Advanced Cancer Care Planning
What Patients and Families Need to Know About Their Choices When Facing Serious Illness
ABOUT ASCO
The American Society of Clinical Oncology (ASCO) is the world’s leading professional organization representing physicians of all oncology subspecialties who care for people with cancer. ASCO’s more than 30,000 members from the United States and abroad set the standard for patient care worldwide and lead the fight for more effective cancer treatments, increased funding for clinical and translational research, and, ultimately, cures for the many different types of cancer that strike an estimated 12 million people worldwide each year.

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

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**Introduction**

Advanced cancer is cancer that cannot be cured. It may be referred to as end-stage or terminal cancer. However, incurable does not mean untreatable. People with advanced cancer continue to have options for treatment and can maintain a good quality of life.

The American Society of Clinical Oncology (ASCO) is working with oncologists (doctors who treat people with cancer) and their care teams to help patients and their families talk about advanced cancer and identify the best, individualized treatment plan for each patient. ASCO is the world’s leading professional organization representing doctors who care for people with cancer. The content in this booklet is adapted from ASCO’s patient information website, Cancer.Net (www.cancer.net).

This booklet is designed to help people with advanced cancer and their family and caregivers understand the diagnosis and treatment options, discuss these options for care throughout the course of the illness, and find support.
About Advanced Cancer

A diagnosis of advanced cancer is usually difficult for you and your family. It may be hard to believe the diagnosis. Or, it may cause anxiety and uncertainty. However, even if treatment is no longer able to cure or stop the growth of your cancer, you still have choices for care. Treatment for advanced cancer includes slowing tumor growth and managing pain and other symptoms of cancer and cancer treatment.

At this time, it is helpful to talk with your cancer care team to understand your treatment options and goals of treatment. It is also important to ask for care that meets your physical, emotional, spiritual, and practical needs and to know that you will continue to receive care and emotional support throughout your illness. Your cancer care team may now include experts in hospice and palliative care to help with these needs.

Care Options
Understanding the types of care available helps you and your doctor develop a personalized treatment plan that takes into account your individual needs, goals, and preferences.

Standard treatment. Standard treatment is the current or most effective treatment available for your cancer, usually based on the type of cancer, the extent of spread, and any specific cancer markers, genes, or proteins (such as HER2 for breast cancer). This type of treatment focuses on directly controlling the disease. Some people with advanced cancer choose to stop receiving standard treatment (disease-directed treatment), because it may cause unpleasant or harmful side effects. Others choose to continue receiving disease-directed treatment, which may include surgery, chemotherapy, and/or radiation therapy. Before choosing to receive disease-directed treatment, it is helpful to know the likelihood of the cancer responding to treatment, what that response may be (such as shrinking a tumor or slowing cancer growth), the risks (especially side effects) of treatment, and the consequences of stopping disease-focused treatment.

Clinical trials. A clinical trial is a highly controlled research study involving people who choose to participate. Clinical trials test new drugs and treatments to find out whether they are safe, effective, and possibly better than the standard treatment of care. Participating in a
ABOUT ADVANCED CANCER

Clinical trial may offer a patient with advanced cancer the chance to help other patients with cancer; or, in some cases, the research may help the patient directly. If patients are interested in participating in research, clinical trials should be considered early in the course of treatment and not considered only as a last resort for a cure.

Palliative/supportive care. Care that manages the symptoms and side effects of cancer and its treatment is called palliative or supportive care. Palliative care focuses on helping people with all stages of cancer, including advanced cancer, live as comfortably as possible for weeks, months, or years. This type of care, which addresses a person’s physical, spiritual, emotional, and practical needs, is provided at the same time as ongoing, curative treatment or on its own. Palliative care also provides support for a patient’s family, friends, and caregivers.

Hospice/home care. Hospice care is a form of palliative care provided to patients with cancer who are expected to live six months or less. The goal of hospice care is to help patients who are no longer receiving disease-directed treatment and their families cope with the physical and emotional effects of death and dying. The focus is no longer a cure; rather, the focus is on ensuring compassionate care that allows for the highest quality of life possible. Hospice care can take place at home (home care) or in a specialized center or facility.

Exploring Your Care Options

Having conversations about your advanced cancer care options is often difficult. However, these conversations will give you the information you need to make informed choices throughout the course of your illness. And, having these conversations early on helps reduce stress for you and your loved ones.

Advanced cancer care decisions are personal. Everyone has his or her own goals for care and for the future. Clearly understanding your
The Role of the Family in Making Treatment Decisions

A person with cancer may have more than one option on how to treat the disease, and it may be difficult to choose among them. In making this choice, patients often ask for the opinions of family members. And, in some cases, family members may disagree with each other and with the patient on the best choice, creating conflict when they need each other's support the most.

If you are involved in selecting treatment, these guiding principles may help you evaluate the choices:

• Informed decision-making: Does the patient understand the risks of treatment and the potential consequences of his or her choices?
• Responsive to the patient's wishes: Are the patient's wishes openly stated and being respected?
• Consistent with personal values: Is this treatment in harmony with the patient's beliefs and values?

In each aspect, the patient's viewpoint is considered first. If you are a person with cancer, you have the right to be heard, the right to change your mind, and the right to state your wishes and have them respected. If you are a family member, remember that the patient has asked for your view because he or she respects your opinion, but various factors may lead him or her to make a different decision. It is important, even when disagreements occur, to remember to keep communicating with each other and to support the patient in his or her choices.

It is also helpful to talk openly about the patient's priorities in undergoing treatment. These could range from surviving as long as possible, regardless of the difficulty of treatment, to maintaining a specific quality of life, even if that means stopping treatment. If this is difficult for your family to talk about, ask someone to facilitate this conversation, such as a doctor, nurse, member of the clergy, social worker, or counselor.
Palliative Care
Palliative care does not cure cancer. Instead, its goal is to improve a patient’s quality of life by:

Treating the symptoms and side effects of cancer and its treatment—Medication, physical therapy, rehabilitation, massage, and a wide range of other therapies are used to manage pain, nausea, breathlessness, insomnia, and other physical symptoms.

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

Treating a patient’s emotional and social needs—Resources are provided to address concerns such as depression, anxiety, and fear.

Addressing a patient’s spiritual needs or concerns—Palliative care experts help people explore their faith and beliefs as they work to accept the concept of end of life, as well as help with religious ceremonies or rituals.

Providing support for the patient’s family, friends, and caregivers—Loved ones receive both emotional and practical support as they work to cope with the challenges that come with caregiving and the loss of a loved one.

Any person, of any age, with any type of cancer, at any stage, may receive palliative care. If you choose to receive palliative care, it does not mean that your doctor has given up on you or that you have given up on yourself. Nor does it mean that you no longer have control over your treatment choices or that you cannot receive disease-directed treatment, if you choose. Palliative care simply aims to eliminate physical and emotional discomfort throughout your cancer experience so you are able to focus less on the disease and more on living.

When and where palliative care is given
Palliative care is given as early as possible in the cancer treatment process and continues through all stages of illness, regardless of whether a cure is the expected outcome. If you decide to stop disease-directed treatment, palliative care focuses on managing the symptoms caused by cancer.
Palliative care is given in a doctor’s office, hospital, cancer center, long-term care facility, or your home. Your doctor or a hospital social worker will help you find palliative care.

**Providers of palliative care**
Depending on your needs and goals, several health care professionals may be a part of your palliative care team. These team members may include doctors, nurses, social workers, chaplains, dietitians, physical and occupational therapists, and grief and bereavement counselors. The team will work with you and your doctor to develop an individualized palliative care plan that meets your specific needs, as well as to adjust the plan as your needs change. Communication between you and your team members is important because it helps to clarify needs and expectations.

**Benefits of palliative care**
Coping with the idea that you have advanced cancer is often difficult for your family members or caregivers. Through palliative care, they receive counseling that helps them cope with the situation, as well as help prepare them for the physical changes and needs that come with the care of a person with advanced cancer.

**Paying for palliative care**
Palliative care is often covered by health insurance. Medicaid and Medicare may also pay depending on the situation. A hospital social worker can help you explore payment options.

**How palliative care differs from hospice care**
Palliative care is given at every step of the treatment process and at all stages. Hospice care is a form of palliative care given to people with cancer who are expected to live six months or less, regardless of their age or type of cancer. When the time is right, palliative care specialists will help you make the transition to hospice care and help you address the physical and emotional issues that come with that choice.
Hospice Care

Many people with advanced cancer decide to enter hospice care. The emphasis of hospice care is similar to palliative care in that it focuses on relieving pain and discomfort. Hospice care also helps you and your family cope with the emotions surrounding the end of life.

Many people with advanced cancer feel overwhelmed when they are told there is little chance of a cure. Hospice care works to ensure that you approach the end of life with confidence and in comfort, peace, and dignity.

Hospice care providers

Because of the availability of hospice programs and other home care services, people with advanced cancer often choose where they would like to spend their last days. Hospice care most often takes place at home and, in this instance, is referred to as home hospice. Hospice care is also delivered in hospitals and private inpatient facilities. The cost, availability of caregivers, and community resources are factors to consider when selecting where to receive hospice services.

Professionals that may be a part of your hospice care team include doctors, nurses, home health aides, social workers, chaplains, therapists (physical, occupational,
and rehabilitation), dietitians, trained hospice volunteers, and grief and bereavement counselors. These professionals also act as a support system for your loved ones. Knowing your loved ones have these resources may help ease your worries about leaving them behind.

Your doctor, nurse, or social worker will help you find hospice care in your area. Other options include contacting your state or local department of health to get a list of licensed agencies or researching online hospice-related organizations that provide resources related to home hospice care; see the Resources section of this booklet for additional information.

**Quality of hospice care**

Some people worry that because they are reaching the end of life, they will not receive the same quality of care as other patients or that their death will occur quicker in hospice. Hospice care is humane and compassionate care, and it does not slow down or speed up end of life. You will receive the same quality of care as patients undergoing curative treatment. The only difference is the focus of care is quality of life, not longevity. In fact, people who use hospice may actually live longer, either because they are more comfortable or because they have fewer side effects from chemotherapy at the end of life.

Other patients worry that they will simply be medicated and unable to make choices or spend their last days as they wish. Your hospice care team will work with you to determine your goals for end of life care and develop a care plan that allows you to meet those goals while keeping you comfortable. Medication is only one part of that plan. Other therapies, such as music and art therapy, physical therapy, nutrition therapy, massage, and more, may be used.

**Hospice care in the home**

In home hospice care, a family member or close friend serves as the primary caregiver and is responsible for coordinating and/or overseeing
most of the patient’s care. Doctors, nurses, home health aides, and personal attendants will work with you and your caregivers to develop a plan tailored to meet the unique needs of your situation. They also regularly meet with you and your caregivers to evaluate your medical and comfort needs and provide any services—medical or day-to-day care, such as help with bathing and eating—your primary caregiver is unable to provide. Hospice professionals are typically on call 24 hours a day, seven days a week.

**Eligibility and costs of hospice care**

Hospice care is available when all treatments to cure your cancer no longer work and you and your doctor are at ease with a treatment plan dedicated to maintaining comfort. In the United States, acceptance into hospice care requires a statement by a doctor that the person has a life expectancy of six months or less. (Hospice care can be continued, though, if you live longer than six months.)

If your condition improves or your cancer goes into remission (temporary or permanent absence of symptoms), hospice care is discontinued and disease-focused treatment may resume.

The Medicare Hospice Benefit covers the costs of hospice care for people who receive Medicare if they are accepted into a Medicare-
certified hospice program. Under Medicare, hospice is primarily delivered in the home setting by a Medicare-approved hospice provider and covers:

• Services provided by the doctors
• Nursing visits to the home with 24-hour on-call services
• Medical appliances and supplies related to the life-limiting illness
• Medications to manage symptoms and relieve pain; at most, patients are responsible for a $5 copayment
• Short-term, acute care, including respite care, either in a hospital or nursing home. Inpatient respite care is provided to give family caregivers temporary relief.
• Home health aide and homemaker services
• Supportive counseling
• Spiritual support and counseling
• Nutritional counseling
• Bereavement support for your family

The following services are not covered under Medicare:

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

Medicaid may also cover some home care services. Private health insurance policy benefits differ from insurer to insurer. A hospital social worker will help you understand your options.
Coping and Finding Support
Near the End of Life

Learning that you have advanced cancer frequently brings about intense feelings of anger, fear, grief, regret, and other strong emotions. It is normal to grieve and mourn the loss of your abilities, the loved ones you will leave behind, and the days you will not have. Talking about your feelings and concerns with family, friends, and caregivers helps bring you comfort.

Patients and their families should not be afraid to express the way they are feeling to doctors, nurses, and social workers. The health care team is there to help, and many team members have special skills and experience to make things easier for patients and their families. In addition to providing emotional support and education, the doctor may prescribe medications to help address a patient's anxiety or depression. Your doctor may also refer you to a counselor, social worker, psychologist, psychiatrist, or support group. Furthermore, patients and their families should be aware that there are resources available in the community to help.

Along with finding support, this may be the time to begin the process of identifying your preferences for care, addressing financial and other concerns, and completing unfinished business. Open communication with your loved ones and with your doctors and nurses will allow them to guide you through the necessary steps. More importantly, it will allow them to serve you well and personalize your care.

Arranging Your Affairs
Although discussing death and dying is difficult and sad, it is recommended that a person with advanced cancer revise and review his or her wishes at the end of life with family and health care professionals. You also may revise your goals and plans as your circumstances or preferences change. Starting the conversation early strengthens your relationship with the health care team. For many people, worrying about
what will happen to their surviving family members is difficult. Planning ahead to settle legal, financial, and business affairs also allows you and your family to concentrate on the emotional aspects of your illness and its effect on your family.

Settling your affairs may include locating and organizing important legal and financial documents, such as your will, marriage and birth certificates, social security card, insurance policies, bank statements, and investment summaries. If you have complicated finances or are concerned about leaving your family with high medical bills or debts, consider talking with a financial advisor or social worker. Financial professionals cannot eliminate bills or debts, but they will help you sort out your finances and lessen the stress of financial worries for you and your family. Some people also find it helpful to plan some aspects of their own funeral or memorial service. This is done with a set of written instructions or by talking with your family or close friends about your wishes.

An important step for many is to create, or perhaps make changes to, an advance directive. An advance directive is a legally binding set of
instructions that explains the kind of medical treatment you want and do not want if you become unable to make those decisions for yourself. An advance directive provides a way for you to communicate your wishes to your family, friends, and health care professionals ahead of time to avoid confusion later on. People who have advance directives know that their wishes will be respected. Although an advance directive may be oral (spoken) in most states, an advance directive is less likely to be challenged if it is in writing. It is a good idea to discuss your advanced directive with your family to clarify your decisions and the values underlying them.

**Types of advance directives**

**Living will.** This is a written set of instructions outlining your wishes about types of medical care you may or may not want in order to sustain life. A living will is also referred to as a Directive to Physicians and Family. It is used in situations when you have a life-limiting illness and can no longer communicate your wishes about medical care. A living will includes statements about:

- Whether you want the medical team to use cardiopulmonary resuscitation (CPR) and/or artificial life support, such as mechanical respirators, if your breathing or heart stops. If you are in a medical setting, such as a hospital or nursing home, and your heart and/or breathing stops, medical personnel will automatically perform CPR unless you have a do-not-resuscitate (DNR) order. It is important to let the doctors and nurses know that a DNR order is in place, especially if you are transferred to a new facility. It may be useful, too, to remind your family members so they know of your wishes and are able to help advocate for you if you are unable to do so.
- Whether you want to receive a feeding tube (artificial nutrition and hydration) if you cannot be fed otherwise
- Whether you want certain procedures, such as kidney dialysis, performed

Unlike other advance directives that are written and signed by the individual (such as a living will or a durable power of attorney for health care), a DNR order must be completed and signed by your doctor or another health care provider, such as a hospice nurse practitioner. Once completed, your DNR order is added to your medical record. Living wills are as detailed as needed to make sure that your desires and wishes for life-sustaining treatments are honored. A living will also includes directions about donating organs.
Durable power of attorney for health care. This type of advance directive designates a person who will make medical decisions for you if you become unable to make them yourself. The person you appoint is often referred to as your health care proxy, agent, or attorney-in-fact and has authority only over medical decisions, not other matters, such as finances. Any competent adult, age 18 or older, may be a health care agent. Your health care agent makes decisions about your medical care after your doctor certifies in writing that you are no longer able to make your own decisions. Once you choose a health care agent, you may still make your own decisions about your medical care; your health care agent will only make decisions once you are unable to do so. It is important to talk with the person you are appointing as your health care agent so that he or she knows your wishes.

Patient Story
Myra finished breast cancer treatment two years ago. Recently, the cancer came back and had spread to her bones. She and her oncologist discussed the laboratory results and the fact that the cancer was still treatable but not curable. Ten months into treatment, it stopped working. At that point, her oncologist informed her that a number of treatment options existed, and she recommend one option, along with aggressive symptom treatment, such as managing Myra’s bone pain. At each meeting, they discussed the joint path of treating the cancer and the symptoms. During these discussions, Myra’s oncologist told her that, at some point, the treatment would transition from treating the cancer to primarily treating the symptoms of cancer.

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

Myra agreed, and after a few more months, Myra’s oncologist recommended transitioning to hospice care at a facility in her neighborhood where Myra died a few weeks later. Myra’s husband later said, “Despite the difficulty of the situation, it was made easier when the doctor helped us understand what would happen at each step of the way. Myra felt cared for until her last day.”
Once you make an advance directive, you may change it if needed. Changes are allowed as long as you still have or regain your ability to make decisions. You will need to notify your health care team if you make any changes.

Completing unfinished business
As you approach the end of your life, there may be certain things you wish to accomplish in the time you have left. These tasks help bring a sense of meaning and completion to your life and may range from fulfilling a lifelong dream to simpler experiences, such as re-reading a favorite book or spending time with those who are important to you. Finding peace in important relationships and saying the things that matter most are also significant aspects of life completion. There may be conflicts you wish to resolve or apologies you want to make. You may want to say goodbye to special people and tell family members how much you love them. If you are able, you may want to accomplish these tasks in person, or you may want to pass on a message in writing, by telephone, or through a family member. It may be possible for you to travel to visit special people or for them to travel to you. Keep in mind that, despite your best efforts, people may not respond the way you want them to. Some people may not feel comfortable visiting you or may be afraid they will say the wrong thing. You may be comforted by knowing that you have done your best to heal a troubled relationship.

Reviewing Your Life
It is only natural to want to leave a legacy (evidence that your life mattered and that you made a difference in the world). Take time to reflect on and celebrate the events in your life—the things you have accomplished, the people you have loved, and the individuals and events that have shaped you. Talk with your family and friends about the times you have spent together and the memories and events you have shared. You will not only be honoring memories of the life you shared together but also creating new memories for them to cherish.
As you review your life, you may want to write down your memories, record them on tape or video, or ask someone to write for you as you talk. Talking about or recording your wishes and dreams for loved ones helps ease regrets about having to leave them and helps them feel connected to you at important times throughout their lives. For young children, it may be enormously helpful to leave videos and albums that remind them of your love and connection. Creating opportunities to celebrate your life will also offer an opportunity to record happy moments that your family and friends will cherish after you are gone.

**Religion and Spirituality**

Many patients with advanced cancer report that religion and spirituality are an important part of their lives. For some, organized religion is a central part of life, and the support of faith and clergy members is an important source of comfort at the end of life. For others, spiritual comfort may lie in a sense of connection to nature or people. What matters is finding such comfort, completion, and peace, which will sustain hope and meaning. Studies show that patients who feel spiritually supported have a better quality of life. Patients and their families should feel comfortable asking for spiritual support and for help in finding these resources from members of the cancer care team.
Questions to Ask About Advanced Cancer

Talking about your or your family member’s cancer diagnosis is difficult, especially when there is a lot of information to learn and there are multiple decisions to make. However, it is important to have honest conversations with your doctor and the cancer care team about your treatment plan. Never be afraid to ask for more information or to express your opinions, preferences, and concerns. If your doctor doesn’t have all the answers, he or she may be able to refer you to other resources.

Use this list of questions to help guide your conversation. You don’t need to ask every question at first; different questions will be relevant at different points in your care. It may help to write down your questions before the appointment and bring a notebook to write down the answers. Finally, remember that these discussions should happen throughout your care, not only at the time of diagnosis.

- What is the diagnosis? What does this mean?
- What is my prognosis (chance of recovery)?
- What are my treatment options?
- What is a clinical trial? What clinical trials are open to me?
- What treatment plan do you recommend? Why?
- What is the goal of this treatment? Is it directly treating the cancer or improving my symptoms, or both?
- Am I healthy enough to undergo the recommended treatment?
- What are the risks and benefits of the treatment you are recommending?
- Are there other alternatives I should consider?
- How often should we check in about my treatment plan?
- What is palliative care?
- What is hospice care?
- Where can I find support for me and my family?
List your questions and write down the responses here:

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## Resources

Find additional information about caregiving, end-of-life care planning, grief and bereavement, cancer treatment, and links to patient support and resource organizations at www.cancer.net.

The following national organizations provide resources about advanced cancer, palliative care, hospice care, medical decision-making, and other topics addressed in this booklet. Because programs and services continually change, visit Cancer.Net to find the most current information.

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<td>American Cancer Society</td>
<td><a href="http://www.cancer.org">www.cancer.org</a></td>
<td>800-227-2345</td>
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<td>American Hospice Foundation</td>
<td><a href="http://www.americanhospice.org">www.americanhospice.org</a></td>
<td>800-347-1413</td>
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<td>CancerCare</td>
<td><a href="http://www.cancercare.org">www.cancercare.org</a></td>
<td>800-813-4673</td>
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<td>Caring Connections from the National Hospice and Palliative Care Organization</td>
<td><a href="http://www.caringinfo.org">www.caringinfo.org</a></td>
<td>800-658-8898, 877-658-8896 (multilingual line)</td>
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<td>Center to Advance Palliative Care</td>
<td><a href="http://www.GetPalliativeCare.org">www.GetPalliativeCare.org</a></td>
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<td>Hospice Education Institute</td>
<td><a href="http://www.hospiceworld.org">www.hospiceworld.org</a></td>
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<td>Hospice Association of America</td>
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<td>International Association for Hospice and Palliative Care (IAHPC)</td>
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<td>National Family Caregivers Association</td>
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