

ASCO[®]answers

Advanced Cancer Care Planning

**A Decision-Making Guide for Patients and
Families Facing Serious Illness from the
American Society of Clinical Oncology**



Cancer.Net

Doctor-Approved Patient Information from ASCO[®]

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ABOUT ASCO

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

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

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

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

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ADVANCED CANCER CARE PLANNING

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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. You and your loved ones likely have a range of feelings about end-of-life issues, and some people find talking about their thoughts, feelings, and wishes very difficult. If being open about feelings has not been your communication style, then it is probably not easy to start talking openly now. Talking with a spiritual counselor or social worker who can help guide these conversations may make it easier to discuss these important issues.

Try to openly share your wishes with your health care team as much as you can. Doing so will help your doctors choose the best plan for your care. You may also gain a sense of control 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 health care team 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 1 or more different types of treatment, including:

- ▶ Standard treatment
- ▶ Clinical trials
- ▶ Palliative (supportive) 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 aim of palliative, or supportive, care is to improve quality of life and maintain independence by reducing symptoms, managing pain, and supporting patients and their families. The aim of hospice care is to help the patient approach the end of life with peace, respect, and dignity, and it includes palliative 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. Most of the time, standard treatment cannot cure advanced cancer. However, some patients, 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, for example, some 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. As a result, some people with advanced cancer choose to stop receiving standard treatment. This is often the case 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 health care team 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 focus on new treatments to find out whether they are safe, effective, and possibly better than the treatment doctors use now. Taking part in a clinical trial may allow a person with advanced cancer to help others with advanced cancer in the future. There is also a chance that the treatment will help you.

A clinical trial is often a good treatment option for people with advanced cancer. People with cancer should consider clinical trials throughout the course of treatment, not just as a last resort.

Palliative Care

Palliative care, also called supportive 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, should receive palliative care as needed.



■ **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 some that are similar to disease-directed treatments:

- ▶ Medication
- ▶ Surgery
- ▶ Radiation therapy
- ▶ Physical therapy
- ▶ Rehabilitation
- ▶ Nutrition advice
- ▶ Calming techniques
- ▶ Massage
- ▶ Mindful meditation

Address practical needs. Patients can receive help addressing financial and legal concerns, transportation issues, employment concerns, and more.

Focus on emotional and social needs. Patients are given access to resources that address depression, anxiety, fear, family and relationship challenges, and other concerns.

Address spiritual needs or concerns. Oncology social workers and other palliative care experts can help people with cancer 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 approaching loss of a person with advanced cancer.

■ **When is palliative care given**

Ideally, palliative care should start at diagnosis 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 shift to mostly 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 the 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 the palliative care team, including:

- ▶ Doctors
- ▶ Nurse practitioners or advanced practice registered nurses (APRNs)
- ▶ Nurses
- ▶ Social workers
- ▶ Dietitians
- ▶ Physical and occupational therapists
- ▶ Chaplains
- ▶ 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. Regular communication between you and your care team is important because it helps clarify your hopes and goals and makes sure that the care plan will meet them.

■ Benefits of palliative care for friends, family, and caregivers

A diagnosis of advanced cancer is a time of intense emotions and 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.

Although one might think that this is only a sad time, many people find the caring, love, and conversation that happens during the final stages of illness very moving and meaningful. It helps family members come to terms with needing to let go of their loved one and helps with the grieving process that follows.

■ Managing the cost of palliative care

Private health insurance plans often cover the cost of palliative care. Public health programs, depending on your location, 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 or hospital financial counselor can help you explore payment options.

Learn more about palliative care or read the ASCO Answers Palliative Care booklet at www.cancer.net/palliative.

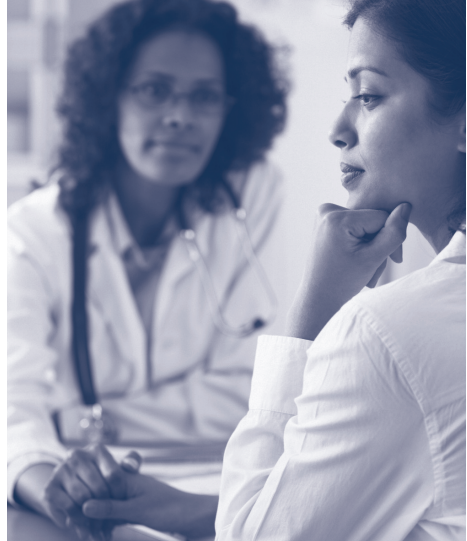
Hospice Care

The word “hospice” describes both a facility and a treatment plan with a focus on care near the end of life. Hospice provides 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. Any person can receive hospice care, regardless of his or her age or cancer type.

■ When is hospice care given

In the United States, acceptance into hospice care requires a statement by a doctor. The statement must confirm that a person is expected to live 6 months or less. However, you can continue to receive hospice care if you live longer than 6 months. If your condition improves, hospice care will stop, and you have the option to consider restarting 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 come faster in hospice. 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 you and your loved ones cope with the emotions that come with that choice, such as fear, guilt, anger, resentment, anxiety, and sadness.

Deciding whether hospice care should be considered often creates conflict among family members. Some people see it as “giving up” and fear that it sends the message to the patient that he or she is not loved enough to continue fighting. Other family members may want to stop the patient’s suffering, making him or her as comfortable as possible and preserving their dignity and quality of life. This is a difficult time for families, and fighting over these issues does not allow space to focus on the emotional needs of the person with cancer and their family. If there is disagreement among loved ones, talking with a social worker can help the family clarify what the family’s priorities are and resolve tensions and conflict.

■ **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 hospice facility or at other health care locations.

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 giving medications? 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?
- ▶ Who will be given information about my condition?

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

■ **Members of the hospice care team**

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

- ▶ Doctors
- ▶ Nurses
- ▶ Home health aides
- ▶ Social workers
- ▶ Physical therapists, occupational therapists, or rehabilitation therapists
- ▶ Dietitians
- ▶ Trained hospice volunteers
- ▶ Chaplains
- ▶ 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.

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 6 to 9 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 6 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."

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 may include giving certain medications 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, 7 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 or facility financial counselor 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 family 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 pay 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.

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. Many people are not emotionally ready to face these issues and understandably find it very difficult to do. Yet doing so is important to make you as comfortable as possible both emotionally and physically.

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. The person you choose must be 18 or older. Your state might have other rules, too. Learn what they are to make sure the person you choose qualifies. Your health care proxy should also be:

- ▶ Someone who knows you well.
- ▶ Someone willing to talk with you openly and honestly about your wishes.
- ▶ Someone willing to speak up for you in the future, even if it is difficult.
- ▶ Someone able to come to your home, hospital, or care facility, if needed.
- ▶ Someone who respects your wishes, even if he or she has different opinions.

Once you choose a health care proxy and he or she agrees, you should fill out your state's health care representative form, sign it, and have it witnessed or notarized. This is a legal document that varies from state to state. Then provide a signed copy of the 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 lists the treatments you think you would want if you were seriously ill. It also includes the treatments you think you would not want, such as:

- ▶ Cardiopulmonary resuscitation (CPR)
- ▶ Artificial life support, such as mechanical respirators
- ▶ Feeding tubes, which provide 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. A “do not resuscitate” order is another way to say what kind of care you want. You can create it along with an advance directive. Or, you can have one by itself. A “do not resuscitate” order is also called a DNR.

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

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

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

Making Changes to an Advance Directive

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

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

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 and health care team 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. You might also want to ask your doctor for as accurate a prognosis as possible.



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.

Sometimes, family relationships have made expressing love or resolution of pain and trauma difficult or impossible. Coming to accept what was and moving toward forgiveness may be all that is possible at this time. Grieving is more complicated when relationships are unresolved and include conflict.

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 to see how others might react.

ALMA'S STORY

Alma was a mother of 2 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 is 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 OK 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. It is helpful to express what you hope for them in their lives in the future, even if you will not be there to see it. Doing this establishes a connection between past and future.



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 gently 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.

THE ROLE OF THE FAMILY IN MAKING TREATMENT DECISIONS

A person with cancer may have more than 1 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 with cancer asks you to help choose a treatment, keep in mind these questions:

- ▶ Does the person with cancer understand the risks of treatment and the potential outcomes of his or her choices?
- ▶ Has the person with cancer openly stated his or her wishes? Are other caregivers respecting these wishes?
- ▶ Is this treatment consistent with the beliefs and values of the person with cancer?

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 with cancer 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 that 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 people with advanced cancer 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. You may want to consider assigning a financial power of attorney, so someone else has authority to make financial decisions on your behalf.

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

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.



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.

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 nauseated, 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 wish 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 2 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 1 option. The oncologist also urged treatment for Myra's symptoms, such as managing her bone pain. At each appointment, they discussed treating the cancer and its symptoms. The oncologist told Myra that, at some point in the future, the main focus of treatment would transition from treating the cancer to 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. Regrets and disappointments are parts of everyone's lives, so it is important to acknowledge those, too, but to keep them in perspective.



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.

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.

American Academy of Hospice and Palliative Medicine

www.palliativedoctors.org

American Cancer Society

www.cancer.org

800-227-2345

CancerCare

www.cancercare.org

800-813-4673

Caregiver Action Network

www.caregiveraction.org

202-454-3970

CaringInfo from the National Hospice and Palliative Care Organization

www.caringinfo.org

703-837-1500

Center to Advance Palliative Care

www.getpalliativecare.org

Help for Cancer Caregivers

www.helpforcancer caregivers.org

Hospice Foundation of America

www.hospicefoundation.org

800-854-3402

International Association for Hospice and Palliative Care

www.hospicecare.com

866-374-2472

Jack & Jill Late Stage Cancer Foundation

www.jajf.org

404-537-5253

Medicare

www.medicare.gov

800-633-4227

National Association for Home Care & Hospice

www.nahc.org

202-547-7424

Looking for Other Patient Information Resources?

ASCO ANSWERS GUIDES

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

ASCO ANSWERS FACT SHEETS

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

ASCO ANSWERS BOOKLETS

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

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

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

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

Cancer.Net

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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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