.

Palliative care can be given in a doctor's office, hospital, cancer center, long-term care facility, or your home, depending on the treatments used and the available resources. Talk with your doctor, nurse, or an oncology social worker about your options.

MEMBERS OF THE PALLIATIVE CARE TEAM

A number of health care professionals may be a part of your palliative care team, including doctors, nurses, social workers, chaplains, dietitians, physical and occupational therapists, and grief and bereavement counselors. The team will work with you and your family to develop an individualized palliative care plan that meets your specific needs and will make adjustments to this plan as your needs change. Communication between you and your care team is important because it helps clarify your hopes, goals, and expectations.

BENEFITS OF PALLIATIVE CARE FOR FRIENDS, FAMILY, AND CAREGIVERS

A diagnosis of advanced cancer often produces intense emotions and triggers fears for family, friends, and caregivers. Palliative care teams are trained to meet the needs of family caregivers and help them deal with the distress and emotional pain caused by physical changes in the person with cancer and the anticipation of loss.

MANAGING THE COST OF PALLIATIVE CARE

Palliative care is often covered by private health insurance plans. Medicaid (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) and Medicare (health insurance provided by the federal government for those 65 and older, as well as for some disabled Americans) may also pay depending on the situation. A hospital social worker can help you explore payment options.

Hospice Care

Hospice refers to both a facility and an attitude toward care near the end of life. Hospice provides palliative care that aims to reduce pain and discomfort so that a person approaches the end of life with peace, respect, and dignity. Hospice care teams work with individual patients and families to develop personalized care plans that may include medications and other therapies, such as massage and music and art therapy.

Recognizing that many people with advanced cancer feel overwhelmed when they are told there is little chance of a cure, hospice care also helps you and your family cope with the emotions surrounding the end of life, such as fear, guilt, anger, resentment, exhaustion, stress, anxiety, and sadness.

HOW HOSPICE CARE IS DIFFERENT FROM PALLIATIVE CARE

Although you may hear these terms used in similar ways, they are slightly different. Palliative care is given at every step of the treatment process and at all stages of illness, whereas hospice care is a specific type of palliative care provided to people with cancer who are expected to live six months or less, regardless of their age or the type of cancer they have. 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.



QUALITY OF HOSPICE CARE

Some people worry that because they are reaching the end of life, they will not receive the same quality of care as other patients or that their death will occur quicker in hospice. However, hospice care is humane and compassionate care, and it does not speed up the end of life. Some people who choose hospice care may actually live longer if their symptoms are well controlled.

CHOOSING WHEN AND WHERE TO RECEIVE HOSPICE CARE

In the United States, acceptance into hospice care requires a statement by a doctor that a person has a life expectancy of six months or less. However, hospice care can be continued if you live longer than six months. If your condition improves, hospice care will be stopped, and you may resume disease-focused treatment.

Because of the availability of hospice programs and other home care services, people with advanced cancer are usually able to choose where they would like to spend their final days.



Hospice care can be delivered at home (home hospice) with the help of a family caregiver and hospice staff or in a specialized facility. Some hospitals have designated hospice beds.

The cost, availability of caregivers, and community resources are factors to consider when deciding where to receive hospice services. Ask your doctor, nurse, or another member of your health care team about the options available to you in advance so you are able to visit the facility and be well prepared.

As you consider your hospice care options, you may also want to ask some or all of these questions:

- Who will manage my pain and other symptoms?
- Will you stay in touch with my oncologist?
- How will my family members be involved in day-to-day care, such as feeding, bathing, giving medication, and monitoring changes in my condition?
- What services do you provide to help with the emotional and spiritual aspects of death and dying?
- Who can my family members call if they have any questions, and what are the phone numbers?
- Is it possible for my family and friends to visit me at any time? (This applies only to inpatient hospice care because the patient and caregivers have control over access at home.)

If you choose to receive care at an inpatient hospice facility, you will want to make sure the location and hours are convenient for visits from family and friends. The facility also should provide peace and quiet and ensure privacy for you, your family members, and other visitors.

MEMBERS OF THE HOSPICE CARE TEAM

Professionals who may be a part of your hospice care team include doctors, nurses, home health aides, social workers, chaplains, therapists (such as physical therapists, occupational therapists, and rehabilitation therapists), dietitians, trained hospice volunteers, and grief

and bereavement counselors. These professionals act as a support system for both you and your loved ones. Knowing that your friends and family have these resources may help ease your worries about leaving them behind.

If you choose to have hospice care at home, a family member or close friend will serve as the primary caregiver and will be responsible for coordinating and overseeing most of your care. Doctors, nurses, home health aides, and personal attendants will provide any medical service or daily care services, such as help with bathing and eating, that your primary caregiver is unable to provide.

GERALD'S STORY

Gerald had been living with lymphoma for nearly 15 years. Recently it became worse, and his current medication stopped controlling the lymphoma. He then developed pneumonia and needed oxygen to help him breathe. The doctor met with Gerald and his family and told them he thought Gerald only had a few months left to live, unless he wanted to try a treatment that would give him six to nine months more.

Gerald and his family decided to go ahead with the chemotherapy, but Gerald had an allergic reaction to it. Because there were no more disease-directed treatment options available, and Gerald still needed the oxygen, the doctor recommended hospice care.

A social worker helped them find an agency that could help and arranged to bring a hospital bed into his home. The hospice team helped Gerald and his family with his medications and made sure he was getting adequate nutrition. During this time, Gerald was able to say goodbye to his children, grandchildren, neighbors, and friends who were so important to him. He died peacefully at home six weeks later.

His daughter said, "Of course we wanted to try everything, but the chemotherapy was so hard on Dad, and we realized we didn't want to say goodbye in the hospital. We were able to be more of a family when he was at home."



WORKING WITH THE HOSPICE CARE TEAM

No matter where you choose to receive care, the hospice staff will work with you and your caregivers to develop a plan tailored to meet the unique needs of your situation. Your care plan will include ways to manage pain and other symptoms and will provide support for you, your family, and caregivers.

Throughout your care, you and your caregivers will have regular meetings with the team to evaluate your medical needs and comfort. In addition to interactions with hospice staff during

these planned meetings, you can contact hospice staff members at any time. They are on call 24 hours a day, seven days a week.

MANAGING THE COST OF HOSPICE CARE

Most private health insurance plans cover hospice care services, as does Medicaid (in most states). However, policy benefits differ from insurer to insurer. Talk with an oncology social worker for help understanding your options.

If you receive Medicare, it covers the costs of hospice care if you are accepted into a Medicare-approved hospice program. Medicare also covers the following services, which are mainly delivered in the home setting:

- Services provided by the doctors
- Nursing visits with 24-hour on-call services
- Medical appliances and supplies related to the life-limiting illness
- Medications to manage symptoms and relieve pain. (Patients may be responsible for a small copayment.)
- Short-term inpatient care to manage symptoms and relieve pain in a Medicare-approved facility, such as a hospital or nursing home
- Short-term inpatient respite care, which is provided to give the usual caregivers temporary relief. (Patients may be responsible for a small copayment.)
- Home health aide and homemaker services

- Supportive counseling
- Spiritual support and counseling
- Nutritional counseling
- Grief and loss support for you and your family

The following services are not covered under Medicare:

- Treatment for the life-limiting illness that is not for pain control or the management of other symptoms
- Care given by another health care provider that was not arranged through the hospice program
- Care given by another health care provider that duplicates care the Medicare-approved hospice provider is required to provide

To learn more about care given near the end of life, visit www.cancer.net/endoflifecare.

Making Decisions About Your Care

As you begin to think about advanced cancer care, it is important to know that this is a very personal choice. Some people want to continue treating the cancer for as long as possible, regardless of the side effects, while others want to focus on being as comfortable and free from pain as possible, even if that means stopping disease-directed treatment. Because these decisions are different for each person, it is important to figure out what an acceptable quality of life means to you. Is it being able to live at home? Doing the activities you enjoy and not being confined to a bed? Or is the amount of time you live the most important thing to you? No matter what you choose, your health care team will continue to support you throughout your illness.

Once you decide what is most important to you, the next step is to clearly communicate your wishes to your family and health care team. You also need to ask yourself: If I am not able to make decisions for myself, who do I want to speak for me? This person, known as your health care proxy or medical power-of-attorney, should be someone you know will make decisions as you would and who can most easily stand at your bedside, if necessary. Your proxy will need to make decisions for you if you are in a coma, have a sudden heart attack or stroke, or are unable to speak for yourself for another medical reason.

Choosing a Health Care Proxy

According to the American Bar Association, a health care proxy should have all of the following characteristics:

- Is over 18 and meets any other legal criteria in your state for acting as a health care proxy
- Is someone you trust with your life
- Is willing to speak on your behalf and separate his/her personal feelings from yours
- Lives close by or could travel to be at your side if needed
- Knows you well and understands what's important to you
- Will talk with you now about sensitive issues and will listen to your wishes



- Will be available for the foreseeable future
- Is able to handle any conflict of opinion that may develop between family members, friends, and medical personnel
- Will advocate strongly for you in the face of any obstacle

Once you choose a health care proxy and he or she agrees, you should tell your family members and your friends whom you've picked and provide a signed copy of the health care proxy form to your doctor. After that, you are still able to make your own decisions about your medical care. Your proxy can only make these decisions after your doctor certifies in writing that you are no longer able to make them for yourself.

Expressing Your Wishes in Writing

Although talking about your wishes with your family, proxy, 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. By putting your wishes in writing, you not only keep control of decisions about your health, even when you can't speak for yourself, but 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.

There are a few specific types of advance directives you may want to consider, including:

Living will. A living will, sometimes called a Directive to Physicians and Family, is a written set of instructions that outlines your wishes about the types of medical care you may or may not want used to keep you alive, including cardiopulmonary resuscitation (CPR), artificial life support (such as mechanical respirators), feeding tubes (artificial nutrition and hydration), or kidney dialysis (a way to filter waste through a machine instead of the kidneys). A living will can also include directions for donating your organs.



CPR or DNR orders. CPR and do-not-resuscitate (DNR) orders specifically state whether you want the medical team to use CPR and/or artificial life support if your breathing or heart stops. If you are in a medical setting, such as a hospital or nursing home, and your heart and/or breathing stops, medical personnel will automatically perform CPR unless you have a DNR order. Unfortunately, CPR is rarely effective

for people with advanced cancer. Even if it is, the person may suffer brain damage (due to a lack of blood flow and oxygen to the brain) or may have to remain on a ventilator and in the intensive care unit indefinitely. Fewer than 5% of people with a serious illness recover enough to be released from the hospital after CPR.

Unlike a living will or health care proxy form that are written and signed by the individual, a DNR order must be completed and signed by the doctor or other health care provider, such as a hospice nurse practitioner. Once completed, the DNR order is added to your medical record.

POLST form. The Physician Orders for Life-Sustaining Treatment (POLST) is a new, more detailed form that is replacing DNR orders in some states for people with advanced illnesses. It includes instructions for CPR, use of antibiotics, intubation, and feeding tubes, and is co-signed by the patient (or health care proxy) and a doctor or other authorized medical provider. POLST forms are available in about half the United States but often go by different names, including MOST, POST, TPOPP, MOLST, and COLST. Talk with your doctor, social worker, or another member of your health care team for more information about the POLST form available in your state.

As you think about what kind of medical treatment you do and don't want in the future, consider the following:

- Are you afraid of losing control, suffering, or being unable to do the things that give you the greatest pleasure in life?
- What other fears, if any, do you have about death and dying?
- Have you talked with your doctor, nurse, or another member of the health care team about your fears?
- Do you believe in an afterlife or have any other strong personal, religious, or spiritual views about dying that may affect what type of care you want at the end of life?
- Have you thought about where you would like to die? In a hospital? At home?

Making Changes to an Advance Directive

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 health care team if you make any changes. You will also want to make sure that you, your health care proxy, 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, such as a hospital, doctor's office, or nursing home.

A NOTE FOR CAREGIVERS, FAMILY, AND FRIENDS

It is important to find out ahead of time if the person you are caring for has created an advance directive. Caregivers and others who care about the person may not always agree with the decisions outlined in an advance directive. However, people with an advanced illness need to know their final wishes will be respected. As a caregiver, following the advance directive is one of the most important things you can do to help the person die with dignity and peace of mind. If the person has a DNR order or filled out a POLST form, make sure to tell any emergency personnel if you need to call 911 (or the emergency services number in your local area).

Communicating Directly and Honestly

KAREN ELSHOUT PHOTOGRAPH



Although people can live for months and even years after being diagnosed with advanced cancer, it is still important to talk directly about end-of-life issues from the very beginning of the advanced cancer care planning process to ensure your wishes are known and respected.

Despite their importance, actually starting these conversations is often difficult. People—patients, families, and health care professionals alike—would much rather talk about what can be done to manage symptoms and treat the disease than plan for death. Still,

it is important to settle your affairs, consider your wishes for care during your final days, and communicate these plans to your family members and health care team, even if you are still benefitting from disease-directed treatment.

Talking With the Health Care Team

To make the best decisions about your care, you need to fully understand your specific situation and your options. It is important to ask your doctor to explain your diagnosis, treatment options, and prognosis (chance of recovery). These may change throughout the course of your illness, so continue to have honest discussions and follow-up visits with your doctor.

The best advanced cancer care occurs when patients and their families work together with the health care team. Never be afraid to ask for more information or to express your

opinions, preferences, and concerns. If your doctor doesn't have all the answers, he or she may be able to refer you to other resources.

Starting these conversations can be challenging, even for your doctor and other members of your health care team, so you may find that you or a family member will need to bring up the subject of death and dying rather than waiting for the doctor to do so. To start this conversation with your doctor, you may want ask some or all of these questions:

- What is my prognosis? Is it possible for me to fully recover from the cancer?
- How will my quality of life change over time?
- Will disease-directed treatment shrink the tumor or slow the cancer's growth or spread?
- What is the goal of my treatment plan? Is it to control the cancer, help me feel better, or both?
- Am I healthy enough to undergo the recommended treatment(s)?
- What are the risks and benefits of the treatment(s) you are recommending?
- Are there other options I should consider?
- How will we know whether the treatment is working?
- Am I at the point where I should consider hospice care? If not, will you tell me when I am?

Talking With Family and Friends

Talking about advanced cancer and end-of-life care can be extremely difficult for friends and family. They may say things like: "Don't talk like that," "Don't lose hope," or "Stay positive" when the topic of death and dying is brought up, as if talking about it will make it come true. However, this fear often keeps people from preparing for the end of life, making it much more difficult when that time comes.



The fact is, talking about end-of-life care early on helps reduce stress for both you and your loved ones. These conversations can provide a sense of peace and confidence that you have made your feelings known and that nothing has been left unsaid. These conversations

also let family members reaffirm their love and promote closeness, which may help ease the pain of separation.

Having this type of conversation isn't easy, so you may want to:

Plan what you want to say. It may help to write down your thoughts and feelings or create a list of the key points you want to get across. Seeing the words on paper can help clarify your thoughts and give you a chance to find the right words.

ALMA'S STORY

Alma was a mother of two in her early 40s when she was diagnosed with metastatic colon cancer that had spread to her liver and lungs. When Alma saw the oncologist, he recommended she undergo chemotherapy. Alma and her family agreed, and the chemotherapy helped for a couple of months. But the cancer continued to spread.

The doctor told the family there was another medication to try, so Alma was given another round of chemotherapy. However, it dramatically lowered her white blood cell counts, and Alma was admitted to the hospital. She recovered, and Alma and her family wanted to try a different chemotherapy option. Her oncologist agreed, but she continued to have low blood counts and couldn't keep any food down, so she was admitted back to the hospital.

This process went on for several more weeks. Alma's family kept hoping each new drug would get rid of the cancer so Alma could come back home. Alma was getting weaker with each round of chemotherapy, and she eventually died from an infection.

Her husband was stunned afterward. He hadn't realized her condition was so serious, and he hadn't been able to prepare the kids for the fact that they were losing their mother. He later said, "I wish someone would have told us the hard facts about the situation and that additional treatment was not likely to help. We didn't know stopping treatment was an option."

Practice the conversation beforehand. Practice what you want to say in advance with a loved one, counselor, or social worker. By practicing with someone you trust, you can get feedback on your tone and choice of words, as well as see how others may react.

Think about how to answer questions. Your family and friends will want to know different things about your diagnosis and treatment plan. Be honest. Talk openly about what you know and be as realistic as possible about what they can expect. It is also important to think about how to respond to insensitive questions or comments. Because people may not have experience with cancer that cannot be cured or may not know what to say, it may help to already have a standard response in mind.

Ask for help. You may want to ask a friend or family member to help keep other people informed about your condition and treatment. Counselors, social workers, and chaplains are always available to help families talk about advanced cancer. In addition, some palliative care services offer grief counseling to friends and family members to help them cope with loss.

Talking With Children

Although it may be challenging, talking with your children or grandchildren about an advanced cancer diagnosis in words they can understand is better than hiding it. Children often can sense that something is wrong, even if they don't know what it is, and avoiding the topic may create feelings of confusion and fear.

Talking openly and honestly about advanced cancer helps prepare children for the future and gives them an opportunity to express their feelings. As you talk with your children or grandchildren, the following suggestions may be helpful and can be adapted to meet your family's needs.



Be honest about the illness. Although cancer is complicated, there are appropriate ways to discuss it with children. For example, it is usually enough to tell very young children, “I am very sick, so I am going to the hospital for special medicine.” For older children, a more detailed explanation is better. The more they understand, the less helpless and afraid they are likely to feel.

Take their feelings seriously. Children have many different reactions when they learn a parent or grandparent has advanced cancer. These feelings often include anger, sadness, guilt, fear, confusion, and frustration. All of these responses are normal. Let them know that it is okay for them to have many different feelings and that you have many of the same feelings too. Reassure them that nothing they or anyone else did caused the cancer.

Encourage questions. Let your children or grandchildren know they are free to ask any question. Be honest, and don’t be afraid to say, “I don’t know.” You may want to tell them, “I don’t know the answer, but I will ask the doctor at my next appointment and get back to you on that.” For children, the amount of information you give them is usually less important than making them feel comfortable with the situation.

Know when to stop. Be aware of signs that your child or grandchild is done talking for the moment, such as changing the subject, looking away, fidgeting, or playing with toys. It is important to respect a child’s need to drop the conversation. You can always talk more when he or she is ready.

Be prepared to discuss death. Although it is difficult and sad, it is important to be prepared to discuss death with your children or grandchildren. You may want to talk with a trained counselor or clergy member first. Consider the child’s age when discussing death. Preschoolers, for instance, do not understand that death is final. In general, by age 10, children begin to understand that death is the end of life.

Each family has its own beliefs about death, and how and when you talk with a child about death and dying is a personal decision. However, try to use clear, specific terms; avoid euphemisms such as “passing away,” “sleeping forever,” or “put to sleep” because children may confuse sleep with death and fear that they may die in their sleep or that you would wake up from death.



It may take a long time for children to fully understand and accept such a loss. So more than anything, children need to know they will not be alone. Let them know they will be taken care of and loved.

Consider counseling. To best address children's unique needs and their developmental stage, many people with advanced cancer consult with counseling professionals soon after they are diagnosed. Such counseling can help parents break the news, manage their children's reactions, and make plans to take care of their family in the future. If you need help, talk with your doctor, nurse, or social worker about the resources available at your treatment center or in your local community.

For more tips on talking with your family about cancer, visit www.cancer.net/talkingaboutcancer.

THE ROLE OF THE FAMILY IN MAKING TREATMENT DECISIONS

A person with cancer may have more than one option for treating the disease, and it may be difficult to choose among them. When making treatment decisions, patients often ask for the opinions of family members. And in some cases, family members may disagree with each other, and with the patient, about the best choice, creating conflict at a time when they need each other's support the most.

If you have been asked to help choose a treatment for a family member, here are a few questions to keep in mind:

- Does my family member understand the risks of treatment and the potential consequences of his or her choices?
- Has my family member openly stated his or her wishes? Are these wishes being respected?
- Is this treatment consistent with my family member's beliefs and values?

The patient's viewpoint should always be considered first because he or she has the right to be heard, the right to change his or her mind, and the right to state his or her wishes and have them respected.

Remember, your family member has asked for your help because he or she respects your opinion, but various factors may lead him or her to make a choice that is different from what you might choose for yourself. It is important, even when disagreements occur, to remember to keep talking with each other and to support your family member's decisions.

It is also helpful to talk openly about the patient's priorities in having treatment. These could range from living as long as possible, regardless of the difficulty of treatment, to maintaining a specific quality of life, even if that means stopping treatment. If this is difficult for your family to talk about, ask someone to facilitate this conversation, such as a doctor, nurse, member of the clergy, social worker, or counselor.

Coping and Finding Support Near the End of Life

Learning your cancer cannot be cured triggers intense emotions, including anger, fear, sadness, and regret. It is normal to grieve and mourn the loss of your abilities, the loved ones you will leave behind, and the days you will not have. It may also be difficult to believe or accept the situation, causing feelings of anxiety and uncertainty. Talking about your feelings and concerns with family, friends, and caregivers can help bring you comfort.

Patients and their families should not be afraid to express the way they are feeling with doctors, nurses, and social workers. The health care team is there to help, and many team members have special skills and experience to make things easier for patients and their families. In addition to providing emotional support and education, your doctor may prescribe medications to help address anxiety or depression. Your doctor may also refer you to a counselor, social worker, psychologist, psychiatrist, support group, or another community resource for help. Along with finding support, this may be the time to begin addressing financial and other concerns and completing any unfinished business.



Putting Your Affairs in Order

Planning ahead to settle legal, financial, and business affairs allows you and your family to concentrate on the emotional aspects of your illness and its effect on your family. During this time, you may want to locate and organize important legal and financial documents, such as your will, marriage and birth certificates, social security card, insurance policies,

bank statements, investment summaries, car and house titles, and passwords to accounts. If you have complicated finances or are concerned about leaving your family with high medical bills or debts, consider talking with a financial advisor or social worker. Although financial professionals cannot eliminate bills or debts, they will help you organize your finances and create a plan to reduce the stress of financial responsibilities on you and your family.

In addition, some people find it helpful to plan some aspects of their own funeral or memorial service. You can create a set of written instructions, or talk with your family or close friends about your wishes.

ORGANIZING PRACTICAL MATTERS: ADVICE FOR CAREGIVERS

Organizing practical matters in advance reduces some of the stress of caregiving and helps caregivers concentrate on spending time with the person. The following are some tips that may help you organize your time and focus your efforts:

- Compile a list of important papers that may be needed and their location, including bank accounts, real estate, stock holdings, and other financial documents, as well as passwords to accounts and online banking.
- Make a list of people who the person would like to see in the final weeks.
- Consider who should be present at or around the time of death. For example, decide whether a clergy member or other spiritual leader should be at the bedside to provide comfort or perform important rituals.
- Make a list of people to call after death occurs, and ask a friend or relative to help make these calls.
- Choose a funeral home, and notify the facility that a death is expected in the near future. Most hospices will call the funeral home for you.
- Make sure you understand the person's wishes for funeral and burial services, such as cremation.
- Notify hospital or hospice staff of cultural or religious customs about death so they can accommodate them. This may include people who should be present before and after the time of death and special customs regarding washing, dressing, or caring for the body after death.

Deciding What's Important to You

As you approach the end of your life, there may be certain things you wish to accomplish in the time you have left. These tasks help bring a sense of meaning and completion to your life. They may range from fulfilling a lifelong dream to travel somewhere or reconnecting with a personal friend or relative from years ago, to having simpler meaningful experiences, such as rereading a favorite book or spending time with people who are important to you.

However, cancer and cancer treatment are demanding in many ways. You may feel fatigued or nauseous, be irritable or depressed, and have frequent medical appointments. It is important to accept that you do not have the time or energy for everything and to be realistic about what you can and cannot do. Still, you can always be ready for a "good day." For example, if you really want to take your family to the beach, have your bags packed and ready to go for the next time you feel energized.



Finding Closure in Relationships

Finding peace in important relationships and saying the things that matter most are also significant steps to bring closure. There may be conflicts you wish to resolve or apologies you want to make. You may want to say goodbye to special people and tell family members how much you love them. If you are able, you may want to do this in person, or you may want to pass on a message in writing, by telephone, or through a family member.

Keep in mind that, despite your best efforts, people may not respond the way you wish. Some people may not feel comfortable visiting you or may be afraid they will say the wrong thing. In these cases, simply knowing you have done your best to heal a troubled relationship may be enough.

Reviewing Your Life



Consider taking time to reflect on and celebrate the events in your life—the things you have accomplished, the people you have loved, and the individuals and events that have shaped you. This may be a good time to talk with your family and friends about the events and special times you have shared together. You will not only be honoring the life you shared but also creating new memories for them to cherish.

As you think back over your life, you may want to write down your memories, record them using an audio or video recorder, or ask someone to write them down as you talk. Stories can become heirlooms, gifts to the people you will leave behind. Sharing your wishes and dreams for loved ones may also ease regrets about leaving them and will give them a sense of connection to you at important times throughout their lives. For young children, you may leave videos and albums that remind them of your love and connection.

Religion and Spirituality

Many people with advanced cancer report that religion and spirituality are an important part of their lives. For some, organized religion is a central part of life, and the support of faith and clergy members is a significant source of comfort at the end of life. For others, spiritual comfort may lie in a sense of connection to nature or people. As you prepare for the end of life, what matters most is seeking spiritual experiences that bring a sense of comfort, meaning, completion, and peace. Studies show that patients who feel spiritually supported have a better quality of life. Talk with a member of your health care team if you need help finding spiritual support.

MYRA'S STORY

Myra finished breast cancer treatment two years ago. Recently, the cancer came back and had spread to her bones. She and her oncologist discussed the laboratory results and the fact that the cancer was still treatable but not curable.

Ten months into treatment, it stopped working. At that point, her oncologist informed her that a number of treatment options existed, and she recommended one option, along with treatment for Myra's symptoms, such as managing her bone pain. At each meeting, they discussed the joint path of treating the cancer and its symptoms. During these discussions, Myra's oncologist told her that, at some point, the treatment would transition from treating the cancer to primarily treating the symptoms.

Three years later, the cancer had spread further. During the next discussion with her oncologist, Myra was told, "Remember when I told you that at some time the appropriate therapy would be to focus on symptom management? Well, this is the time for that. I would like to stop further chemotherapy and make sure we focus on stopping the bone pain and help you breathe more easily. I want to have our palliative care experts manage your care. How does that sound?"

Myra agreed, and after a few more months, Myra's oncologist recommended transitioning to hospice care at a facility in her neighborhood where Myra died a few weeks later. Myra's husband later said, "Despite the difficulty of the situation, it was made easier when the doctor helped us understand what would happen at each step along the way. Myra felt cared for until her last day."

Learn more about coping with the physical and emotional effects of advanced cancer at www.cancer.net/coping.

Resources

You can find additional information about caregiving, end-of-life care, grief and bereavement, cancer treatment, and links to patient support and resource organizations on Cancer.Net (www.cancer.net).

The following national organizations also provide resources about advanced cancer, 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

American Hospice Foundation

www.americanhospice.org
800-347-1413

CancerCare

www.cancercare.org
800-813-4673

Caregiver Action Network

caregiveraction.org
301-942-6430

Caring Connections from the National Hospice and Palliative Care Organization

www.caringinfo.org
800-658-8898
877-658-8896 (multilingual line)

Center to Advance Palliative Care

www.GetPalliativeCare.org

Hospice Association of America

www.nahc.org/haa
202-546-4759

Hospice Education Institute

www.hospiceworld.org
800-331-1620

International Association for Hospice and Palliative Care (IAHPC)

www.hospicecare.com
866-374-2472

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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.

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