



**ASCO**answers

# 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 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 ground-breaking research and programs that make a tangible difference in the lives of people with cancer. For ASCO information and resources, visit [www.asco.org](http://www.asco.org). Patient-oriented cancer information is available at [www.cancer.net](http://www.cancer.net).



## 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](http://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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# Advanced Cancer Care Planning

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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

Although cancer treatments continue to advance, not everyone recovers from cancer. Sometimes a cure or long-term remission, a period with no signs of cancer, becomes unlikely or isn't possible. Doctors call this stage of disease advanced, end-stage, or terminal cancer.

Even if a cancer can't be cured, it can still be treated. People with advanced cancer continue to have treatment options. They may be able to 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. It explains the treatment options available throughout the course of the illness. It also has information on talking about these options and finding support.

It is important for you to clarify what you value and hope for during this time. Then you should openly share these wishes with your health care team. Doing so will help your doctors choose the best plan for your care. You may also gain a sense of power when everything else may feel like it is out of your control.



# Care Options for Advanced Cancer

If you have been diagnosed with advanced cancer, curing the cancer is usually not a realistic goal. However, you still have treatment choices. Talk with your doctor to understand your treatment options and the goals of each treatment. Your treatment plan may change based on the changing goals of your care.

Your doctor may suggest a number of different types of treatment, including:

- Standard treatment
- Clinical trials
- Palliative care
- Hospice care

The aim of standard treatment and some clinical trials is to shrink tumors or stop them from growing. This is called disease-directed treatment. The main goal of other treatments is to manage pain or relieve symptoms. This is called palliative care. Controlling symptoms gives many people a better quality of life and helps them maintain their independence.

## 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. Most of the time, standard treatment cannot cure advanced cancer. However, some patients,



JOHN ANDREW HUGHES

families, and doctors choose surgery, chemotherapy, radiation therapy, or other disease-directed treatment with the hope that it will slow or stop the cancer's growth.

Standard treatment allows some people with some types of cancer to live for years with a good quality of life. This includes women with advanced breast or ovarian cancer. However, standard treatment may not improve the quality or length of life for people with other types of advanced cancers, like advanced lung cancer that has already been treated in a number of different ways. As a result, some people with advanced cancer choose to stop receiving standard treatment. This is especially true if the treatment causes unpleasant or harmful side effects.

Before you decide to begin or continue standard treatment, it is helpful to talk with your doctor about these topics:

- Chance that the cancer will respond to treatment
- Goals of treatment, such as shrinking a tumor or slowing cancer growth
- Risks, especially side effects
- What will happen after 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 standard treatment. Taking part in a clinical trial may allow a person with advanced cancer to help others in the future. Or, in some cases, the research may provide a personal benefit.

A clinical trial is often a good treatment option for people with advanced cancer. You and your family should consider clinical trials throughout the course of treatment rather than as a last resort.

## **Palliative Care**

Palliative care is any treatment that focuses on reducing 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.

## **GOALS OF PALLIATIVE CARE**

**Manage the symptoms of cancer and the side effects of treatment.** Cancer and its treatment may cause discomfort that affects how you are able to live your life. This may include pain, fatigue, difficulty breathing, nausea, or weight loss. A wide range of therapies can help manage symptoms and side effects, including:

- Medication
- Physical therapy
- Rehabilitation
- Nutrition advice
- Calming techniques
- Massage

### **Address a patient's practical needs.**

Patients receive help addressing financial and legal concerns, transportation issues, employment concerns, and more.

### **Focus on a patient's emotional and social needs.**

Patients get access to resources that address depression, anxiety, fear, family and relationship challenges, and other concerns.



**Address a patient's spiritual needs or concerns.** Oncology social workers and other palliative care experts can help people explore their faith and beliefs as they work to accept the concept of completing their life. These experts can also connect patients and their families to local spiritual and religious resources.

**Provide support for the patient's family, friends, and caregivers.** The health care team gives family caregivers emotional and practical support as they cope with caregiving's daily challenges. These experts can also help a person deal with feelings that surround the coming loss of a person with advanced cancer.

## **WHEN 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. At some point during your illness, though, your doctor may suggest that the focus of your treatment becomes palliative care.

This doesn't mean that your health care team has "given up". And if you choose to stop standard treatment, this doesn't mean you have stopped "fighting" the disease. Instead, choosing to focus on palliative care helps you get relief from burdensome symptoms and receive more support in all areas of your life.



## **WHERE YOU CAN RECEIVE PALLIATIVE CARE**

Several places provide palliative care. Where you receive it will depend on your treatment plan. These locations include:

- Doctors' offices
- Hospitals
- Cancer centers
- Long-term care facilities

Sometimes, a health care or wellness professional can provide palliative care in a person's home. Talk with your doctor, nurse, or an oncology social worker about your options.

## **MEMBERS OF THE PALLIATIVE CARE TEAM**

Several health care providers may be a part of your palliative care team, including:

- Doctors
- Nurses
- Social workers
- Chaplains
- Dietitians
- Physical and occupational therapists
- Grief and bereavement counselors

The team will work with you and your family to develop a tailored care plan that meets your specific needs. As your needs change, the team will adjust this plan. Communication between you and your care team is important because it helps clarify your hopes and goals.



## **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. Cancer care teams help loved ones manage the distress and emotional pain caused by physical changes in the person with cancer. Oncology social workers, counselors, and other team members also teach family and caregivers ways to deal with the coming loss of a loved one.



## **MANAGING THE COST OF PALLIATIVE CARE**

Private health insurance plans often cover the cost of palliative care. Public health programs that may also pay for these services include:

- **Medicaid.** This is a health insurance program run by each state that covers people with lower incomes, older adults, people with disabilities, and certain people in families with dependent children.
- **Medicare.** This is health insurance the federal government provides for those 65 and older, as well as for some disabled Americans.

A hospital social worker can help you explore payment options.

## **Hospice Care**

The word “hospice” describes both a facility and an attitude toward care near the end of life. A hospice provides palliative care that aims to reduce a person’s pain and discomfort. The goal is to help the person approach the end of life with peace, respect, and dignity. A person can receive hospice care regardless of his or her age or cancer type.

## **HOW HOSPICE CARE IS DIFFERENT FROM PALLIATIVE CARE**

Although you may hear the terms hospice care and palliative care used in similar ways, they are slightly different. The health care team provides palliative care every step of the treatment process and at all stages of illness. Hospice care is a type of palliative care given to people who likely have six months or less to live.



## **WHEN HOSPICE CARE IS GIVEN**

In the United States, acceptance into hospice care requires a statement by a doctor. The statement must confirm that a person has a life expectancy of six months or less. However, you can continue to receive hospice care if you live longer than six months. If your condition improves, hospice care will stop, and you can choose to restart standard treatment.

Some people worry that because they are reaching the end of life, they won't get high-quality care. They may also worry that their death will occur quicker in hospice. However, hospice provides compassionate care, and it does not speed up the end of life. Some people who choose hospice care may actually live longer if hospice specialists control their symptoms well.

If you decide to begin hospice care, members of your health care team will help with the transition. They will also help patients and families cope with the emotions that come with that choice, such as fear, guilt, anger, resentment, anxiety, and sadness.

## **WHERE YOU CAN RECEIVE HOSPICE CARE**

There are many hospice programs and other home care services. As a result, people with advanced cancer can usually choose where they would like to spend their final days. You can receive hospice care at home with the help of a family caregiver and hospice staff. This is called home care. You can also receive care in a specialized facility or at some hospitals.

Cost, caregiver availability, 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.

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

- Who will manage my pain and other symptoms?
- Will the hospice staff stay in touch with my oncologist?
- How will my family members be involved in my day-to-day care, such as feeding, bathing, and medication-giving? How will you help them monitor 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 with questions, and what are the phone numbers?

If you are thinking about receiving care at an inpatient facility, you will also want to consider if:

- The location is convenient for visits from family and friends
- It is possible for family and friends to visit at any time
- There is peaceful, quiet, private space for you, your family members, and other visitors to be together

### **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. He told them he thought Gerald only had a few months left to live. However, Gerald could try treatment with chemotherapy that might 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 standard treatment options available, and Gerald still needed the oxygen, the doctor suggested hospice care.

A social worker helped Gerald and his family find an agency 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. 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. 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."

## MEMBERS OF THE HOSPICE CARE TEAM

Experts who may be a part of your hospice care team include:

- Doctors
- Nurses
- Home health aides
- Social workers
- Chaplains
- Physical therapists, occupational therapists, or rehabilitation therapists
- Dietitians
- Trained hospice volunteers
- Grief and bereavement counselors

These experts are a support system for 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 home hospice care, a family member or close friend will serve as the main caregiver. This person will oversee most of your care. Doctors, nurses, home health aides, and personal attendants will provide medical or daily care services the caregiver can't provide. Examples of these services include giving medication or helping with bathing.



### WORKING WITH THE HOSPICE CARE TEAM

Wherever you choose to receive hospice care, the staff will help you and your caregivers develop a care plan. The staff tailors the plan to your unique needs. Your plan will include ways to manage pain and other symptoms, and provide support for you, your family, and caregivers. A plan may include medication and other therapies, such as massage and music and art therapy.

You and your caregivers will meet regularly with the hospice staff to discuss your medical needs and comfort level. In addition to talking with the staff during these planned meetings, you can contact them 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 the cost of hospice care services. So does Medicaid, in most states. However, policy benefits differ from insurer to insurer. Talk with an oncology social worker about your options.

If a Medicare-approved hospice program accepts you, Medicare will pay for your hospice care. Medicare also covers the following services, delivered mainly in the home setting:

- Services provided by 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\*
- Short-term inpatient care in a Medicare-approved facility, like a hospital or nursing home to manage symptoms and relieve pain
- Short-term inpatient respite care, which specialists provide to give the usual caregivers temporary relief\*
- Home health aide and homemaker services
- Supportive counseling
- Spiritual support and counseling
- Nutritional counseling
- Grief and loss support for you and your family

\* Patients may need to cover a small copayment.

Medicare does not cover the following services:

- Treatment for the illness that is not focused on controlling pain or managing other symptoms
- Care given by another health care provider that a patient or caregiver did not arrange through the hospice program
- Care given by another health care provider that duplicates care the Medicare-approved hospice provider must provide by law

To learn more about care given near the end of life, visit [www.cancer.net/endoflifecare](http://www.cancer.net/endoflifecare).

# Making Decisions About Your Care

Advanced cancer care involves very personal choices. Some people want to continue treating the cancer as long as possible, no matter what side effects occur. Others want to focus on feeling as well as possible, even if that means stopping disease-directed treatment.

As you work with your health care team to create a care plan, it is important to figure out what you consider to be acceptable quality of life. Does this mean being able to live at home? Continuing to do the activities you enjoy? Or is the amount of time you live most important? No matter what you decide, your health care team will continue to support you throughout your illness.

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 things that give you 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? Do you have any other strong personal, religious, or spiritual views about dying?
- Have you thought about where you would like to die? In a hospital? At home?

## Choosing a Health Care Proxy

There may come a time when you are unable to make medical decisions for yourself. For example, if you fall into a coma or have a heart attack or stroke. For this reason, it is important to choose a person who can make medical decisions on your behalf. This person is known as your health care proxy or medical power-of-attorney.



Your proxy should be someone you trust to make treatment choices you would agree with and who can be at your bedside. 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 is important to you
- Will talk with you now about sensitive issues and will listen to your wishes
- Is 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 fill out a health care proxy form. This is a legal document that varies from state to state. Then 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 medical decisions after your doctor certifies in writing that you no longer can.

## Expressing Your Wishes in Writing



Talking about your wishes with your family, proxy, and health care team is very important. But there are also legally binding documents you can sign, known as advance directives. These documents explain the types of medical treatment you want and do not want. Your health care team will refer to the documents when you can't speak for yourself.

By putting your wishes in writing, you keep control of decisions about your health. Advance directives also help relieve your family members of guilt and anxiety. They no longer have to guess which treatments and approach to your care you would want.

Below are a few specific types of advance directives you may want to consider:

**Living will.** A living will is a written set of instructions that is sometimes called a Directive to Physicians and Family. This document outlines the types of medical care you want or do not want used to keep you alive, including:

- Cardiopulmonary resuscitation (CPR)
- Artificial life support, such as mechanical respirators
- Feeding tubes, which provide artificial nutrition and hydration
- Kidney dialysis, which is a way to filter waste through a machine

A living will may also include directions for donating your organs.

**CPR or do-not-resuscitate (DNR) orders.** CPR and DNR orders state whether you want the medical team to use CPR and/or artificial life support, if needed. If your heart or breathing stops, medical staff in places like a hospital or nursing home must perform CPR. However, they will not if you have a DNR order.

Unfortunately, CPR rarely works on people with advanced cancer. Even if it is successful, the person may suffer brain damage from reduced blood flow and oxygen to the brain. Or the person may have to remain on a ventilator and in the intensive care unit until their death. Hospitals release fewer than 5% of people with a serious illness from the hospital after CPR.



A doctor or other health care provider, such as a hospice nurse practitioner, must complete and sign a DNR order. The provider then adds the order to your medical file.

**Physician Orders for Life-Sustaining Treatment (POLST) form.** POLST is a new, more detailed form that is replacing DNR orders in some states for people with advanced illnesses. The form includes instructions for CPR, use of antibiotics, intubation, and feeding tubes. The patient or health care proxy and a doctor or other authorized medical provider must co-sign it.

POLST forms are available in about half the United States but often go by different names, including MOST, POST, TPOPP, MOLST, and COLST. Your doctor, social worker, or another health care team member can give you information on your state's version of the POLST form.

## Making Changes to an Advance Directive

You can change an advance directive as long as you still have or regain your ability to decide on treatment. You should notify your health care team if you make any changes. Also make sure that you and your health care proxy have up-to-date copies that are easy to access. You should consider giving copies to any other people involved in decisions about your health care. 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 know if the person you are caring for has an advance directive. Caregivers and others who care about the person may not always agree with the decisions outlined in the directive. However, people with advanced cancer need to know you will respect their final wishes.

As a caregiver, following the advance directive is one of the most important things you can do. Doing so helps the person die with dignity and peace of mind. If you need to call 911 or the emergency services number in your area, be sure to tell responders if the person has a DNR order or filled out a POLST form.

# Communicating Directly and Honestly

KAREN ELSHOUT PHOTOGRAPH



People can live for months and even years after being diagnosed with advanced cancer. However, it is still important to talk about end-of-life issues from the start of the advanced cancer care planning process. This will help ensure your caregivers know and respect your wishes.

Starting these important discussions is often difficult for everyone—patients, families, and health care professionals alike. People would much rather talk about managing symptoms and treating the disease than plan for death. Still, it is important to settle your affairs and consider

your wishes for care during your final days. Share your plans with family members and caregivers, even if standard treatment or a clinical trial is still helping manage the disease.

## Talking With the Health Care Team

To make informed decisions about your care, you need to fully understand your disease and your options. Ask your doctor to explain your diagnosis, treatment options, and prognosis, which is the chance of recovery. These may change over time. Continue to discuss your care with your doctor during follow-up visits.

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 can refer you to other resources.

Starting these discussions can be challenging, even for your doctor and other members of your health care team. As a result, you or a family member may need to bring up topics related to death and dying with your doctor. You can begin by asking 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 its growth and 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 have the treatment(s) you have recommended?
- What are the risks and benefits of the treatment(s) you have recommended?
- 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 very hard for friends and family. They may say: “Don’t talk like that,” “Don’t lose hope,” or “Stay positive,” when you bring up death and dying. However, this fear often keeps people from preparing for the end of life. This makes it much harder when that time comes.



The fact is, talking about end-of-life care early on helps reduce stress for you and your loved ones. It reassures your loved ones that they are making the best choices for you. Your family and friends may feel guilty or anxious without a plan to refer to when they need it. In addition, these discussions may provide a sense of peace and confidence that you have left nothing unsaid. These discussions let family members reaffirm their love and promote closeness, which may help ease the pain of separation.

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

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

**Practice beforehand.** Practice what you want to say in advance with a loved one, counselor, or social worker. This allows you to get feedback on your tone and choice of words, and see how others might react.

### **ALMA'S STORY**

Alma was a mother of two in her early 40s when she was diagnosed with metastatic colon cancer. The cancer had spread to her liver and lungs. The doctor recommended she have chemotherapy. Alma and her family agreed. The chemotherapy helped for a couple of months, but after that the cancer continued to spread.

The doctor said Alma could try another medication, and she started another round of chemotherapy. However, the treatment severely lowered her white blood cell counts. Alma's doctor admitted her to the hospital. Alma recovered, and she and her family wanted to try a different chemotherapy option. Her doctor agreed, but Alma continued to have low blood counts and could not keep food down. The doctor sent her 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 in time, she died from an infection.

Her husband was stunned afterward because he hadn't realized her condition was so serious. 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 that more treatment was unlikely to help. We didn't know stopping chemotherapy was an option."

**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 thoughtless questions or comments. People may not have experience with advanced cancer or may not know what to say. Having a standard response in mind may help in these situations.

**Ask for help.** You may want to ask a friend or family member to help keep others informed about your condition and treatment. Some people choose to use a website to let others know how things are going. 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 is better than hiding the issue. Children often sense that something is wrong, even if they don't know what it is. Avoiding the topic may create feelings of confusion and fear. Talking openly about advanced cancer helps prepare children for the future and allows them to express their feelings.

As you talk with your children or grandchildren, the following suggestions may be helpful. You can adapt the suggestions to meet your family's needs.



**Be honest about the illness.** There are ways to discuss cancer with children using words they can understand. Telling very young children, "I am very sick, so I am going to the hospital for special medicine," is usually enough. For older children, a more detailed

description 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 it is okay for them to have many different feelings. Explain 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 they may have. Then be honest in your replies. Don't be afraid to say, "I don't know." You may want to tell them: "I don't know the answer. I will ask the doctor at my next appointment and get back to you on that." The amount of information you give children is usually less important than making them feel comfortable with the situation.

**Know when to stop.** Watch for signs that your child or grandchild wants to stop talking for the moment. He or she may change the subject, look away, fidget, or play with toys. Respect a child's need to take a break from this tough topic. You can always talk more when the child is ready.

**Be prepared to discuss death.** Although it is hard and sad, it is important to prepare yourself 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 talking about death. Preschoolers, for instance, don't 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. How and when you talk with a child about death and dying is a personal decision. However, try to use clear, specific terms. Avoid using terms such as "passing away," "sleeping forever," or "put to sleep." Children may confuse sleep with death. They may also fear that they will die in their sleep or believe a person can wake up from death.

It may take a long time for children to fully understand and accept such a loss. More than anything, children need to know they won't be alone. Make sure they understand that family and other loved ones will take care of them.



**Consider counseling.** After an advanced cancer diagnosis, many people talk with counseling professionals. Counseling can help parents break the news, manage their children's reactions, and make plans to take care of their family in the future. Talk with your doctor, nurse, or social worker about counseling resources in your treatment center or community.

For more tips on talking with your family about cancer, visit [www.cancer.net/talkingaboutcancer](http://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. Sometimes it is hard to choose among them. When making treatment decisions, patients often ask family members for their opinions. In some cases, family members may disagree with each other, and with the patient, about the best choice. This can create conflict at a time when they need each other's support the most.

If a family member asks you to help choose a treatment, keep in mind these questions:

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

Always consider the patient's viewpoint first. The patient has the right to be heard and the right to change his or her mind. The patient also has 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. However, that person may make a choice that is different from what you might choose for yourself. It is important, even when conflict occurs, 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 treatment priorities. The patient may want to live as long as possible, regardless of how hard treatment is. Or he or she may wish to maintain a specific quality of life, even if that means stopping treatment. These topics can be hard for your family to talk about. If so, you can ask a doctor, nurse, clergy member, social worker, or counselor to lead the discussion.



# Coping and Finding Support Near the End of Life

Learning you have advanced cancer triggers intense emotions, including anger, fear, sadness, and regret. It is normal for you to mourn the loss of your abilities. You may grieve for the loved ones you will leave behind and the days you will not have. You may also find it hard to believe or accept your disease is incurable, 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 shouldn't be afraid to tell doctors, nurses, and social workers how they feel. The health care team is there to help. Many team members have special skills and experience to make life easier for patients and their families. In addition to providing emotional support and education, your doctor may prescribe medications to help with anxiety or depression. Your doctor may also refer you to other community resources, including a social worker, counselor, psychologist, psychiatrist, or support group.

## Putting Your Affairs in Order

Along with finding support, this may be the time to start settling your legal, financial, and business affairs and addressing other practical concerns. This allows you and your family to focus on the emotional effects of your illness.

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
- Passwords to online accounts

### **ORGANIZING PRACTICAL MATTERS: ADVICE FOR CAREGIVERS**

Sorting out practical matters in advance helps reduce some caregiving stress. Being organized will also help you focus on spending time with the person. The following tips may help you simplify your efforts:

- Compile a list of important papers that you may need and their location. These can include bank accounts, real estate, stock holdings, and other financial documents. Also make sure you have 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 spiritual leader should be at the bedside to provide comfort or perform important rituals.
- Make a list of people to call after death occurs. Ask a friend or relative to help make these calls.
- Choose a funeral home, and notify the facility that you expect your loved one to die soon. 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. Explain any special customs regarding washing, dressing, or caring for the person's body after death.

Your finances may be complex or you may worry about leaving your family with high medical bills or debts. If so, consider talking with a financial advisor or social worker. Financial experts can't get rid of bills or debts, but they will help organize your finances. They can create a plan to reduce the stress of financial burdens 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 written guide, or talk with your family or close friends about your wishes.

## Deciding What's Important to You

As you approach the end of your life, you may wish to accomplish certain things. These tasks can help bring a sense of meaning and completion to your life. They may range from fulfilling a lifelong dream to travel somewhere to catching up with someone from years ago. Or they can be simpler experiences, such as rereading a favorite book or spending time with certain people.



Keep in mind that 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 won't always have the time or energy for everything. You must 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. That way you will be ready to go 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 want to settle 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 at ease 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.

### **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 test results and the fact that the cancer was still treatable but not curable.

Ten months into treatment, it stopped working. At that point, Myra's oncologist explained to her that a number of treatment options existed and suggested one option. The oncologist also urged treatment for Myra's symptoms, such as managing her bone pain. At each appointment, they discussed the joint path of treating the cancer and its symptoms. The oncologist told Myra that, at some point, the treatment would transition from treating the cancer to mainly managing symptoms.

Three years later, the cancer had spread further. Myra's oncologist said: "Remember when I told you that at some time the right therapy would focus only on symptom management? Well, this is the time for that. I would like to stop chemotherapy and work on relieving the bone pain and helping you breathe more easily. I want to have our palliative care experts manage your care. How does that sound?"

Myra agreed. After a few more months, Myra's oncologist recommended moving to hospice care at a facility in her neighborhood. Myra died there a few weeks later. Myra's husband later said, "The doctor made a hard journey easier when she helped us understand what would happen at each step along the way. Myra felt cared for until her last day."

## Reviewing Your Life

Consider taking time to reflect on and celebrate the events in your life. What have you accomplished? Which people did you love? What people and events shaped you? This may be a good time to talk with family and friends about the events and special times you shared. You will be honoring the life you had with them and creating new memories for them to cherish.

As you think back over your life, you may want to write down your memories. You could also record or videotape them, or ask someone to write them 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. For young children, you may want to leave videos and photo albums that remind them of your love and connection. This will give them a sense of connection to you at important times throughout their lives.



## 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. As a result, support from faith and clergy members is a significant source of comfort for these people. For others, spiritual comfort may lie in a sense of connection to nature or people. 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.

Learn more about coping with the physical and emotional effects of advanced cancer at [www.cancer.net/coping](http://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](http://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.

**American Academy of Hospice and Palliative Medicine**

[www.palliativedoctors.org](http://www.palliativedoctors.org)  
847-375-4712

**American Cancer Society**

[www.cancer.org](http://www.cancer.org)  
800-227-2345

**CancerCare**

[www.cancercares.org](http://www.cancercares.org)  
800-813-4673

**Caregiver Action Network**

[caregiveraction.org](http://caregiveraction.org)  
202-454-3970

**Caring Connections from the National Hospice and Palliative Care Organization**

[www.caringinfo.org](http://www.caringinfo.org)  
800-658-8898  
877-658-8896 (multilingual line)

**Center to Advance Palliative Care**

[www.getpalliativecare.org](http://www.getpalliativecare.org)

**Hospice Association of America**

[www.nahc.org/haa](http://www.nahc.org/haa)  
202-546-4759

**Hospice Education Institute**

[www.hospiceworld.org](http://www.hospiceworld.org)  
800-331-1620

**International Association for Hospice and Palliative Care**

[www.hospicecare.com](http://www.hospicecare.com)  
866-374-2472

**Jack & Jill Late Stage Cancer Foundation**

[www.jajf.org](http://www.jajf.org)  
404-537-5253

**Medicare**

[www.medicare.gov](http://www.medicare.gov)  
800-633-4227

**National Association for Home Care & Hospice**

[www.nahc.org](http://www.nahc.org)  
202-547-7424



**American Society of Clinical Oncology**

2318 Mill Road, Suite 800 | Alexandria, VA 22314

Phone: 571-483-1300 | Fax: 571-366-9530

[www.asco.org](http://www.asco.org) | [www.cancer.net](http://www.cancer.net)

For more information about ASCO's patient information resources, call toll-free 888-651-3038 or e-mail [contactus@cancer.net](mailto:contactus@cancer.net). To order more copies of this booklet, call 888-273-3508 or visit [www.cancer.net/estore](http://www.cancer.net/estore).

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