

Advanced Cancer and Palliative Care

Treatment Guidelines for Patients

Version II/January 2008



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The mutual goal of the National Comprehensive Cancer Network® (NCCN®) and the American Cancer Society (ACS) partnership is to provide patients and the general public with state-of-the-art cancer treatment information in an easy-to-understand language. This information, based on the NCCN's Clinical Practice Guidelines, is intended to help you when you talk with your doctor. These guidelines do not replace the expertise and clinical judgment of your doctor.

NCCN Clinical Practice Guidelines are developed by a diverse panel of experts. The guidelines are a statement of consensus of its authors regarding the scientific evidence and their views of currently accepted approaches to treatment. The NCCN guidelines are updated as new information becomes available. The Patient Information version is updated accordingly and is available on-line through the American Cancer Society and NCCN web sites. To ensure you have the most recent version, contact the American Cancer Society at 1-800-ACS-2345 or the NCCN at 1-888-909-NCCN.

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Contents

Introduction	5
What is palliative care?	5
Understanding your cancer treatment goals	9
Are clinical trials an option for you?	9
Complementary and alternative treatments	11
Hospice care	11
Cost of care	12
Advanced directives (advance care planning)	12
Support from others	14
Facing death	16
Caregivers section	18
Grieving for the loss of a loved one	21
<i>Treatment Guidelines</i>	23
Decision Trees	
Screening for and assessing palliative care needs	24
Palliative care assessment	26
Complex care assessment	32
Palliative care: Cancer treatment	34
Palliative care: Your personal goals and expectations	39
Palliative care: Managing symptoms – pain	42
Palliative care: Managing symptoms – difficulty breathing	46
Palliative care: Loss of appetite and weight loss	50
Palliative care: Nausea and vomiting	54
Persistent nausea and vomiting	56
Palliative care: Constipation	58
Palliative care: Bowel blockage (obstruction)	60
Palliative care: Confusion	64
Palliative care: Advance directives (advance care planning)	68
Palliative care: Social support	72
Palliative care: Complex care	78
Palliative care: Specialized care during the final days to hours	80
Palliative care: Care for the family and caregivers after death	82

City of Hope

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Massachusetts General Hospital Cancer Center

Duke Comprehensive Cancer Center

Fox Chase Cancer Center

Huntsman Cancer Institute at the University of Utah

Fred Hutchinson Cancer Research Center/
Seattle Cancer Care Alliance

Arthur G. James Cancer Hospital and Richard J. Solove
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The Sidney Kimmel Comprehensive Cancer Center
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Introduction

With this booklet, patients have access to information on how cancer care decisions near the end of life are made at the nation's leading cancer centers. Originally developed for cancer specialists by the National Comprehensive Cancer Network (NCCN), these treatment guidelines have now been translated for the general public by the American Cancer Society (ACS). To get a printed copy of these guidelines, as well as more information, call the American Cancer Society at 1-800-ACS-2345 or the NCCN at 1-888-909-NCCN, or visit these organizations' Web sites at www.cancer.org (ACS) and www.nccn.org (NCCN).

Since 1995, doctors have looked to the NCCN for advice on treating cancer. The NCCN Clinical Practice Guidelines were developed by a diverse panel of experts from 21 of the nation's leading cancer centers.

For more than 90 years, the public has relied on the American Cancer Society for information about cancer. The Society's books, brochures and Web pages provide comprehensive, current, and understandable information to hundreds of thousands of patients, their families, and friends. This collaboration between the NCCN and ACS provides an authoritative and understandable source of cancer treatment information for the general public. These patient guidelines will help you better understand how to make important decisions about your care.

In this booklet you'll find flow charts that doctors call "algorithms" or "decision trees." Each one shows you step-by-step how you

and your doctor can arrive at the choices you need to make about your treatment.

You may also find helpful information about finances, support, talking with others, and more in the American Cancer Society (ACS) document or the Web page, "Nearing the End of Life." These are available on the ACS Web site at www.cancer.org, or by calling 1-800-ACS-2345.

What is palliative care?

Palliative care is care that prevents and relieves pain and suffering and promotes comfort and improved quality of life for patients and their families. Some health professionals call this supportive care.

Palliative care is given to patients at all stages of cancer. For example, the person who receives medicines to control nausea and vomiting during chemotherapy is getting supportive or palliative care.

At some point, cancer may start growing and spread to vital organs. This is called advanced cancer. As the cancer progresses and choices for further cancer treatment become limited, palliative care increases and becomes the major focus of care for the patient and family. Symptoms increase and more attention is needed to help control them. As an example, the person with advanced cancer who gets medicines to control his/her cancer pain near the end of life is receiving palliative care.

Although palliative care is given throughout all stages of cancer to some degree, and is a very important part of comfort and quality

of life, in this guideline, the NCCN's focus is on palliative care during the last year of life.

It is hard to think and talk about this subject. Everyone with cancer hopes that their cancer will be cured, and when that turns out not to be possible, it can be very difficult to think about your life while looking at what may be your "last year." When it becomes apparent that a person's cancer is growing, and treatment choices are limited, the cancer care team may begin to make some predictions about end of life. While the cancer treatment can continue; the goal may no longer be to cure the cancer, but to control symptoms caused by the cancer so patients can still do some of the activities they enjoy. When symptoms increase, the focus of care begins to change to helping control symptoms and making the patient comfortable.

This guideline will help you and your family better understand care during the last year of life and help prepare you for making decisions about the type of care you wish to get at this time. You have the chance to think ahead about the decisions you, and not someone else, would want to make about your care.

Common symptoms that are treated and controlled or relieved by palliative care can include:

- cancer-related pain
- difficulty breathing
- loss of appetite and weight loss
- fatigue and weakness
- depression and anxiety
- confusion
- nausea and vomiting
- constipation
- bowel blockage (obstruction)

Cancer-related pain

About one-third of patients being treated for cancer have pain. More than two-thirds of patients with advanced cancer (cancer that has come back or spread) have pain. For these people, controlling pain and managing symptoms are important goals of treatment.

Pain affects a person's life. Those who have chronic pain (pain that can range from mild to severe and lasts for a long time) may not be able to take part in their regular activities as much. They may have sleeping and eating problems and may feel frustrated that family and friends do not always understand how their pain affects them.

Cancer pain is a common problem, but many people are afraid to take pain medicines because they are afraid of the side effects or becoming addicted. People who have pain rarely become addicted, and your doctor or cancer care team can usually prevent or control side effects.

To learn more about coping with cancer-related pain, please call the American Cancer Society at 1-800-ACS-2345 and ask for a copy of the booklet, "Cancer Pain Treatment Guidelines for Patients."

Breathing difficulties

A person may notice trouble breathing when the body is not getting enough oxygen. People with cancer may be short of breath or have difficulty breathing because of a number of different problems including:

- chronic lung diseases such as emphysema and other diseases not related to cancer
- airway obstruction (blockage of a breathing tube)

- pneumonia
- pain
- trouble moving, sometimes not being able to move at all
- malnutrition (lack of adequate nutrients for the body)
- obesity
- stress or anxiety
- surgery
- anemia
- side effects of chemotherapy or radiation therapy
- the cancer itself
- fluid in the lungs

These problems either prevent the lungs from breathing in enough air, or keep them from getting enough oxygen for the cells of the body.

When a person has breathing problems in the last few weeks or days of life, he or she is less likely to be helped by a machine that breathes for them (called a ventilator). Instead, the person is more likely to be treated with opioid pain medicines, anti-anxiety medicines to reduce cough and ease the distress caused by shortness of breath, and other medicines to help dry up mucus in the lung (secretions).

Loss of appetite and weight loss

Nutrition sustains life. Eating the right kinds of foods before, during, and after treatment can help patients feel better and stay stronger. This may change when cancer becomes advanced. Patients often have no appetite and may lose a lot of weight. This is often caused by the cancer itself and is not within the patient's control. They understand the importance of

eating and may want to eat to help themselves, but they cannot force themselves to eat. In the final days of life the body cannot use the food or fluid. Continued feeding or extra fluids may make the patient more uncomfortable. Here decisions must be made about the importance of nutrition in helping patients meet their goals.

Typically, care related to hydration and nutrition in the final weeks of life includes treatment of dry mouth and thirst, Family members often feel as if they have failed when they are unable to tempt the patient to eat or drink. It is important that the family and caregivers understand and accept that they cannot control this. They may also need ways to cope with their feelings about letting the patient stop eating.

Fatigue

Fatigue is the feeling of being tired physically, mentally, and emotionally. It means having less energy to do the things you normally do or want to do.

Cancer-related fatigue is defined as an unusual and ongoing sense of being tired that can happen with cancer or cancer treatment. It can become chronic, meaning that it can last over time and can interfere with usual activities. This fatigue is different from the fatigue of everyday life, which is usually short-term and relieved by rest. This fatigue is more severe and distressing. Rest does not always relieve it. For some people, this kind of fatigue can be more distressing than pain, nausea and vomiting, or depression. Cancer-related fatigue can:

- be unpredictable from one day to the next in how unpleasant and severe it is, and how long it lasts
- be overwhelming and keep you from feeling well
- make being with your friends and family difficult
- decrease your ability to continue normal activities, including going to work
- make it difficult to follow your cancer treatment plan

Patients with cancer say fatigue is the most distressing side effect of their cancer and its treatment. It is one that drastically affects the quality of their life. However, they rarely describe their symptom as ‘fatigue’ unless their health care team suggests it.

To learn more about how to deal with cancer-related fatigue, please call the American Cancer Society at 1-800-ACS-2345 and ask for a copy of “Cancer-Related Fatigue Treatment Guidelines for Patients.”

Depression and anxiety

Some degree of depression and anxiety is common in people who are coping with cancer. But when a person is emotionally upset for a long time or is having trouble doing day-to-day activities, that person may have clinical depression or severe anxiety that requires medical attention. About 1 in 4 people with cancer are clinically depressed. This can cause them great distress and limit their ability to follow a treatment schedule.

Family and friends should watch for symptoms of distress. If they notice signs of depression or anxiety, they should help the person with cancer get help from a health care

professional. Anxiety and clinical depression can be treated many different ways, including medicines, psychotherapy, a combination of both, or other treatments. These treatments can help the person feel better and improve their quality of life.

Confusion

Sometimes, a patient’s thoughts are disturbed and they have trouble thinking and acting normally. For example, the patient may not know who or where they are or what day it is. Many different things can cause confusion:

- liver disease
- bowel blockage (obstruction)
- bladder blockage
- medicines that affect the central nervous system or brain
- medicine withdrawal

It is not uncommon for a person with advancing disease to have little emotion or to become restless, anxious, depressed, irritable, or angry. These are often signs of delirium, which is an advanced state of confusion. One minute the person may appear sleepy and not respond to questions, but be awake the next. Or they may be loud and agitated but unable to say why. Delirium often shows up as confusion, in which the patient may appear to not know where he is. He or she may see and hear things that are not really there, and say things that don’t make sense to others. These symptoms should be reported to the doctor, since this kind of confusion can often be treated.

Nausea and vomiting

Nausea and vomiting are common side effects of cancer treatments, such as chemotherapy

and radiation therapy. Sometimes nausea and vomiting are caused by the cancer itself. Treatment focuses on finding and treating the cause of the symptoms. In addition, there are a number of drugs to treat nausea and vomiting that are very effective.

Constipation

A common side effect of strong pain medicines (opioids, such as morphine) is constipation. Because of this, ways to prevent constipation must be considered whenever a patient starts taking these medicines. Prevention includes drinking enough fluids, getting plenty of fiber, and taking laxatives before the problem starts. A number of drugs and laxatives can be used to treat constipation.

Bowel blockage

A blocked intestine (bowel obstruction) may have other causes besides cancer, such as scarring, hernia, or the side effects of radiation. Some of these causes can be treated with surgery. However, surgery may not be the best choice depending on the patient's life expectancy and treatment goals. For example, surgery is not usually appropriate if the patient's life expectancy can be measured in weeks or days. There are other less invasive ways to treat the symptoms of a blocked bowel. For example, a tube can be placed through the skin into the stomach to drain off fluids that may worsen nausea and vomiting. A small tube called a stent can be placed through an area of blocked intestine to keep it open. All of these treatment options must be carefully discussed with the doctor to choose the one that best meets the patient's needs and expectations.

Understanding your cancer treatment goals

At any stage of cancer, the goal of any cancer treatment should be clear to both the patient and family. The goal may be to cure the cancer, extend life, or help with symptoms. Sometimes this can be confusing because some treatments used to cure cancer are also used to relieve symptoms. For example, radiation therapy can be used to cure cancer, but it can also be used to control bone pain. If you are not sure why something is being done, ask your doctor or cancer care team about it.

Some people believe that if their cancer cannot be cured, nothing more can be done. So they stop all treatment. Some doctors think this way as well. But something can almost always be done. Radiation, chemotherapy, surgery, and other treatments can help control symptoms and extend life. And relieving symptoms like pain, upset stomach, vomiting, and difficulty breathing can help the patient feel better.

Are clinical trials an option for you?

All drugs used to treat cancer or other diseases must undergo clinical trials in order to determine their safety and effectiveness before the Food and Drug Administration (FDA) can approve them for use. Treatments used in clinical trials are often found to have real benefits. Researchers conduct studies of new treatments to answer the following questions:

- Is the treatment helpful?
- How does this new type of treatment work?
- Does it work better than other treatments already available?
- What side effects does the treatment cause?
- Do the benefits outweigh the risks, including side effects?
- Which patients will the treatment most likely help?

During cancer treatment, the doctor may suggest taking part in a clinical trial. Scientists conduct clinical trials only when they believe that the treatment being studied may be better than other treatments.

All patients in a clinical trial are closely watched by a team of experts to monitor their progress very carefully. The study is done to find out if the new treatment will work better than the standard treatment and if the side effects are worse or less. The new treatment may have some side effects, which the doctor will discuss with the patient before the clinical trial is started.

Deciding to enter a clinical trial

Taking part in any clinical trial is completely voluntary. Doctors and nurses explain the study in detail and provide a consent form to read and sign. This form states that the patient understands the risks and wants to participate. Even after signing the form and the trial begins, the patient may leave the study at any time, for any reason.

Taking part in the study will not keep anyone from getting other medical care they may need. Patients should always check with

their health insurance company to find out whether it will cover the costs of taking part in a clinical trial.

Participating in a clinical trial evaluating new, improved methods for treating cancer may help the patient directly, and it may help other people with cancer in the future. For these reasons, members of the National Comprehensive Cancer Network and the American Cancer Society encourage participation in clinical trials.

How can I find out more about clinical trials that might be right for me?

The American Cancer Society offers a clinical trials matching service that will help you find a clinical trial that is right for you. You can reach this service at 1-800-303-5691 or our Web site <http://clinicaltrials.cancer.org>. Based on the information you give about your cancer type, stage, and previous treatments, this service compiles a list of clinical trials that match your medical needs. The service will also ask where you live and whether you are willing to travel so that it can look for a treatment center you can get to.

You can also get a list of current clinical trials by calling the National Cancer Institute's Cancer Information Service toll free at 1-800-4-CANCER (1-800-422-6237) or by visiting the NCI clinical trials Web site at www.cancer.gov/clinical_trials/.

More information about clinical trials is available through the American Cancer Society's toll-free number at 1-800-ACS-2345 or on our Web site at www.cancer.org.

Complementary and alternative treatments

When you have cancer you are likely to hear about ways to treat your cancer or relieve symptoms that are different from mainstream (standard) medical treatment. Especially as patients near the end of life they may begin to think about alternative therapies. This is also a time when well-meaning family and friends may suggest treatments that they have heard or read about. These treatments can include vitamins, herbs, and special diets, or acupuncture and massage, and many others.

The American Cancer Society defines complementary treatment methods as those that are used along with your regular medical care. Some methods that can be used in a complementary way are meditation to reduce stress, acupuncture to relieve pain, or peppermint tea to relieve nausea. There are many others. Some of these methods are known to help and may add to your comfort and well being, while others have not been tested. Some have been proven not to be helpful. A few have even been found harmful.

Alternative treatments are defined as those that are used instead of standard medical care. These treatments have not been proven to be safe and effective in clinical trials. Some may even be dangerous or have life-threatening side effects. The most common danger is that you may lose the chance to be helped by standard treatment.

Deciding what to do: It is easy to see why people with cancer may consider alternative treatments. You want to do all you can to fight the cancer. Sometimes mainstream treatments

such as chemotherapy can be hard to take. And sometimes they stop working.

At times like this, when people suggest that their treatment can cure your cancer without serious side effects, it's normal to want to believe them. But the truth is that most non-standard treatments have not been tested and proven to be effective for treating cancer. As you consider your options, talk to your doctor or nurse about any treatment you are thinking about using. Call the American Cancer Society at 1-800-ACS-2345 or visit www.cancer.org to learn more about the specific treatments you are looking at.

With reliable information and the support of your health care team, you may be able to safely use methods that can help you while avoiding those that could be harmful.

Hospice care

Hospice care is supportive or palliative care given near the end of life. The right time for hospice care is when treatment aimed at curing or controlling the cancer is no longer helping the patient. Together, the patient, family, and doctor decide when hospice care should begin. Typically, patients are eligible for a hospice program when they are thought to have about 6 months to live. Hospice care usually can continue longer than 6 months if your doctor continues to certify the prognosis.

Hospice seeks to manage a patient's physical and emotional symptoms. The goal of hospice is to help patients live their last days with dignity and quality, surrounded by loved ones. Hospice care affirms life and neither

hurries nor postpones death. Its focus is on quality of life, rather than length of life.

Hospice programs offer family-centered care. They include the patient and family in making decisions. Hospice care is usually given in the home, but it can also be given in a hospital, nursing home, or private hospice center.

In a hospice program, the hospice team will have a doctor who is the medical director, a nurse, a nurse's aide, a social worker, and a chaplain. In most cases, your own doctor will also play a role.

Deciding to begin hospice care can be hard. An honest talk with your doctor can help you decide if hospice care is the right thing to do. Consider the following:

- Ask whether any treatment your doctor suggests offers hope for a cure.
- If a cure is not possible, will the treatment prolong your life or relieve any of your symptoms?

You should think about hospice if your doctor can't assure you that treatment will meet any of these goals. A hospice program will have the best chance of controlling your symptoms and keeping the quality of your life.

For more information, you may want to contact the National Hospice and Palliative Care Organization (NHPCO) at www.nhpco.org or 1-800-658-8898.

Cost of care

It is always important to consider the cost of cancer care, whether for cancer treatment or palliative care. Insurance policies differ widely. Always check with your insurance company

to find out which services are covered. Many insurance companies will have a case coordinator who will be the main contact. This person decides what is covered for each case. Most health insurance plans cover hospice care. Medicare has a special hospice benefit that not only covers care but also pays for all medicines, with some restrictions.

For Medicare information, call the Medicare Hotline at CMS (Center for Medicare and Medicaid Services): 1-800-633-4227 (1-800-MEDICARE), or TTY/TDD: 1-877-486-2048. They can explain what Medicare covers and how to qualify. You can also visit them on the Web at: www.cms.hhs.gov.

Serious illnesses often create a need for a lot of money right away. In many states, death benefits from life insurance policies can be turned into "living benefits." These benefits are available in several ways, such as selling the policy or borrowing against it.

Advanced directives (advance care planning)

Patients have the right to control their medical treatment. You can choose your course of treatment, kind of treatment, and refuse any treatment that you do not want. Every state recognizes this right of "informed consent." This means that the doctor or nurse explains the purpose, benefits, risks, and alternatives of the treatment before starting it. Generally, treatment can be given only if you agree to it. It is also generally accepted that a competent adult patient may refuse life-sustaining medical treatment or ask that such treatment be stopped even if the patient will die as a result.

Informed consent includes the right to refuse treatment, as well as to agree to it. (For more information, see the American Cancer Society document, “Informed Consent.”)

However, this right is not absolute; for example, if you are unable to give consent or receive information and you are in need of immediate care. In such instances, family members make medical decisions for spouses, parents, or adult children who cannot speak for themselves. Whether such an informal arrangement will be accepted depends on the medical provider. Also, many states have passed family agency acts that decide which family members (in a listed order of priority) may act on behalf of a person who cannot speak for her or himself. One way to keep your rights is by writing down your wishes about your future health care choices in what is called an advance directive.

An advance directive is a legal document that states your wishes about health care choices. Even though others may be able to make health care decisions for you without an advance directive, the directive offers more assurance that your wishes will be carried out. It contains written directions or guidance concerning future medical care, and/or selects a surrogate (a substitute, also called a proxy or agent) to act for you when you cannot act for yourself.

Advance directives can be general, with few directions about your care. Or, they can be very specific, detailing your wishes regarding acceptance or refusal of all types of life-sustaining treatments. The directive may just name a proxy or surrogate person to make these decisions for you if you are unable to do

so. Or it may include instructions, as well as choosing your proxy. Some types of advance directives are limited to certain situations such as the living will, organ or tissue donation, or your wishes not to be resuscitated (revived) if your heart or breathing stops. Regardless of the type, no one will be able to control your money or other property based on your advance health care directive. It may also help to know that you can also change or revoke (take back) these directives at any time.

There are different formats for advance health care directives. Some follow forms outlined in state laws, and others are created by lawyers or even the patients themselves. The validity of these documents is decided by state law and the courts. Although all states and the District of Columbia have laws about advance health care directives, the exact names of the documents, restrictions, and other formalities vary quite a bit due to differences in state laws.

States generally do not require the use of a specific form, although the states do have legal requirements about what must be included and how the document is set up. Because language on a form may be vague and not reflect your individual wishes, you should review and change the words to reflect personal values, priorities, and wishes. You should also know your state’s requirements for writing and legalizing advance directives. For example, states define the minimum age required to have a directive. In addition, all states require that at least one adult not related by blood, marriage, or adoption witness your signature and date on the advance directive. Some states require 2 witnesses. You can

usually get sample forms for advance directives from your state, state bar association, or from the National Hospice and Palliative Care Organization.

Before you create an advance directive, you will also want to talk with your doctor, your loved ones, and the person that you choose as your proxy or surrogate (substitute decision-maker) about your situation, wishes, and fears. You will need to consider your options with them because they are the ones who will help put your wishes into effect if you are unable to do so.

All people receiving medical care in hospitals, enrolling in health plans, and entering into hospice or home care agreements must be given written information on their state's laws concerning their rights to make decisions about medical care. This includes the right to accept or refuse medical or surgical treatment. In addition, you are entitled receive information about your right to make an advance directive. Simple advance directive forms are also usually available. However, it may not be a good idea to wait until you are hospitalized to fill out a form. You may not be able to complete the form when you are admitted and, even if you are, these forms are very general and may not provide for all of your wishes.

You will find more detailed information on the American Cancer Society Web page in the document "Advance Directives." These are available at www.cancer.org or by calling 1-800-ACS-2345.

Support from others

A person with a life-threatening illness has a great need for other people in his or her life to help deal with the illness and its emotional effects. These people provide what is called "social support." Studies have shown that patients who have social support are better able to adjust to their situation.

Support can come from family and friends, members of a church, mental health professionals, support groups, or community members. Asking for support is one way you can control your situation.

If you do not have support from friends and family, seek it elsewhere. There are others in your community who need your companionship as much as you need theirs. The mutual support of others with cancer might also be a source of comfort. Ask your health care team or a member of the clergy for resources in your community.

Support programs and groups

A support group can be a powerful tool for both patients and families. Talking with others in the same situation as yours can help ease loneliness. And you can also get useful ideas from others that might help you.

Support programs exist in many different formats and some include individual or group counseling and support groups. Some groups are formal and focus on learning about cancer or dealing with feelings. Others are informal and social. Some groups include only people with cancer or only caregivers, while others include spouses, family members,

or friends. Other groups focus on specific types of cancer or stages of disease. The length of time groups meet can range from a certain number of weeks to an ongoing program. Some programs have closed membership and others are open to new, drop-in members.

For those who cannot attend meetings or appointments, counseling over the telephone is offered by some organizations. Some people may find online support groups helpful because they like being anonymous. It may be comforting to exchange emails with other people facing similar situations. Chat rooms and message boards, however, are not the best source of cancer information, especially if they are not monitored by trained professionals or experts.

Regardless of the group's structure, it is important for you to feel comfortable in the group and with the facilitator. If you have any fears or uncertainties before entering a group, feel free to discuss them with the group's facilitator.

Support in any form allows you to discuss your feelings and develop coping skills. Studies have found that people who take part in support groups have an improved quality of life, including sleep and appetite.

People with cancer often say that lack of communication in their families is a problem. Changes in responsibilities can cause resentment and anxiety. Family counseling may help family members learn to deal with changes within the family. It can also help members discuss their feelings more comfortably. Counseling is especially helpful in families where some members are not comfortable openly discussing their feelings.

Religious or spiritual support

For many, religion can be a source of strength. Some find new faith during a cancer experience. Others find their cancer strengthens their existing faith or their faith provides newfound strength. A minister, rabbi, other leader of your faith, or a trained pastoral counselor can help you identify your spiritual needs and find spiritual support. Some members of the clergy are specially trained to minister effectively to people with cancer and their families. Some hospitals have chaplains available at their facility.

Ask your health care team about the resources available at your hospital. You can also contact your American Cancer Society to find out about sources of support that are available in your community.

Family issues

Advanced cancer changes the way family members relate to one another. Typically, families that solve conflict well and are supportive of each other do best in dealing with a loved one's cancer. Other families may have a harder time with advanced cancer, and may need more outside help.

Roles within the family may change. How family members take on new tasks and fill in for the patient will affect how they adjust to losing that person.

For the person with cancer, the changes in family roles can trigger the grief that comes with loss. For example, a woman who is bedridden may be anguished about not being the wife and mother she once was. Understanding this and helping the patient to find ways to still contribute and feel included may benefit both the patient and the family.

What else can friends do to help?

One of the first things a friend or family member will often say is “What can I do to help?” You may be tempted to say “Oh, nothing right now. We’re just fine,” because you want your privacy and feel you have all you can handle without having people around you. Remember that people really do want to help and it is likely that you will need some extra help during your cancer treatment. Your friends and family need to do things for you and support you. It helps them feel they are a part of your life. Allow them to help you by being as specific as possible about the kind of help you need. For example, tell them when you will need a ride to the doctor, or find out if they can help you with housecleaning, meals, yard work, or child care. There will probably be times when you won’t know what you need, but even just saying that will be helpful.

Caregiver support

Research has shown that the support of friends and family is important to both the person with cancer and the caregiver. Caregivers often tend to feel isolated, depressed, anxious, and are less likely to reach out for help. They may also develop physical problems such as heart disease, high blood pressure, sleep problems, an increased risk of infectious illness, and fatigue. Caregivers may not think much about it, but while they are helping their loved one, they must also take care of themselves.

Overwhelming concern for a sick loved one may be distracting. The caregiver may be torn between the needs of the patient, their own needs, and the needs of the family. Many caregivers forget to eat, don’t get enough sleep

or exercise, and ignore their own physical health concerns. It is important for them to keep their own doctor appointments, get enough sleep, exercise, eat healthy foods, and keep their normal routine as much as possible. It is important that they not feel guilty or selfish when asking for help or taking time for themselves. By taking care of themselves, they are better able to take care of the person with cancer. This also means taking time to do things they enjoy.

Facing death

Anyone with advanced cancer will at some point understand that he or she will not live forever. Family members will recognize this, too. Even if the person with cancer is doing well, death is a likely part of the future at some point. But thinking about death can be frightening and painful. Patients and families worry about suffering before death and being alone when death occurs.

Many people with cancer want to be at home until the end. A long illness and dying at home can be easier with the support of family and medical staff. Often everyone’s goal is to help the person with cancer die at home, with his or her loved ones, with little or no pain.

The main goal for a death that cannot be avoided is a “good death.” A “good death” is defined as one with the least possible amount of pain, discomfort, or suffering for the patient, and the least possible suffering for the family and caregivers. A “good death” is one that is in line with the patient’s and loved ones’ wishes, including their culture, values, and ethics. Loved ones are supported in being with the

Caregivers section

Possible changes in body function

- Weakness, has trouble moving around in bed
- Unable to change positions without help
- Trouble swallowing food, medicines, or even liquids
- Involuntary movement of any muscle, jerking of hands, arms, legs, or face

What caregivers can do

- Help the patient turn and change positions every hour or two.
- Avoid sudden noises or movements to lessen the startle reflex.
- Speak in a calm, quiet voice to reduce chances of startling the patient.
- If the patient has trouble swallowing pain medicines, ask the doctor or hospice nurse for liquid pain medicines or pain patch.
- If the patient is having trouble swallowing, avoid solid foods. Give ice chips or sips of liquid.
- Do not push fluids. Near the end of life, some dehydration is normal, and is more comfortable for the patient.
- Apply cool, moist wash cloths to head, face, and body for comfort.

Possible changes in consciousness

- More sleeping during the day, hard to wake or rouse from sleep
- Confusion about time, place, or people
- Restlessness, may pick or pull at bed linen
- May talk about things unrelated to the events or people present
- May have more anxiety, restlessness, fear, and loneliness at night
- After a period of sleepiness and confusion, may have a short time when he or she is mentally clear before lapsing back into semi-consciousness

What caregivers can do

- Plan your times with the patient when he or she is most alert or during the night when your presence may be comforting.
- When talking with the patient, remind her or him who you are and what day and time it is.
- Continue pain medicines up to the end of life.
- If patient is very restless, try to find out if he or she is in pain. If it appears so, give breakthrough pain medicines as prescribed, or check with the doctor or hospice nurse if needed.
- When talking with a confused person, use calm, confident tones to reduce chances of startling or frightening the patient.
- Touching, caressing, holding, and rocking are all appropriate and comforting.

Possible changes in metabolism

- Less interest in food, as needs for food and drink decrease
- Mouth may dry out (see changes in secretions)
- May no longer need some of his or her medicines, such as vitamins, chemotherapy, replacement hormones, blood pressure medicines, and diuretics (unless they help make the patient more comfortable)

What caregivers can do

- Apply lubricant or petroleum jelly (Vaseline) to the lips to prevent drying.
- Give ice chips from a spoon, or sips of water or juice from a straw may be enough for the patient.
- Check with the doctor to see which medicines may be stopped. Medicines for pain, nausea, fever, seizures, or anxiety should be continued to keep the patient comfortable.

Possible changes in secretions

- Mucus in the mouth may collect in the back of the throat (This may be a very distressing sound to hear, but doesn't usually cause discomfort to the patient.)
- Secretions may thicken and build up due to a lower fluid intake and inability to cough

What caregivers can do

- If mouth secretions increase, keep them loose by adding humidity to the room with a cool mist humidifier.
- If patient can swallow, ice chips or sips of liquid through a straw may thin secretions.
- Change patient's position—turning to the side may help secretions drain from the mouth. Clean the mouth with a soft toothbrush or toothette.
- Certain medicines may help. Ask your hospice or homecare nurse.

Possible changes in circulation and temperature

- Arms and legs may feel cool to the touch as circulation decreases
- Skin of arms, legs, hands, and feet may darken in color and appear mottled
- Other areas of the body may become either darker or pale
- Skin may feel cold and either dry or damp
- Heart rate may become fast, faint, or irregular
- Blood pressure may get lower and become hard to hear

What caregivers can do

- Keep patient warm with blankets or light bed coverings.
- Avoid use of electric blankets, heating pads, etc.

Possible changes senses and perception

- Vision may become blurry or dim
- Hearing may decrease, but most patients are able to hear you even after they can no longer speak
- Leave indirect lights on as vision decreases.

What caregivers can do

- Never assume the patient cannot hear you.
- Continue to speak with and touch the patient to reassure him or her of your presence. Your words of endearment and support are likely to be understood and appreciated.

Possible changes in breathing

- Breathing may speed up and slow down due to less blood circulation and build up of waste products in the body
- Rattling or gurgling with each breath may happen due to mucus in the back of the throat
- Longer pauses in breathing may occur, usually lasting from 10 to 30 seconds

What caregivers can do

- Put the patient on his or her back, or slightly to one side.
- Raising the patient's head may give some relief.
- Use pillows to prop head and chest at an angle or raise the head of a hospital bed.
- Any position that seems to make breathing easier is okay, including sitting up with good support. A small child may be more comfortable in your arms.

Possible changes in elimination

- Urine may become darker and decrease in amount
- Loss of control (incontinence) of urine and stool may occur when death is near.

What caregivers can do

- Pad bed with layers of disposable waterproof pads beneath the patient.
- If the patient has a catheter, the home health nurse will teach you to care for it.

Signs that death has occurred

- Breathing stops
- Pulse stops
- Eyes stop moving
- Pupils of the eye stay large, even in the light
- Control of bowels or bladder is lost as the muscles relax

What caregivers can do

- After death it is okay to sit with your loved one for a while. There is no rush to get anything done right away. Many families find this is an important time to pray or talk together and reconfirm their love for each other as well as for the person who has passed away.
- If the patient dies at home, certain people must be called. Rules or laws about who must be called and how the body is removed differ from one community to another. Your doctor or nurse can help you with this information. If you have a hospice or homecare agency involved, call them. If you have completed funeral arrangements, you may only need to notify the funeral director and doctor.

Grieving for the loss of a loved one

When a person loses someone important to them, they go through a normal process called grieving. Grieving is a natural and expected process which, over time, can allow a person to accept and understand their loss. Grieving involves feeling many different emotions over a period of time, all of which eventually help the person to come to terms with the loss of a loved one.

Bereavement and mourning are other words that are commonly used to describe the grieving process. Bereavement is what a person experiences when someone close to them dies. It is the state of having suffered a

loss. Mourning is the expression of one's loss and grief. Mourning includes behaviors and rituals that are specific to each person's culture, personality, and religion.

Many people think of grief as a single instance or very short period of pain or sadness in reaction to a loss—for example, the tears shed at a loved one's funeral. However, the term refers to the entire emotional process of coping with a loss. Normal grieving allows us to let a loved one go and continue with our lives in a healthy way. Though grieving is painful, it is important that those who have suffered a loss be allowed to express their grief, and that they be supported throughout the process.

Treatment Guidelines

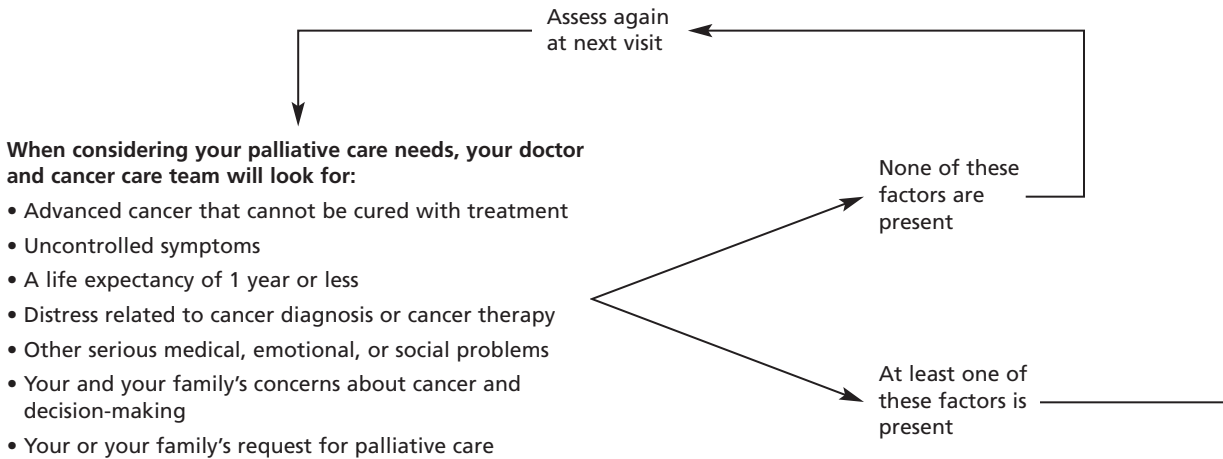
Decision Trees

The Decision Trees, or flowcharts, on the following pages represent different aspects of palliative care. Each one shows you step-by-step how you and your doctor can arrive at the choices you need to make about your treatment. One constant theme throughout the decision trees is frequent checking and re-checking to find out whether care is satisfactory or not. Satisfactory care is defined as the relief of the specific symptoms, and whether or not care meets the family's expectations and goals. Other important aspects of satisfactory care are to maintain the best possible quality of life, and to make sure that patients feel like they have enough control over their care.

Keep in mind that the information in the decision trees is not meant to be used without the expertise of your doctor, who is familiar with your situation, medical history, and personal preferences.

The NCCN guidelines are updated as new significant data become available. To be sure that you have the most recent version, consult the Web sites of the ACS (www.cancer.org) or NCCN (www.nccn.org). You may also call the NCCN at 1-800-909-NCCN or the ACS at 1-800-ACS-2345 for the most recent information on these guidelines or for information on cancer in general.

Screening



Screening for and assessing palliative care needs

The purpose of screening is to find out if palliative care is needed. This screening is done by the health care team. Any one of several situations suggest that palliative care could be helpful. It should be considered for patients who:

- have advanced cancer that cannot be cured
- have uncontrolled symptoms
- are expected to live less than a year
- have distress related to cancer diagnosis or treatment
- have other serious medical, emotional, or social problems

- have concerns about cancer and decision-making
- ask for palliative care or symptom relief

The cancer care team considers several factors to help them determine if the patient is expected to live a year or less. These factors include:

- How well the person can care for themselves and carry out daily activities
- Whether the patient has complications of advanced cancer such as:
 - too much calcium in the blood (hypercalcemia)
 - liver or kidney problems
 - other serious medical conditions

Screening for and assessing palliative care needs

Assessment

Your doctor or cancer care team will discuss the following with you:

- What are the benefits and risks of more cancer treatment? (see page 26)
- What are your goals, expectations and concerns? (see page 38)
- What symptoms do you have? (see page 28)
- • What type of information do you and your family need? (see page 31)
- Do you have an advance directive (advance care plan)? (see page 29)
- Are you or your family distressed about any emotional, spiritual, family, or financial matters? (see page 30)
- Will you need complex palliative care or early referral for palliative care? (see page 32)

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- involvement of the central nervous system (brain and spinal cord)
- superior vena cava syndrome (swelling of the face or body, shortness of breath, and other problems caused by a partly blocked vein near the heart)
- spinal cord compression (pressure on the spinal cord causing pain and problems with urinating and walking)
- malignant effusions (fluid leaking into the space around the lungs, heart, or abdominal organs caused by cancer)
- weight loss and loss of appetite

If none of these situations or factors is present, the cancer team should check again at the next visit. If one or more is present, the patient's doctor or cancer care team will do a full review of the patient's palliative care needs. This is called a palliative care assessment (or evaluation).

During the palliative care assessment, the doctor or cancer care team will consider the questions listed on the Decision Tree. Each of these is discussed more thoroughly in individual Decision Trees.

Issue

Assessment

What are the benefits and risks of more cancer treatment?



Your doctor or cancer care team will consider:

- The usual course (typical history) of your type of cancer
- Likelihood of a response to treatment at this time
- How the cancer and its treatment have affected your vital organs
- Your ability to take care of yourself and do normal daily activities
- You and your family's understanding of goals of cancer therapy
- Other medical conditions

What symptoms are present?



Your doctor or cancer care team will ask you about:

- Pain _____
- Breathing problems _____
- Loss of appetite and weight loss _____
- Fatigue and weakness _____
- Problems with sleeping _____
- Confusion _____
- Depression or anxiety _____
- Nausea and vomiting _____
- Constipation _____
- Bowel blockage _____

Do you have an advance directive (advance care plan)?



Your doctor or cancer care team will ask you about:

- Living will or power of attorney for health care _____
- Your preferences about CPR _____

Palliative care assessment

Benefits and risks of more cancer treatment

If cancer has spread throughout the body, it generally cannot be cured. After a long battle with cancer, the risks and discomforts of cancer treatment may start to outweigh its benefits. Many people become aware, after

repeated treatments for cancer, that the treatments are no longer working. Only the patient can say whether or not they want to go on with treatment that is meant to prolong life. That is why it is important to know about the risks and benefits of any treatment before making a decision.

Palliative care assessment

Treatment

→ See the Decision Tree for Cancer Treatment (page 34)

→ See the Decision Tree for Pain on page 42.

→ See the Decision Tree for Difficulty breathing on page 46.

→ See the Decision Tree for Loss of appetite and weight loss on page 50.

→ Your doctor is referred to the NCCN Cancer-Related Fatigue and Anemia Guidelines*

→ See the Decision Tree for Confusion on page 64.

→ Your doctor is referred to the NCCN Distress Management Guidelines*

→ See the Decision Tree for Nausea and vomiting on page 54.

→ See the Decision Tree for Constipation on page 58.

→ See the Decision Tree for Bowel blockage on page 60.

→ See Advance care planning on page 68.

** A free copy of the patient version of this treatment guideline is available by calling 1-800-ACS-2345. Your doctor can view these guidelines at www.nccn.org under professional treatment guidelines*

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Recommendations for additional cancer treatment are generally based on existing NCCN treatment guidelines for the person's specific cancer type (for example, breast, prostate, or

colorectal cancer), any past treatment and response to treatment, current status of their cancer, how well vital organs are working, and the patient's overall health and ability to

Issue

Assessment

Distress related to:

- Family
- Community
- Spiritual
- Financial
- Religious
- Social support problems
- Mental health issues

Your doctor or cancer care team will ask you about:

- Your current support system
- Your past coping strategies, strengths, vulnerabilities
- Financial problems

What are the patient's goals and expectations?

Your doctor or cancer care team will consider:

- Your wishes and family needs
- Priorities of palliative care (i.e., goals of cancer treatment, quality of life)
- Whether you are ready for hospice or specialized palliative care services

What information does the patient and family need?

Your doctor or cancer care team will consider:

- Your and your family's values and preferences and how information is communicated
- What you and your family already know about the status of your cancer
- Cultural factors that affect your care

Emotional or social distress

Distress is a common symptom in patients with advanced cancer. It can be related to many things, such as a patient's individual reaction to the cancer prognosis (outlook for survival or progress of disease), lack of social support, and/or financial problems. Social support is given to patients by people who care about them. It might include someone to talk to and discuss goals and plans with, someone to hold their hand and listen or take them for a


walk. It can also mean someone to help with buying groceries or yard work. Support can come from family, friends, your community, or cultural, spiritual, and/or religious groups.

Personal goals and expectations


Patients should talk about their wishes and family needs. Goals, hopes, expectations, and concerns regarding personal, spiritual or religious, and cultural needs should also be discussed and respected by the cancer care

Palliative care assessment (continued)

Treatment



See the Decision Tree for Social support on page 72



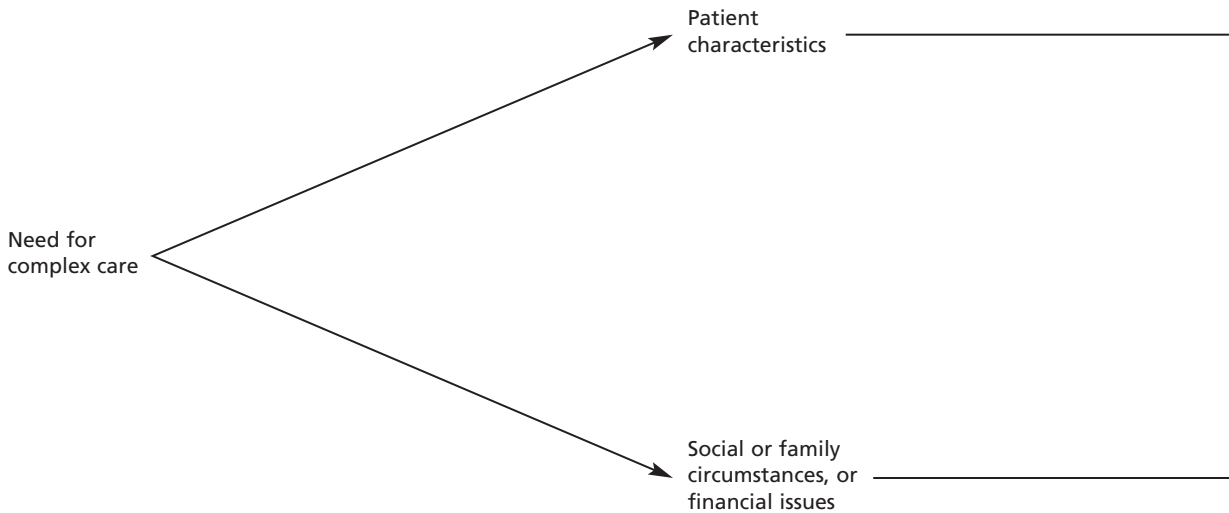
See the Decision Tree for Your personal goals and expectations (page 38)

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team. This is the time for patients to say what they would like to accomplish or do before they die. Further cancer treatment and what it might mean for the patient and family may be part of this discussion. At some point, symptom control and quality of life may become more important than cancer treatment. The treatment team will talk with the patient about whether he or she is ready for palliative or hospice care.

Education and information needs

The cancer care team will want to know what the patient and the family understands about the cancer and prognosis, and what more they want to know. Ask them to explain anything you are unsure about or want to know. Make sure your cancer care team understands any cultural factors that may affect your cancer care.

Issue**Complex care assessment**

Some patients are likely to need more complex palliative care than others. This is because they have unique needs. For example, the dosage of medicine will be different if the patient is an older adult or a child. The doctor or cancer care team will ask the patient specific questions to find out whether complex palliative care is needed. Reasons for complex care can be divided into those that are related to the patient, and those related to patient's social circumstances, including the family and

support system. Patients who need complex care can often benefit from having the palliative care team called in earlier than those with fewer problems. This gives the team and family more time to resolve palliative care issues. Patient-related issues are listed above.

Social circumstances, family, and financial issues

Social and/or family-related issues are outlined in the Decision Tree. Your cancer care team will consider these, too. After looking

Complex care assessment

Assessment

Treatment

Your doctor or cancer care team will assess for:

- Limited treatment options
- Poor pain control or other symptoms
- Past or present mental or emotional problems, including alcohol or drug abuse
- Unexpected admissions to the intensive care unit
- Bad reactions to treatments for pain and symptom control
- Whether you have a high distress score
- Confusion or trouble thinking clearly
- Severe medical problems
- Problems with communication (i.e. language problems, trouble reading, or physical barriers)
- Repeated requests for physician-assisted suicide

See Complex care
(page 78)

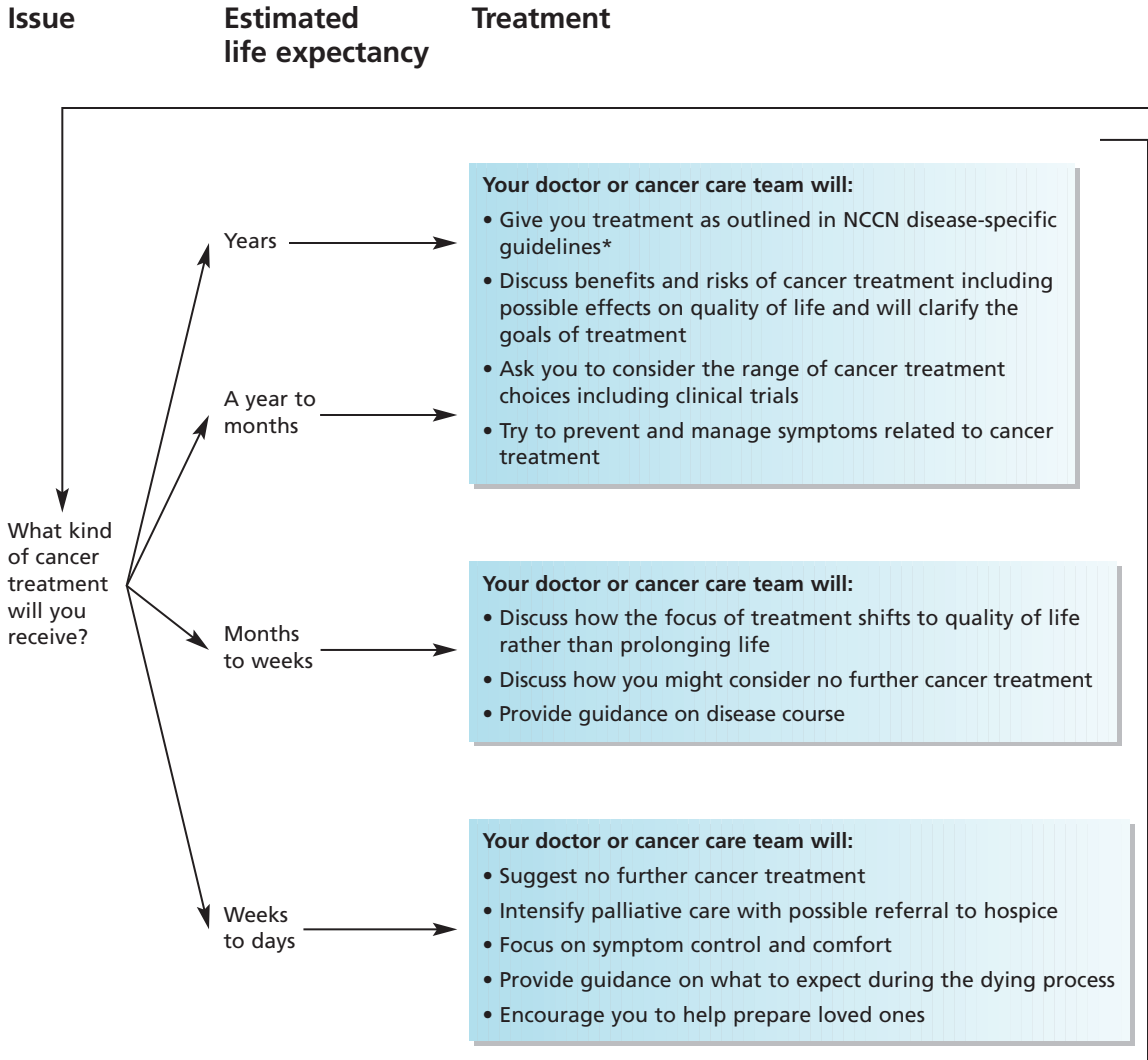
Your doctor or cancer care team will ask you about:

- Lack of social support (family and friends)
- Relationships in which someone depends on you a great deal (for example, young children)
- Family conflicts
- Limited access to care
- Multiple prior losses
- Spiritual crisis (questioning faith or the meaning or purpose of life)
- Money problems
- Concerns about care of dependents
- Family or caregiver limitations

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at each of the listed factors, your doctor or cancer care team will decide if complex palliative care is needed at this time. If it is, care will involve a team of doctors, nurses, mental health professionals, and chaplains. It may be

necessary to call in a hospice/palliative care specialist or team to help develop the palliative care plan. The decision trees that follow discuss specific palliative treatments or ways to deal with these problems.



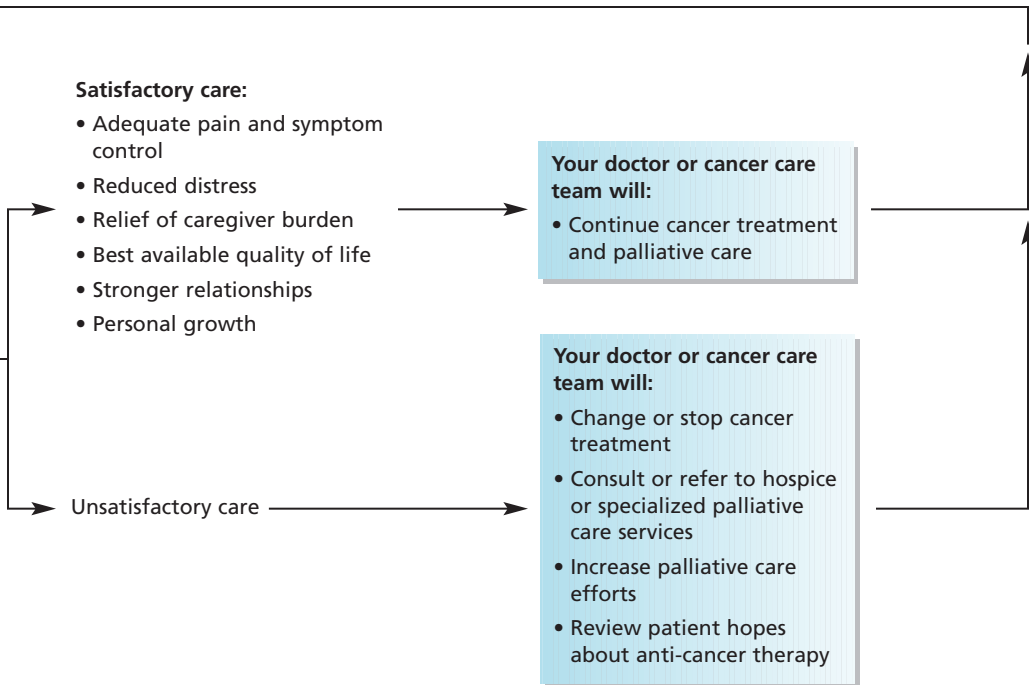
Palliative care: Cancer treatment

At any time during cancer treatment, your doctors are weighing the benefits and risks of treatment. If the treatment is not going to make you live longer or improve your ability to do some of the things you want to do, it is

even more important for the doctor to explain the risks and benefits of the types of treatment that are still available. You will then be asked to make a difficult decision about continuing treatment or about different treatments or clinical trials.

Palliative care: Cancer treatment

Reassessment



* These are available for your doctor at www.nccn.org. Some patient versions are also available by calling 1-800-ACS-2345.

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When making these difficult decisions about cancer treatment, the doctor and cancer care team consider how long the patient is likely to live (estimated life expectancy). They usually consider it in terms of blocks of time:

- Years to months
- Months to weeks
- Weeks to days

Years to months life expectancy: Treatment during this time will be guided by the NCCN cancer treatment guidelines for the patient's specific cancer. For example, if a patient has prostate cancer, the doctor will review the NCCN Prostate Cancer Treatment Guidelines for recommendations about how to treat the cancer. He/she will discuss the

benefits and risks of the cancer treatment and make sure the patient understands the treatment goals. The doctor will also try to both prevent and treat any symptoms related to the cancer treatment and maintain the patient's quality of life.

Patients who feel good and are able to do their daily activities may be interested in continuing cancer treatment to try to live longer and/or try to reduce symptoms caused by their cancer. There may be a number of different cancer treatments to consider, including a clinical trial. However, your doctor should make it clear that while the proposed palliative treatment may reduce symptoms or prolong life, it will not cure the cancer. As long as the patient is doing well on this treatment, this treatment will be continued.

Months to weeks life expectancy: Patients here are likely to be growing tired of treatment, are at home, and may be more concerned about the side effects of more treatment. Your doctor should tell you what is expected to happen with the cancer and outline what might be achieved with further cancer treatment. Patients may choose to stop cancer treatment at this point and shift their focus from treatment intended to prolong life to treatment to improve the quality of their life. Patients should also be told what will happen when they stop treatment, so that they and their family or caregiver will have an idea of what to expect. Referral to a hospice is also possible.

NOTES

Palliative care: Cancer treatment (continued)

Weeks to days life expectancy: At this point, care focuses on day-to-day symptom control and comfort. Cancer treatment is usually stopped, unless it is providing comfort for the patient. Patients may consider hospice care. Your doctor can begin to tell you what to expect during the dying process, and encourage the patient to help prepare loved ones for death.

After symptom control treatment is started, the cancer care team will determine if the treatment has been satisfactory. Satisfactory treatment provides pain and

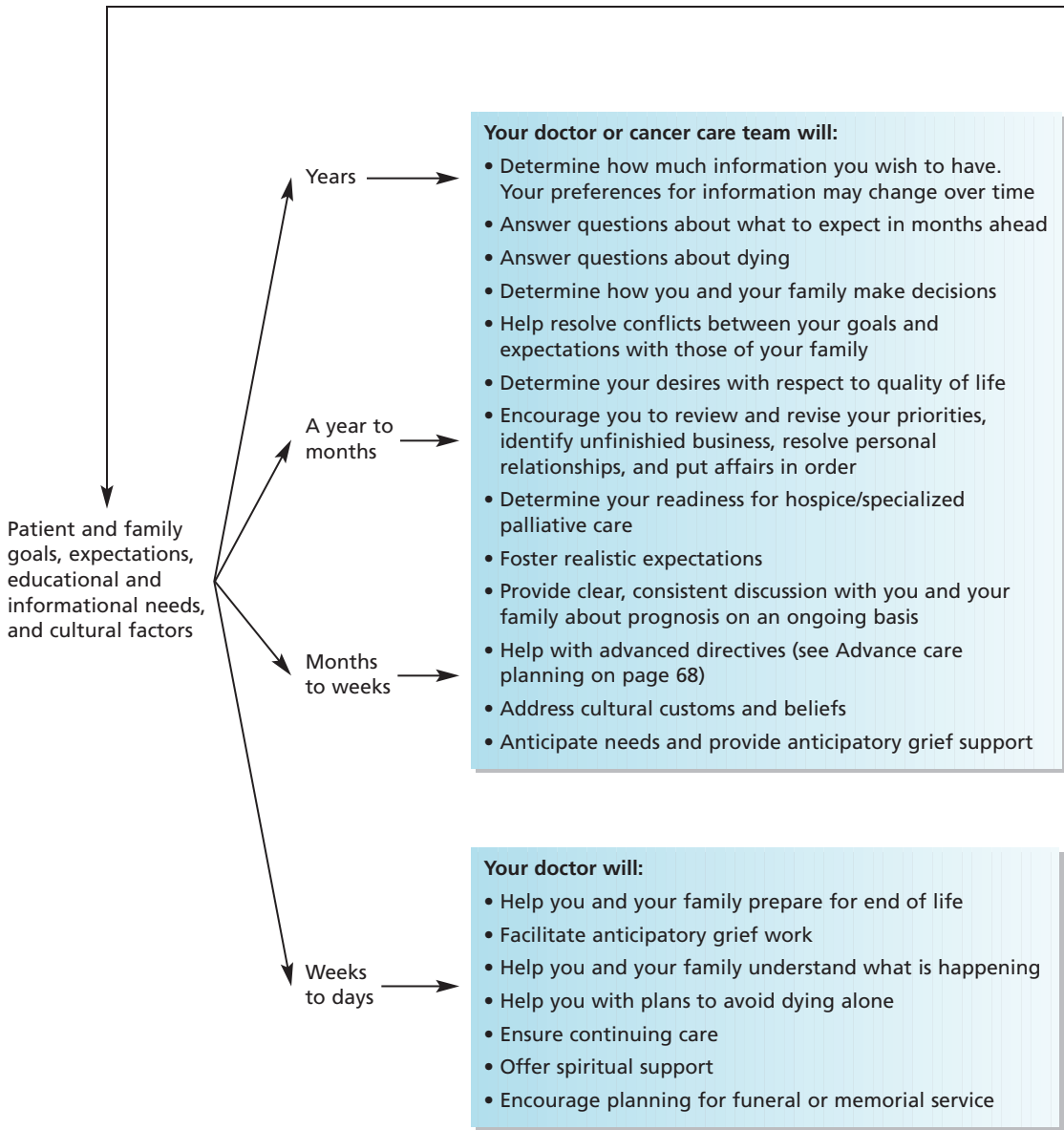
symptom control, does not prolong dying, promotes a sense of control for the patient, helps relieve the caregiver burden, provides the best quality of life available to the patient, and strengthens patient and family relationships. If the treatment is satisfactory, it will be continued. If the treatment is not satisfactory, it will be changed or stopped. The cancer care team may talk with a hospice or palliative care team for help in making changes in the care. They may refer the patient to the team for specialized palliative care services.

NOTES

Issue

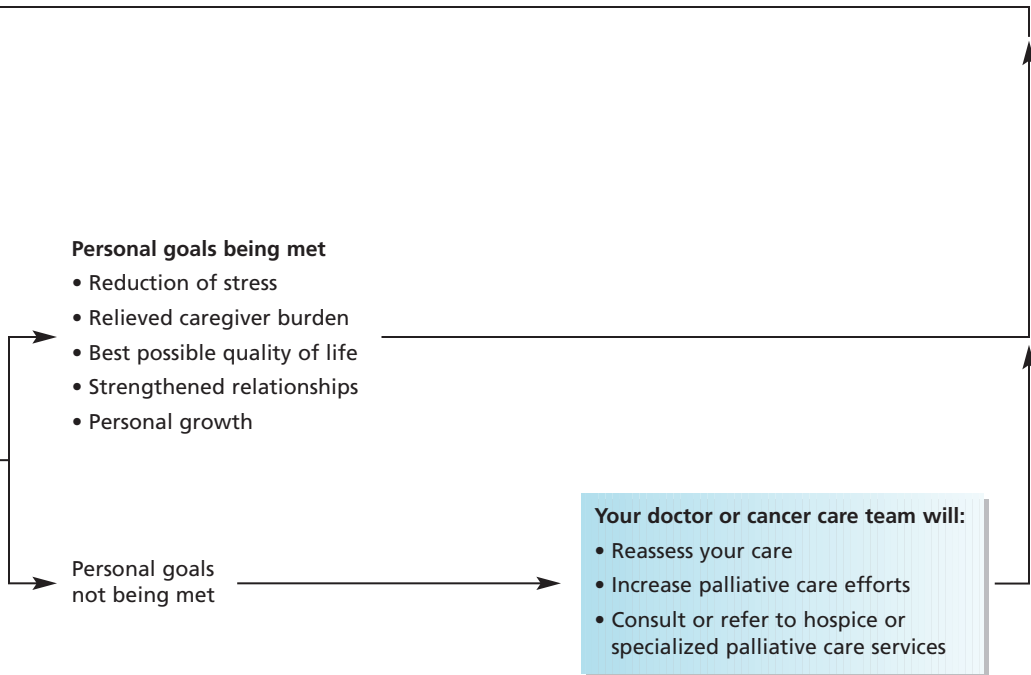
**Estimated
life expectancy**

Treatment



Palliative care: Your personal goals and expectations

Reassessment



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Palliative care: Your personal goals and expectations

At any stage of cancer, the goal of any treatment should be clear to both the patient and family. You should know if the goal of the treatment is to cure the cancer, extend your life, or help with symptoms. Knowing the extent of the disease and its prognosis can

help you decide which type of care you wish to receive. The patient's personal beliefs, values, and wishes should be considered in making decisions about care.

Many people begin to question their life's goals and purpose when their cancer continues to advance.

A patient's personal goals and expectations may vary throughout the last year of life. If someone has years to months to live, it is important to be sure they are mentally able to make decisions and to understand their desires with respect to their remaining life. The doctor or cancer care team will ask how much information the patient wishes to have and will let the patient take the lead on asking questions about dying. How the family makes decisions will also be looked at, to help ensure that patient and family goals are the same. It should be noted that involvement of the family may change over time. The

doctor or cancer care team will try to help resolve any family conflicts and talk about any cultural customs that may affect care. Patients are encouraged to review and reconsider what is important to them. Is there unfinished business they wish to take care of? Or a difficult personal relationship they wish to resolve? Affairs should be put in order.

The cancer care team will continue to keep the patient and family informed about the expected course of the disease. They will decide if the patient is ready for hospice or specialized palliative care. The cancer care team can also help with advance care planning

NOTES

Palliative care: Your personal goals and expectations (continued)

(see page 68) and support the patient and family in the grieving process that begins when death is anticipated.

The cancer care team can help the patient and family prepare for the end of life, including making sure that adequate care continues even as the patient's needs change. Arrangements will be discussed to have someone with the patient so that he or she does not die alone.

Family members will need to understand what is happening and what to expect next. They often begin to grieve for the patient, and the doctor or cancer care team will watch the family closely for any signs of

abnormal grieving. The cancer care team can provide spiritual support and also encourage family members to start planning a funeral or memorial service.

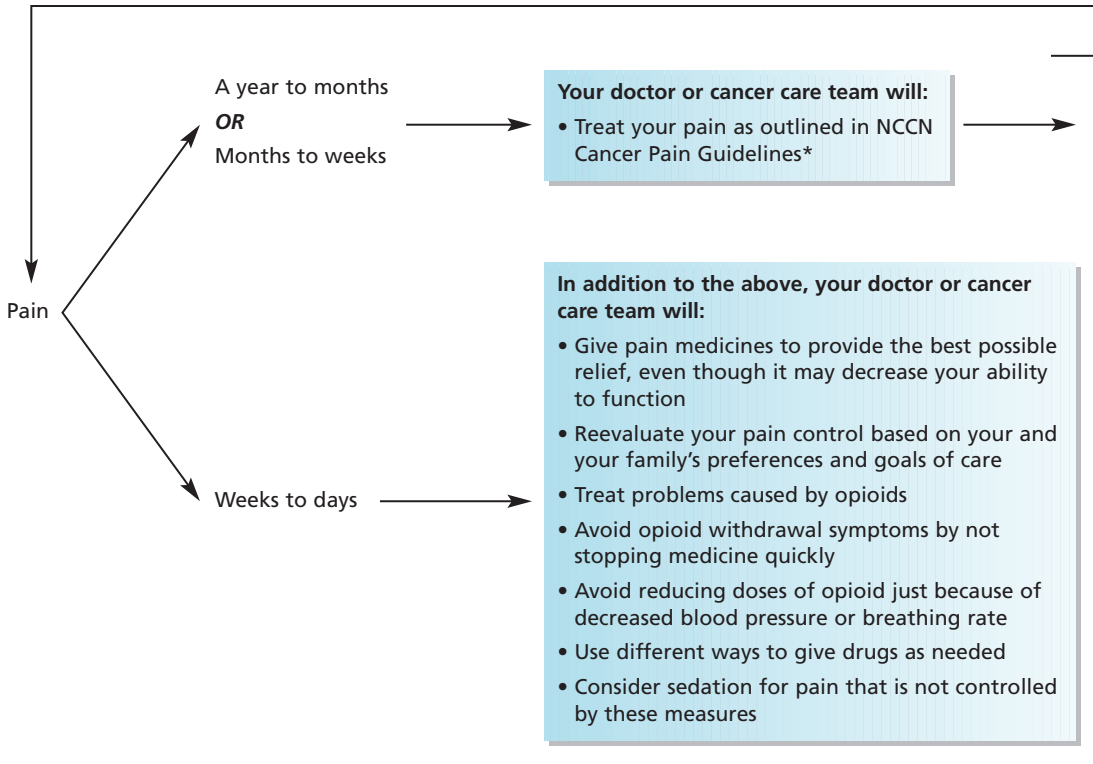
Once these things have been done, the cancer care team will again assess whether the patient's personal goals are being met. If the care is satisfactory, it will be continued. If the care is not satisfactory, it will be changed or stopped. The cancer care team may talk with a hospice or palliative care team for help in making changes in care. They may refer the patient to the team for specialized palliative care services.

NOTES

Symptom

**Estimated
life expectancy**

Treatment



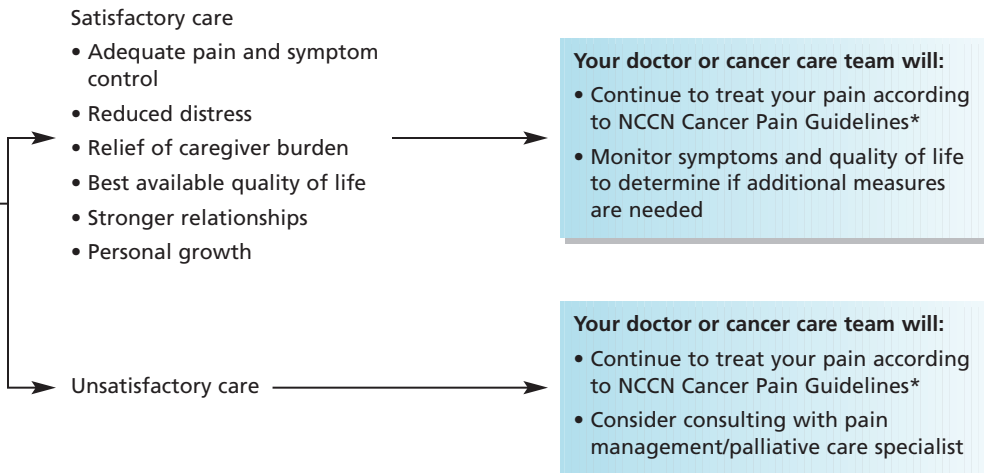
Palliative care: Managing symptoms – pain

A Year to Months or Months to Weeks: During this time, the cancer care team will treat pain following the NCCN Cancer Pain Treatment Guidelines. These specific guidelines treat cancer pain based on what is causing the pain and how severe it is. The guidelines also outline what the cancer care team should do if the patient's pain is not being controlled.

Weeks to Days: The NCCN Cancer Pain Treatment Guidelines are used to help manage the patient's pain. However, as death nears, the goal is to provide care based on what the patient wants. The cancer care team will ask if there has been any change in patient or family preferences. Changes in pain treatment will continue to be made to keep the patient comfortable while at the same time continuing to function (for instance, to try and minimize

Palliative care: Managing symptoms – pain

Reassessment



* A free copy of the patient version of the treatment guideline is available by calling 1-800-ACS-2345

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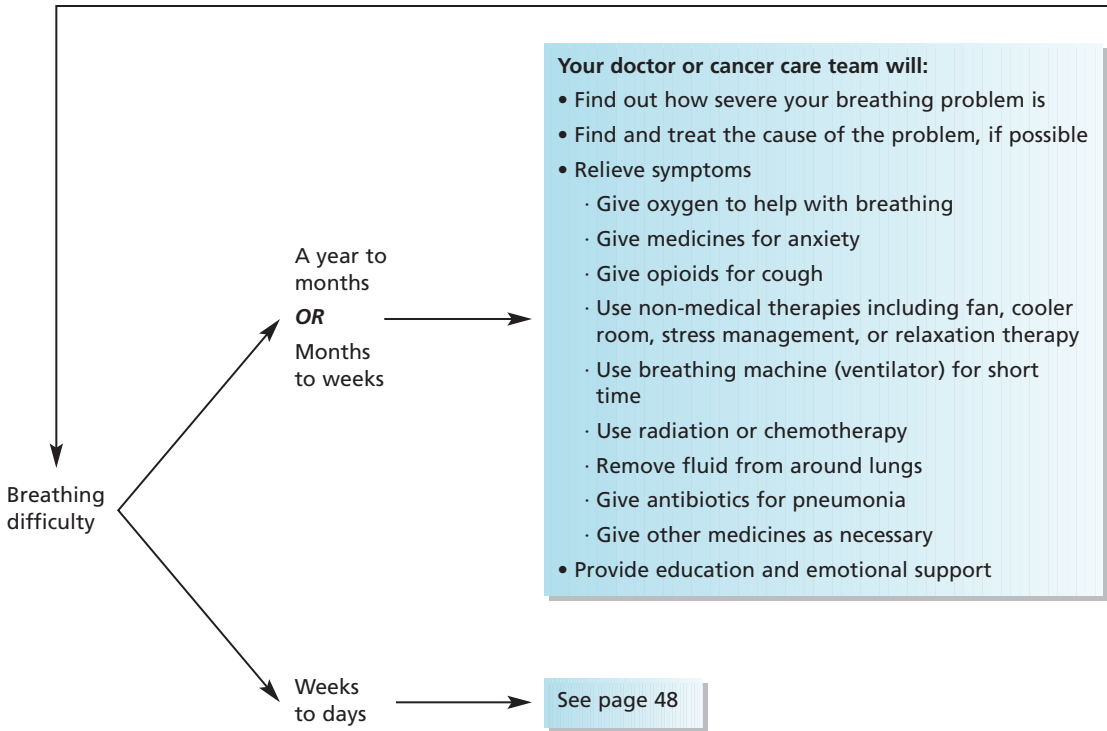
sleepiness, dizziness, or other side effects). However, this will depend on the patient's preferences. Many patients will be receiving opioids (morphine-like drugs) for pain. Sometimes the dose of opioid pain medicine needed to control pain may make the patient sleepy or dizzy. The cancer care team will carefully monitor these drugs to make sure

that the dose is optimal and any side effects from the opioids are managed. The doctor may change the way a drug is given if needed, for example, if the patient becomes unable to swallow a pill. Pain medicines can be given by injection ("shot"), under the tongue, rectally, or as a patch on the skin. To make sure the patient is comfortable at this stage, drug

Symptom

**Estimated
life expectancy**

Treatment



Palliative care: Managing symptoms – difficulty breathing

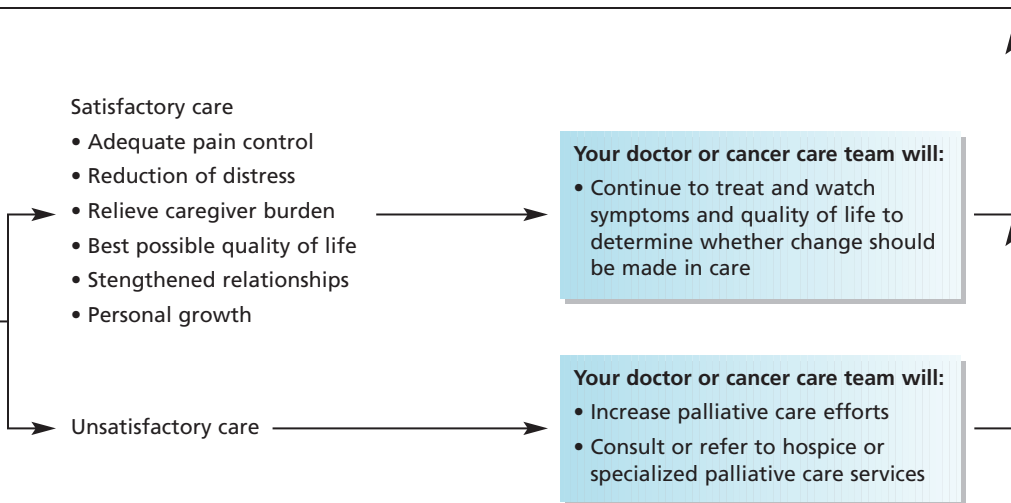
A Year to Months or Months to Weeks:

During this time, the cancer care team will find out what is causing the breathing problem and how severe it is, and then treat the cause of the problem if possible. For example, if breathing difficulty is caused by anemia,

then the anemia will be treated; or if it's caused by pain, then the pain will be treated. Oxygen may be given during this time to help with breathing. A respirator or ventilator (machine that breathes for the patient) may even be used for a short time if the problem is likely to get better with treatment. Other options to help with breathing may include

Palliative care: Managing symptoms – difficulty breathing

Reassessment



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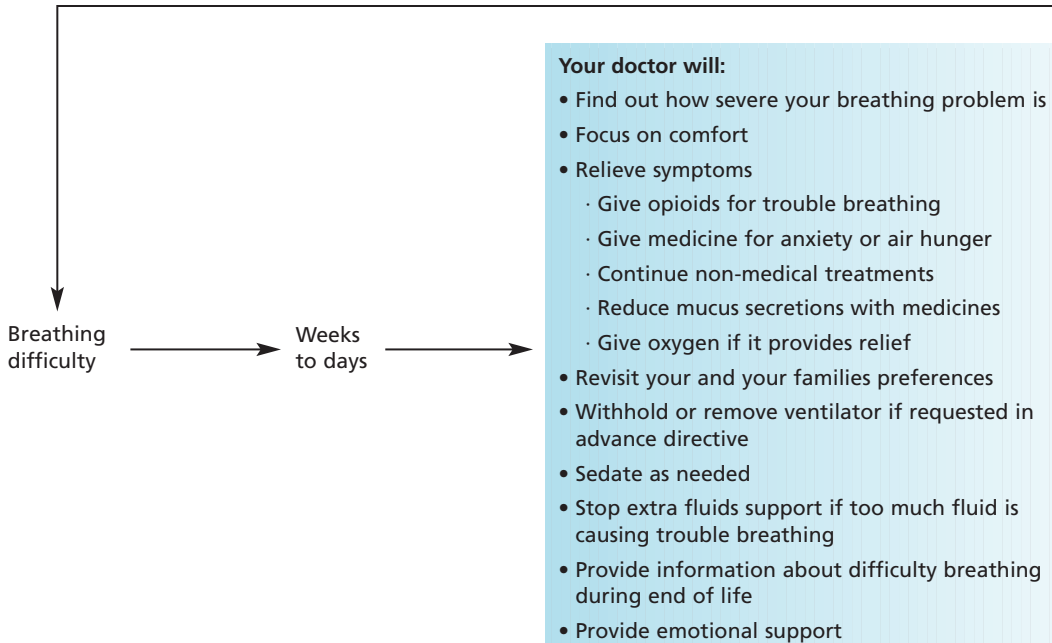
radiation or chemotherapy treatment, or removal of fluid that may have collected around the lungs. Antibiotics can be given for pneumonia. Other medicines can be used to expand the airways or reduce the mucus in the lungs. Usually patients feel anxious when they are unable to breathe well. This anxiety

can be treated with medicines to relieve this symptom. Opioid pain medicines will be used to help reduce coughing. Non-medical treatments such as a fan, a cooler room, and relaxation and stress management may also be used to help with symptoms.

Symptom

Estimated
life expectancy

Treatment

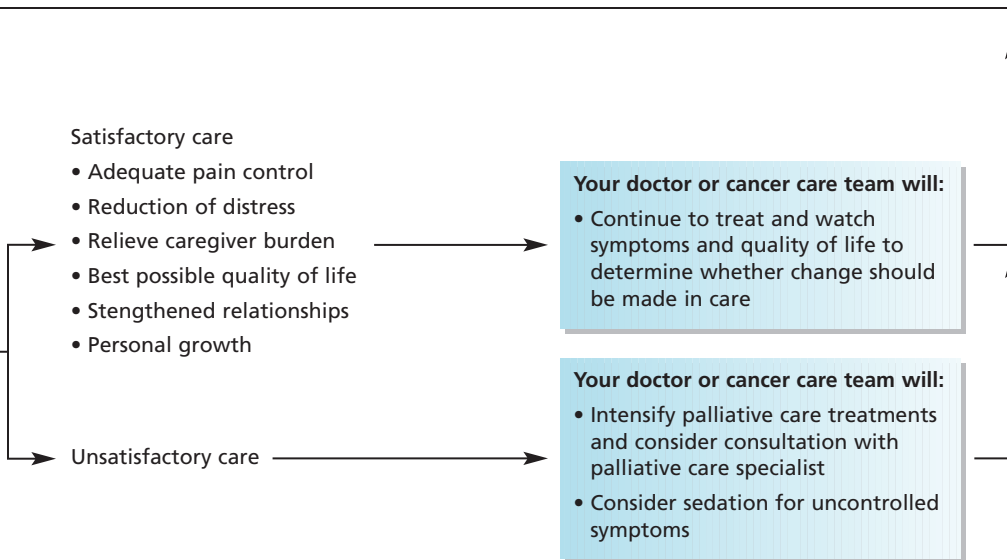


Weeks to days: Your doctor or cancer care team will increase treatments to provide comfort and relieve symptoms. The opioid medicines, those for anxiety or air hunger, and medicines to reduce mucus in the lungs will be continued. Oxygen will be given if it makes the patient comfortable. Use of a ventilator will be continued, withheld, or removed, based on the patient's expressed wishes or advance

directives. Sedation (giving medicines that make the patient sleep most of the time) may help some patients. The doctor or cancer care team will once again speak with the patient and family about their preferences. Extra fluids may be stopped if too much fluid is causing the breathing problem. Sometimes, medicine to get rid of extra fluid in the body may be needed. The doctor or cancer care

Palliative care: Managing symptoms – difficulty breathing (continued)

Reassessment



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team will talk with the family about how breathing problems may change or worsen near the end of life.

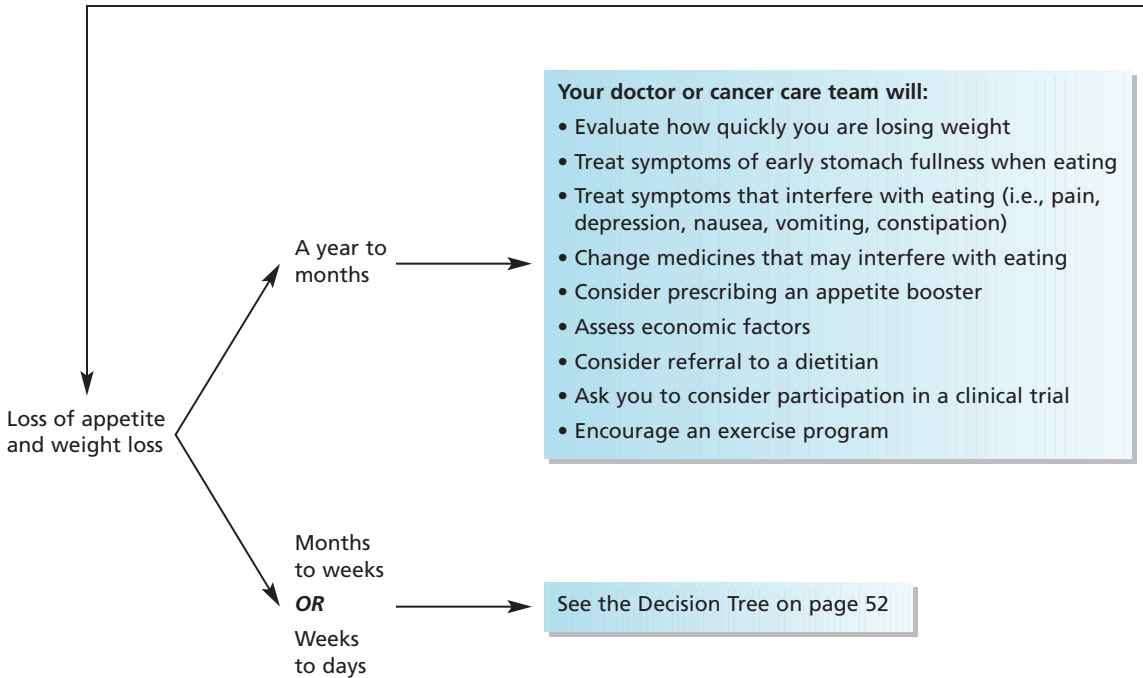
Once these symptoms are being treated, the cancer care team will determine whether the patient's personal goals are being met. Satisfactory care provides adequate control of breathing, does not prolong dying, promotes a sense of control for the patient, helps relieve

caregiver burden, and strengthens patient and family relationships. If the care is satisfactory, it will be continued. If the care is not satisfactory, it will be changed. The cancer care team may talk with the pain management or palliative care team for help in making changes in care. They may refer the patient to the team for specialized palliative care services.

Symptom

**Estimated
life expectancy**

Treatment



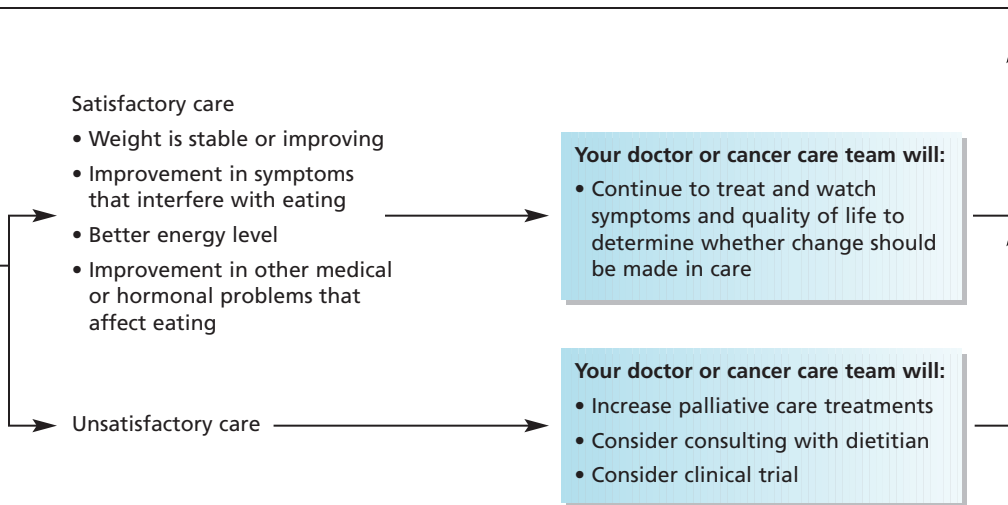
Palliative care: Loss of appetite and weight loss

Years to months: Patient care will focus on finding and treating the cause of loss of appetite and weight loss. The doctor will determine how much and how quickly weight has been lost, and then search for underlying causes that can be treated. For example, sometimes patients may feel full early in a meal, so they stop eating. This may be treated with medicines.

A number of medical problems such as pain, nausea and vomiting, depression, constipation, or sores in the mouth or intestine may also cause a person to eat less. All of these conditions can be treated. Hormone problems, such as abnormal thyroid function, or low levels of sex hormones, such as testosterone, may affect food intake, so the doctor may want to check hormone levels. The doctor or cancer care team will also review all the medicines that a patient is taking to make sure that they

Palliative care: Loss of appetite and weight loss

Reassessment



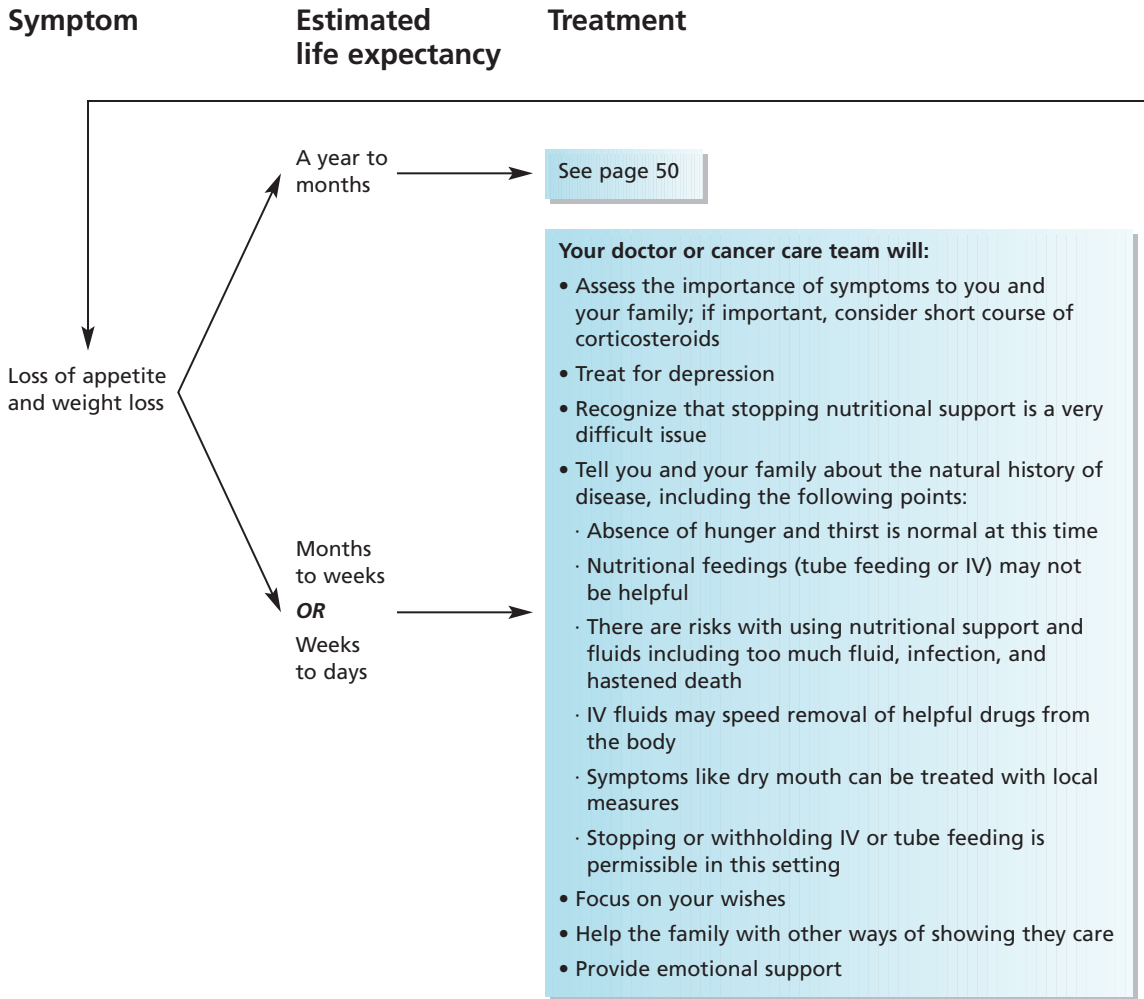
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have not caused the appetite loss. In some cases, eating disorders or not having money to buy enough food can cause or contribute to eating less.

If no treatable medical cause can be found, the doctor may prescribe drugs to stimulate appetite. Referral to a nutritionist or participation in a nutrition support clinical trial may also be considered. Finally, if the patient is able, an exercise program may help build-up strength and prevent muscle loss.

Once these treatments have been started, the cancer care team and doctor will re-evaluate

to find out if the care is satisfactory. Weight should be stable or improve, symptoms that interfere with eating should be better, and energy levels should be higher. Any hormone abnormalities or metabolic problems should be improved. If care is satisfactory, care and monitoring continues. If not, the care team will increase efforts at palliative care, consult with nutritionist, or consider a nutrition support clinical trial if one is available for which the patient qualifies.

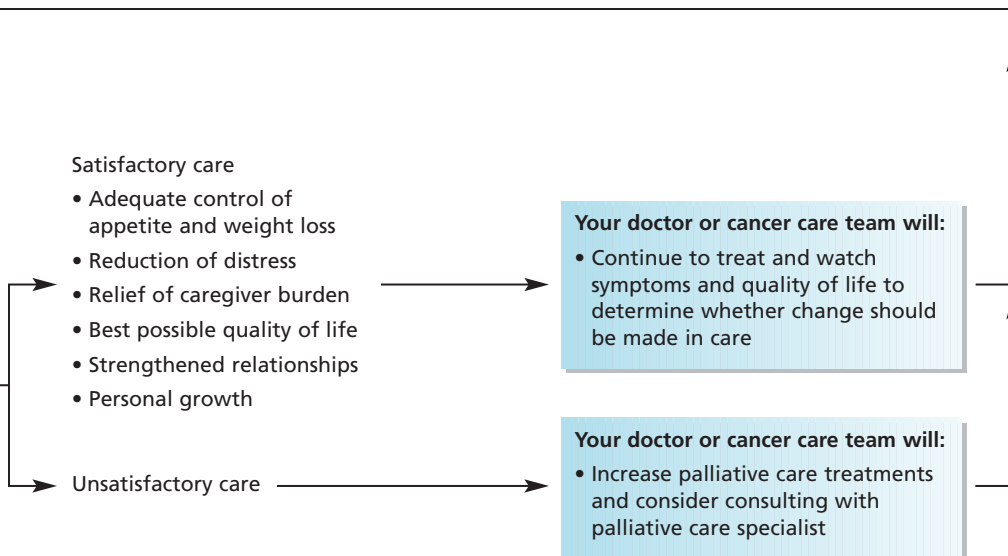


Months to weeks or weeks to days: The cancer care team will assess the importance of patient symptoms related to nutrition. Recognizing that stopping food and fluids is a very difficult issue for the patient and family, the cancer care team will discuss what is going on with the cancer and explain that patients usually are not hungry or thirsty at

this time. If the patient wants to be treated, a short course of steroids may be helpful. If the patient is depressed, treating it may improve appetite. The risks of nutritional support (intravenous or tube feeding) will be discussed, including the risks of too much fluid in the body and infection. Giving nutrition and fluid support can actually hasten death in some

Palliative care: Loss of appetite and weight loss (continued)

Reassessment



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cases as a result of the complications that can occur. Also, intravenous (IV) fluids can speed up the excretion of drugs from the body when these drugs are providing benefit to the patient.

Stopping IV or tube feedings is okay at this time. It will not increase symptoms and it may improve some. Dry mouth can be treated with local measures such as giving small amounts of liquid or ice chips, cleaning the mouth, and moistening the lips.

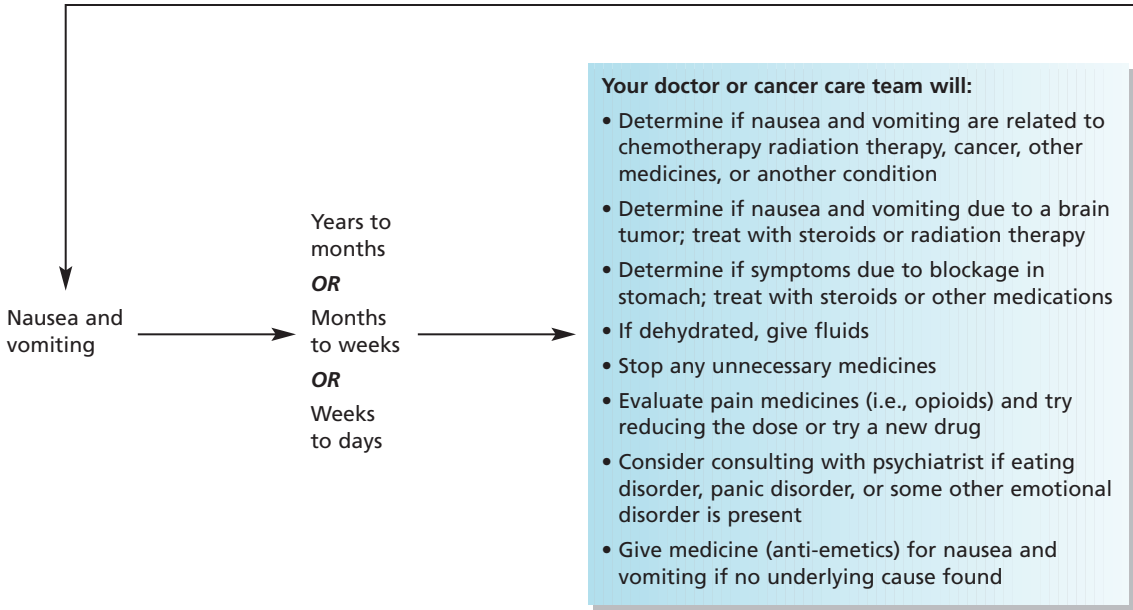
Now the focus is on what the patient wants. Once these symptoms are being treated, the cancer care team will check to find out

whether the patient's personal goals are being met. Satisfactory care provides control of uncomfortable symptoms, reduces patient and family distress, does not prolong dying, promotes a sense of control for the patient, reduces caregiver burden, and strengthens patient and family relationships. If the care is satisfactory, it will be continued. If the care is not satisfactory, it will be changed. The cancer care team may talk with the pain management or palliative care team for help in making changes in care. They may refer the patient to the team for specialized palliative care services.

Symptom

**Estimated
life expectancy**

Treatment



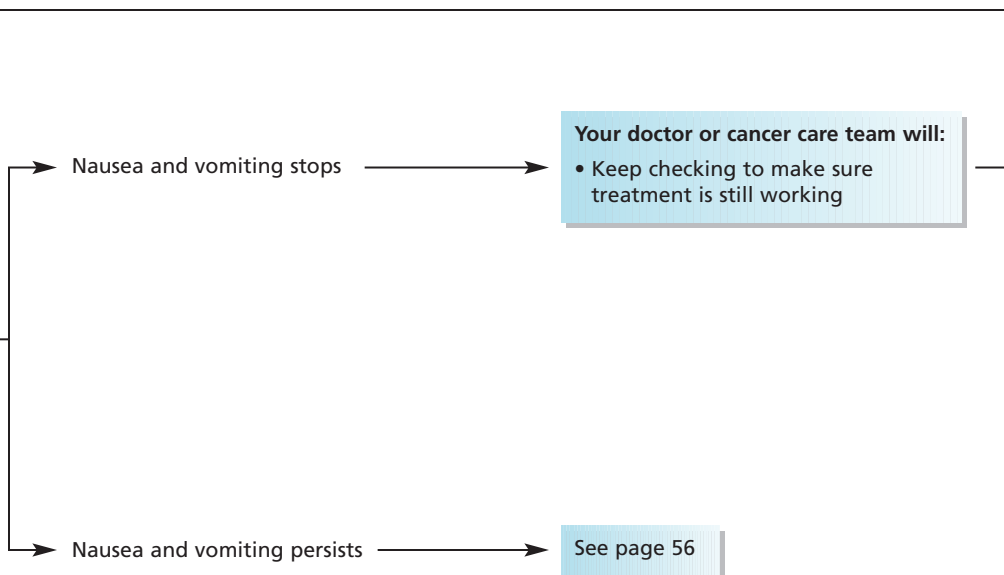
Palliative care: Nausea and vomiting

Nausea and vomiting are usually treated the same regardless of the life expectancy. However, it may be handled differently when it first appears than if it continues (becomes chronic or persistent). The first step is to find out if the nausea and vomiting is related to cancer treatment (usually either radiation or chemotherapy). If this is the case, the doctor will use the NCCN Nausea and Vomiting Treatment Guidelines. Nausea and vomiting may also be due to other medicines, the cancer itself, or some other cause. If possible, treatment is focused on the underlying cause.

For example, sometimes dehydration can cause nausea and vomiting. This may be corrected by either drinking more fluids, or if it is severe, giving IV fluids. If nausea and vomiting are caused by a brain tumor, radiation may be used to shrink the tumor and reduce symptoms. Any underlying problems with the liver or kidney will be corrected when possible. All the medicines that the patient is taking will be looked at to see if they might be making the problem worse. For instance, opioid drugs used to treat pain can cause nausea and vomiting. If this is the case, a different opioid drug or a different dose can be tried. Sometimes the offending drug can be stopped altogether.

Palliative care: Nausea and vomiting

Reassessment



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A psychiatric evaluation may be helpful if the patient has an underlying eating disorder, phobia, or panic disorder.

If no underlying cause can be found, medicines (anti-emetics) are given to treat the nausea and vomiting as symptoms. These drugs are usually given by mouth, but if the nausea and vomiting is too severe, the drugs may be given as IV (intravenous), as an injection under the skin (subcutaneous or SQ), or

as a rectal suppository. Steroids can be given by mouth if the nausea and vomiting is related to brain cancer or tumor blocking the stomach.

If the nausea and vomiting stops, the cancer care team will keep re-checking to make sure that the treatment is still working. If nausea and vomiting persist, additional treatment is required, as described in the next Decision Tree.

Symptom

Treatment

Persistent
nausea and
vomiting



Your doctor or cancer care team will:

- Treat you with a 5-HT3 antagonist (such as ondansetron or Zofran®) with or without an anticholinergic, with or without an antihistamine.

If nausea and vomiting persists:

- Treat you with a corticosteroid.

If nausea and vomiting persists:

- Consider using IV or subcutaneous injection anti-nausea medicine.

If nausea and vomiting persists:

- Consider other therapies, including other medicines, sedation, or acupuncture

Persistent nausea and vomiting

Persistent nausea and vomiting is treated by adding treatments until symptoms are relieved.

In the first step any combination of 3 classes of drugs may be used:

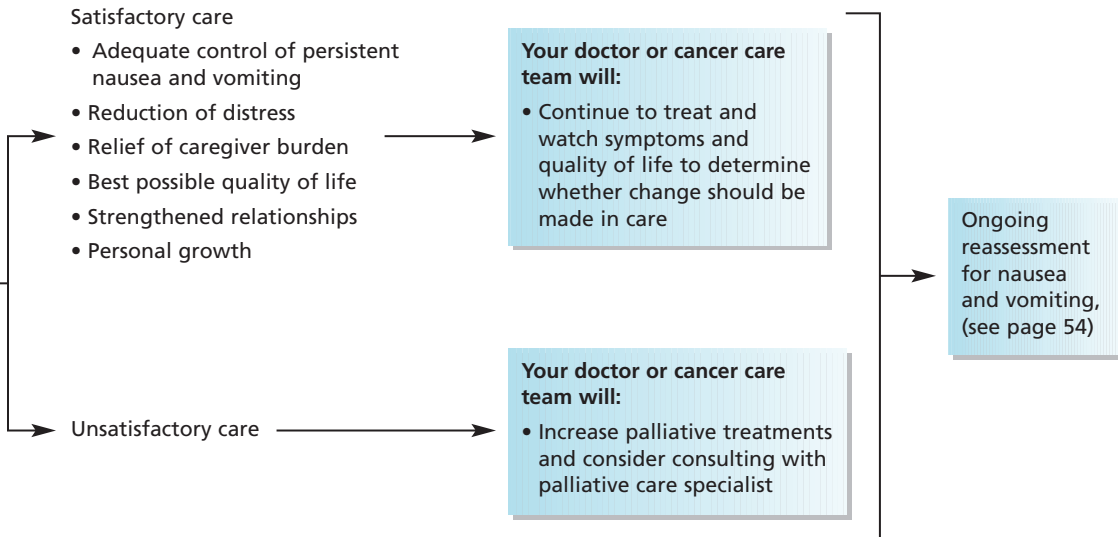
- 5-HT3 antagonists (newer drugs such as ondansetron or Zofran®, commonly used to control nausea from chemotherapy)
- anticholinergics (older drugs such as scopolamine that are often used for motion sickness or intestinal cramps)

- antihistamines (intended for allergies, but sometimes used to treat vertigo or improve appetite).

If the response is not good, oral steroids may be added. If the symptoms are still not controlled, different routes for the medicines will be considered, such as intravenous (IV) or subcutaneous injection (a “shot”). Finally, other measures such as cannabinoids (which are compounds found in marijuana that are used to improve appetite) or sedation (giving medicines to make the patient sleep most of

Persistent nausea and vomiting

Reassessment

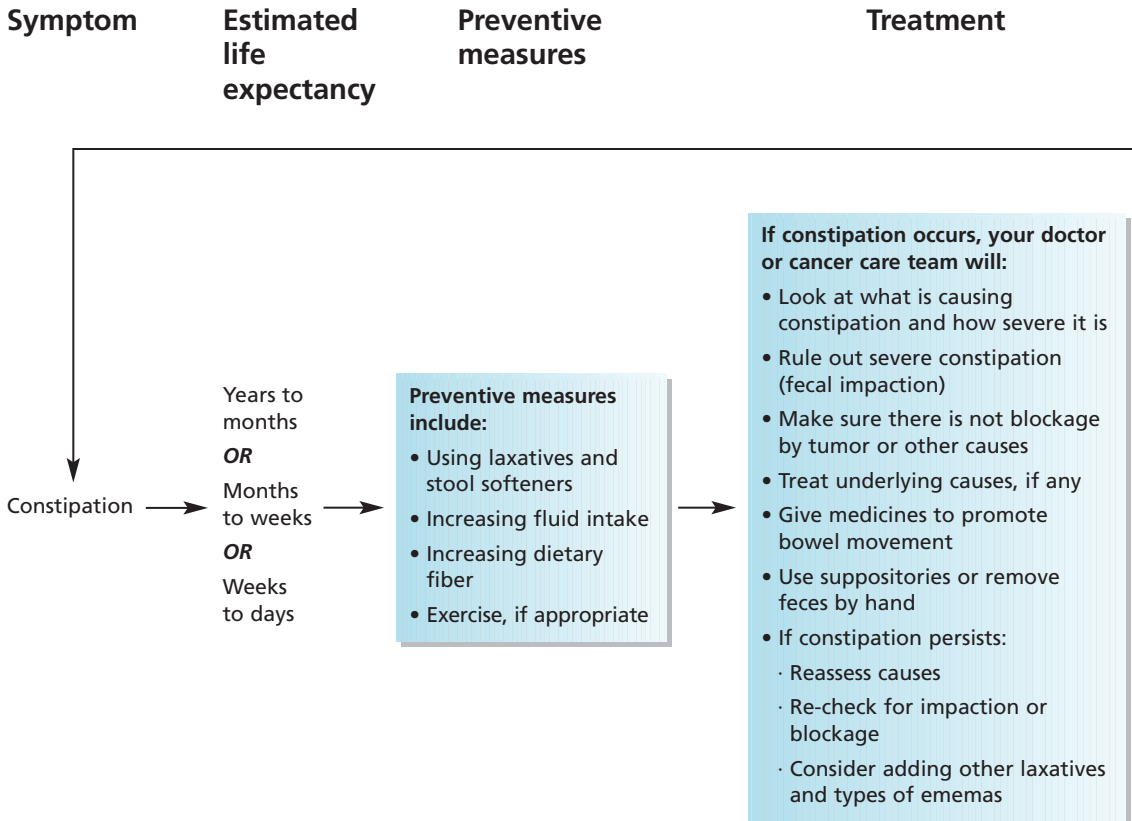


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the time) may be added. Alternative treatments such as acupuncture may also be tried.

Once these symptom management treatments are in place, the cancer care team will check to find out whether the patient's personal goals are being met. Satisfactory care provides adequate control of nausea and vomiting, does not prolong dying, promotes a sense of control for the patient, helps relieve caregiver

burden, and strengthens patient and family relationships. If the care is satisfactory, it will be continued. If the care is not satisfactory, it will be changed. The cancer care team may talk with the pain management or palliative care team for help in making changes in care. They may refer the patient for specialized palliative care services or for hospice.



Palliative care: Constipation

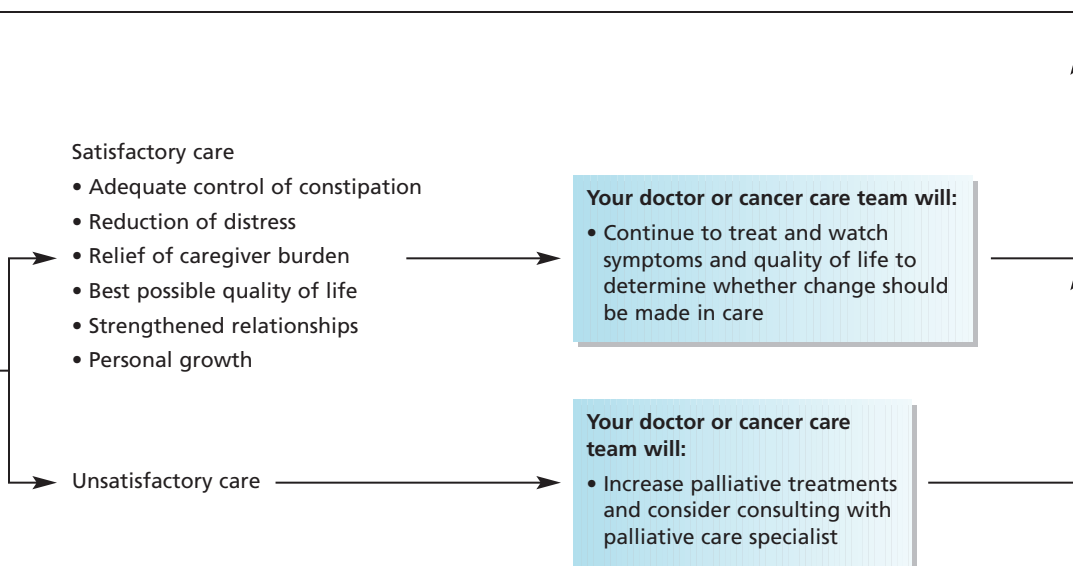
The evaluation and treatment of constipation is the same regardless of the life expectancy. Measures can be looked at as either preventing or treating constipation. Because many of the drugs that are used to treat pain are known to cause constipation, preventive treatments such as stool softeners and laxatives are usually started at the same time these medicines are started. Taking in enough fluid is important because dehydration worsens constipation.

Getting enough fiber is also helpful to increase stool bulk. Finally, an exercise program is recommended if the patient is able. The goal of these measures is for the patient to have one unforced bowel movement every day or two.

If constipation does occur, the first step is to search for and treat any underlying cause. This may involve x-rays to make sure that the intestine is not blocked by cancer or other conditions. A fecal impaction is a severe form of constipation where there is a mass of hard

Palliative care: Constipation

Reassessment

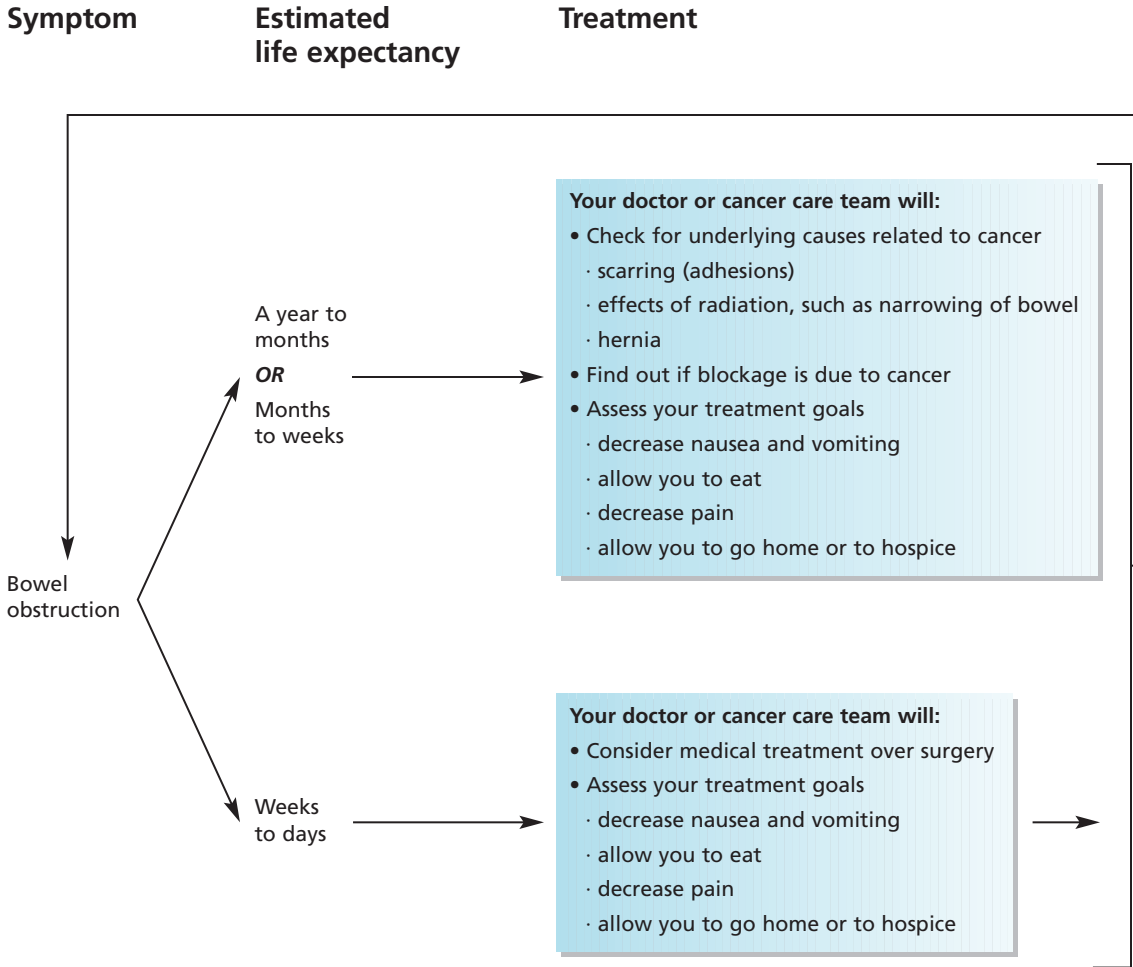


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stool blocking the rectum. Fecal impaction may require enemas or removal of the stool by hand. If constipation persists, other laxatives, enemas, or agents may be recommended.

Once this symptoms is treated, the cancer care team will determine whether the patient's personal goals are being met. Satisfactory care provides adequate control of constipation, does not prolong dying, promotes a sense of

control for the patient, helps relieve caregiver burden, and strengthens patient and family relationships. If the care is satisfactory, it will be continued. If the care is not satisfactory, it will be changed. The cancer care team may talk with the pain management or palliative care team for help in making changes in care. They may refer the patient to the team for specialized palliative care services.



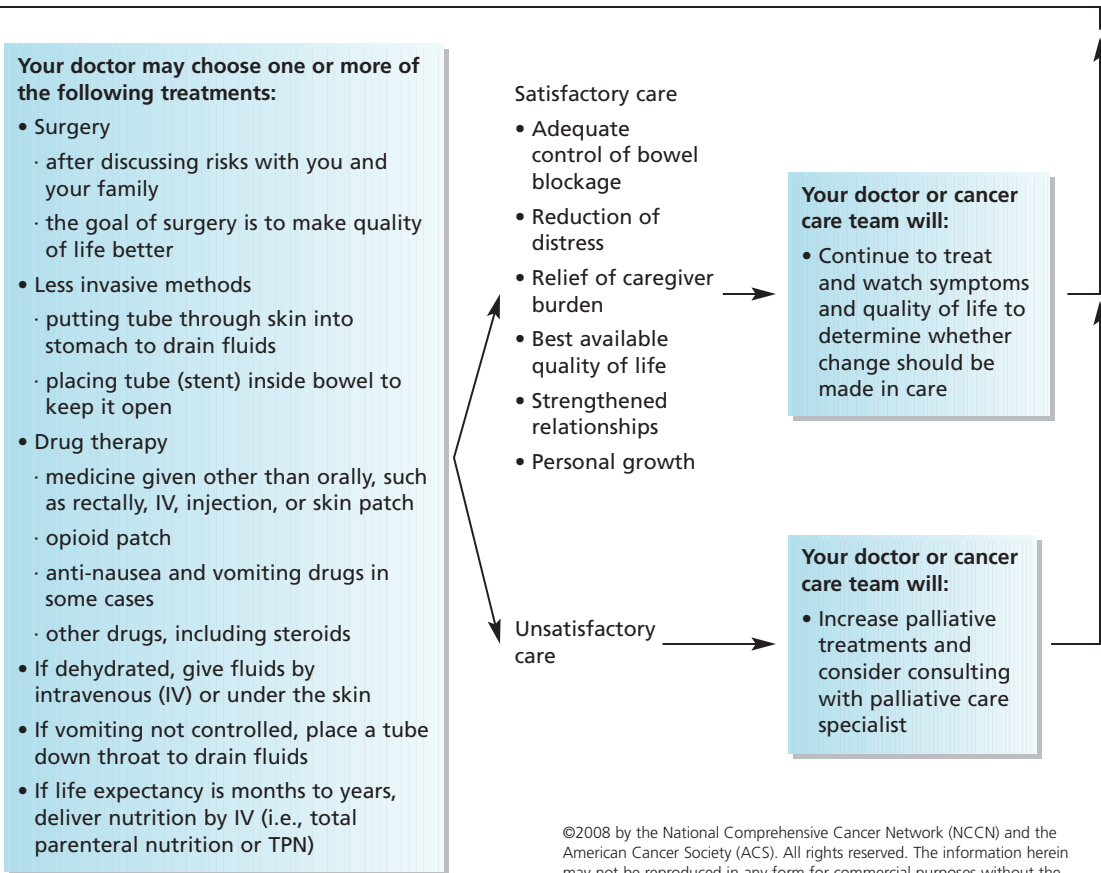
Palliative care: Bowel blockage (obstruction)

Years to months/months to weeks: The first evaluation of a blocked bowel (also called malignant bowel obstruction) focuses on finding causes that can be treated. Prior radiation therapy or even a hernia can cause

scarring or tightening that can block the intestine. Blockage can also be caused by the underlying cancer, which can block the intestine from the inside, or press on it from the outside. The intestine may be partly or completely blocked, but it sometimes starts out partly blocked and slowly gets worse.

Palliative care: Bowel blockage (obstruction)

Reassessment



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Once the cause of the blockage is found, the main concern is whether or not it should be treated with surgery. This decision will be made in light of the other symptoms and the patient's goals and wishes. For example, bowel obstruction may be causing nausea and vomiting or inability to eat. It may be the reason

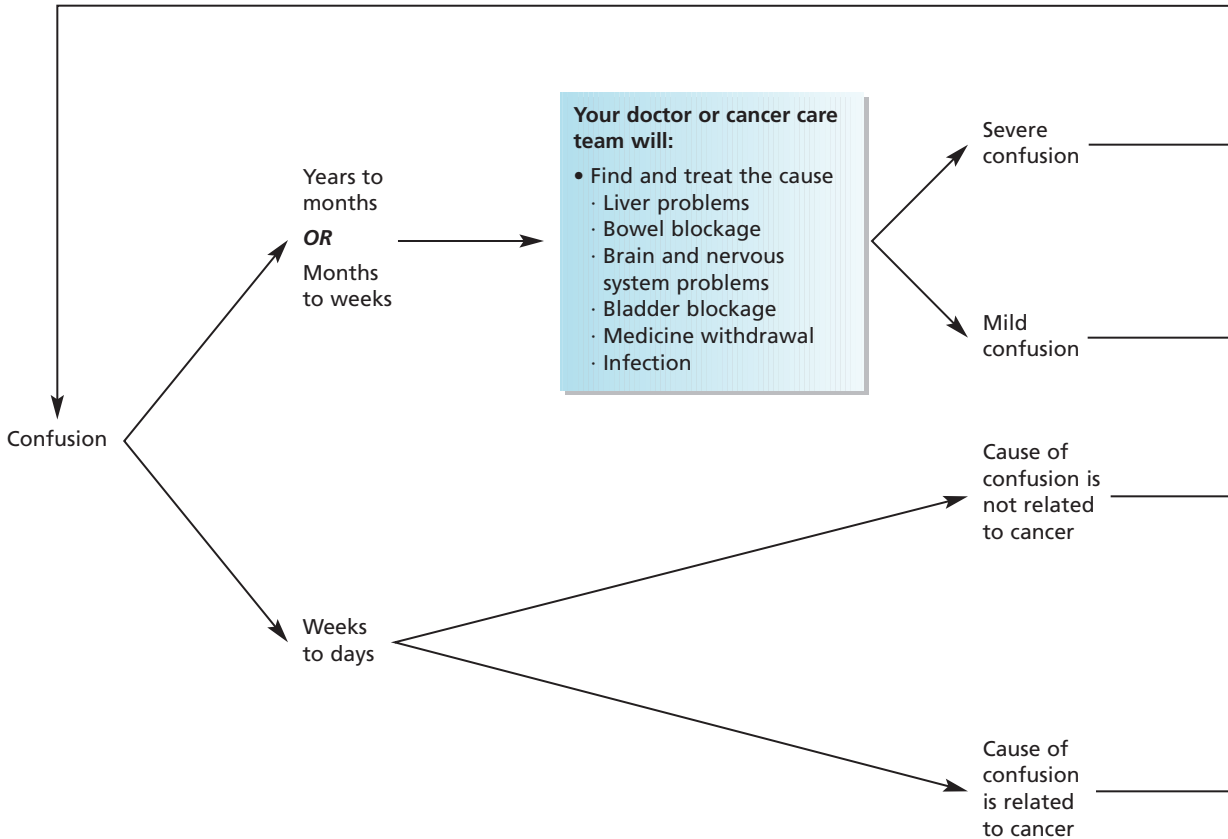
the patient is hospitalized. Treating the blockage may ease these symptoms and allow the patient to go home or back to hospice care.

Besides surgery, there are less invasive ways to help relieve symptoms. A tube can be placed through the skin into the stomach to drain out fluids that cause vomiting. Fluids

Symptom

Estimated life expectancy

Treatment



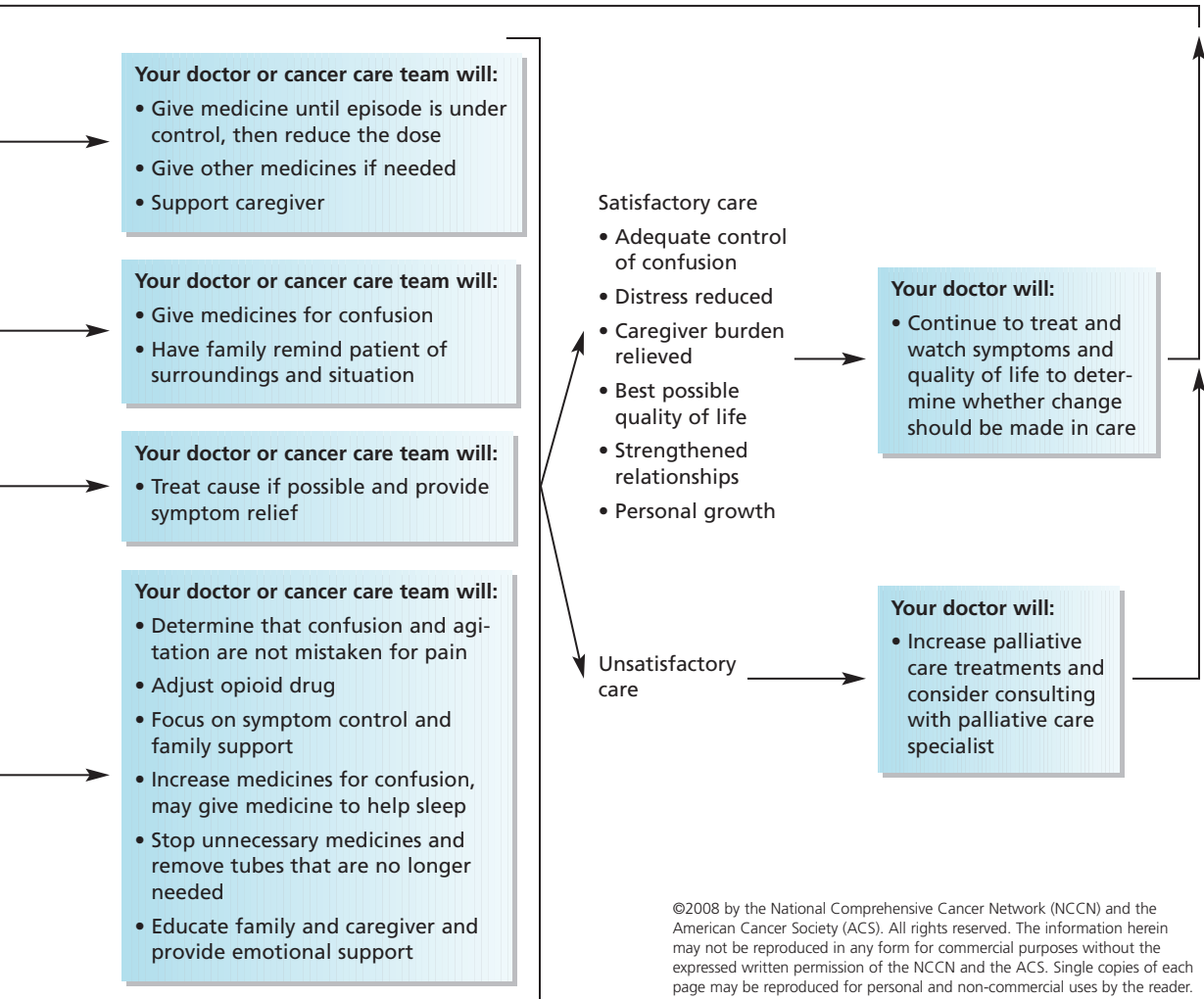
Palliative care: Confusion

A year to months and months to weeks: The doctor or cancer care team will first look at what might be causing the confusion in order to treat it. Sometimes confusion is caused by another problem in the body. Confusion will often improve when the other problem is treated. Infection, blood chemistry imbal-

ances, and blockage of the bladder or bowel are examples of problems that can make a person confused. If the confusion is severe, a neuroleptic drug may be used until the patient’s symptoms are under control. (Neuroleptic drugs, sometimes called “major tranquilizers,” are often used to help people who have lost touch with reality.) An anti-

Palliative care: Confusion

Reassessment

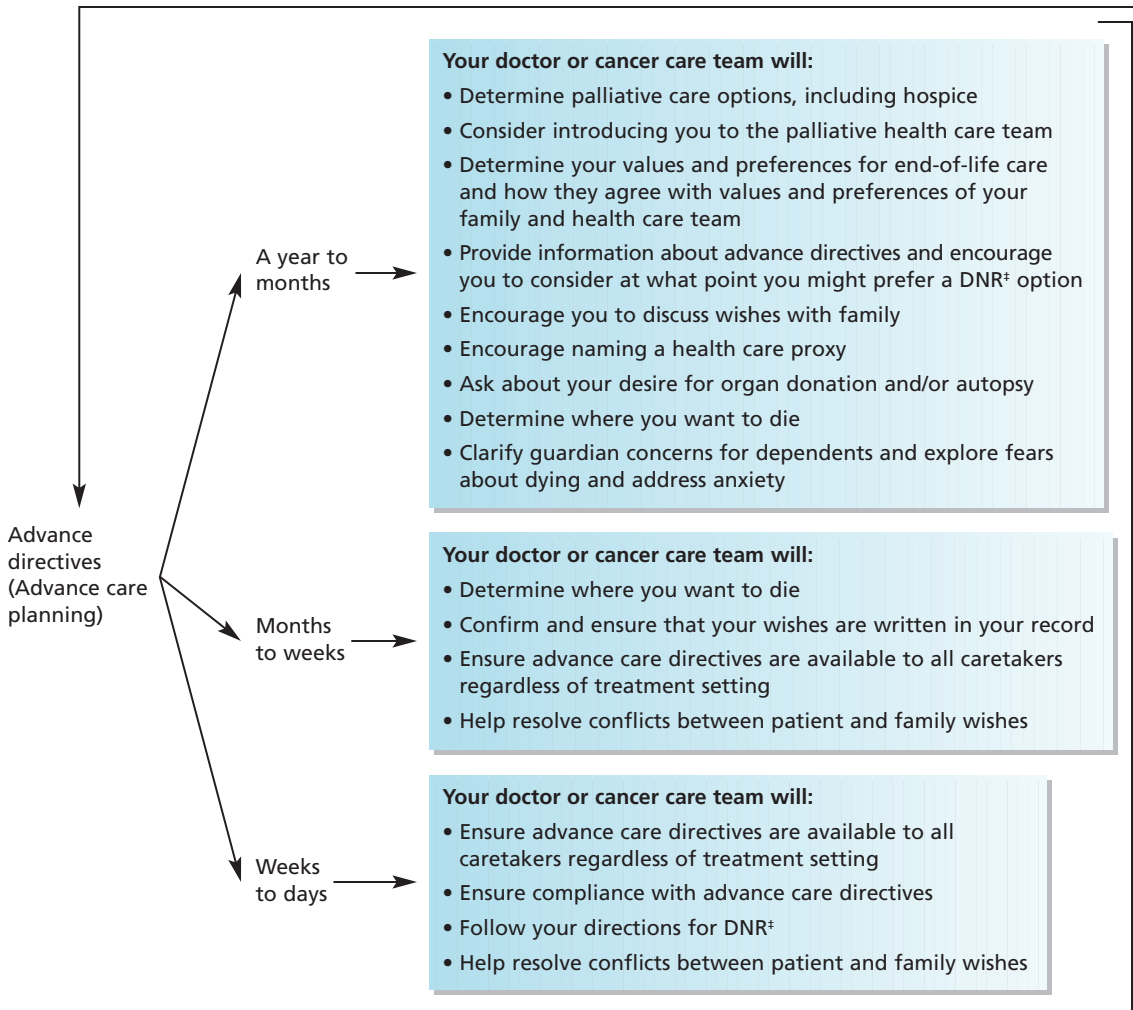


anxiety medicine may be added if the patient is agitated. If the confusion is mild, the anti-anxiety drug is not usually needed. With mild confusion, it helps for the family to be present

and remind the patient often about things he or she forgets, such as where they are and what's going on.

Estimated life expectancy

Treatment



Palliative care: Advance directives (advance care planning)

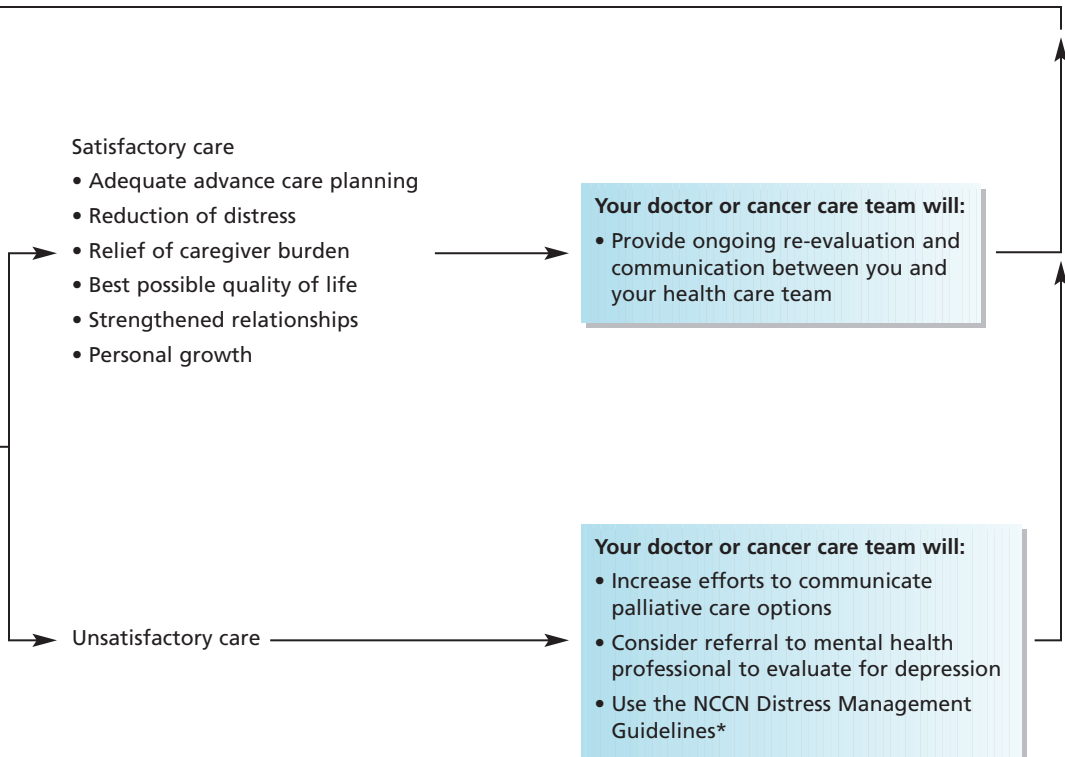
Advance care plans are developed by the patients, and are discussed on page 12. Examples of advance directives include a

living will, health care power of attorney, CPR preference, and readiness for hospice or special palliative care.

A year to months: Advance care planning in patients with months to a year to live

Palliative care: Advance directives (advance care planning)

Reassessment



‡ DNR = “do not resuscitate,” a decision not to do CPR

* The guideline for your doctor is available at www.nccn.org. A free copy of the patient version is available by calling 1-800-ACS-2345.

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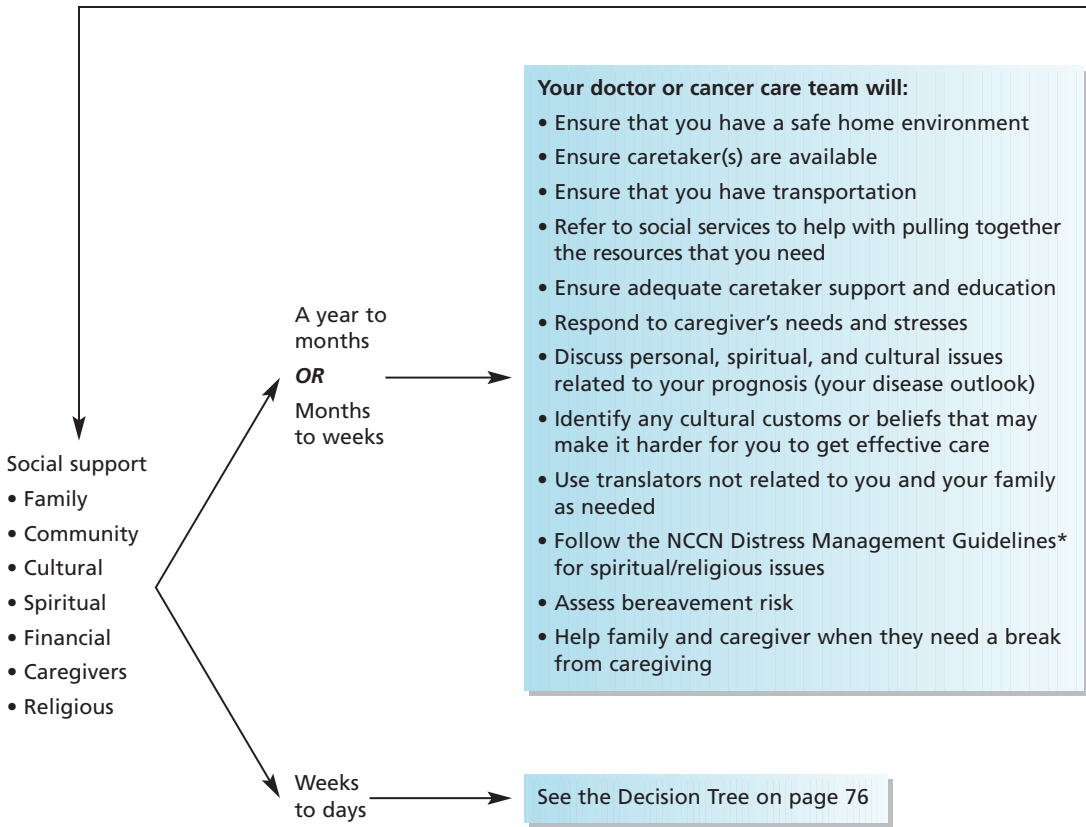
should include an open discussion of the option of palliative care, how the patient feels about palliative care, and the patient’s values and preferences for end-of-life care. The cancer care team will compare the patient’s requests with those of the family and members of the cancer care team.

They will discuss with the patient what advance directives are and ask the patient to think about whether resuscitation is desired. Where the patient wishes to die – at home or in a hospital – should be decided and made known. The patient will be asked for the name of the person who will serve as the

Issue

**Estimated
life expectancy**

Treatment



Your doctor or cancer care team will:

- Ensure that you have a safe home environment
- Ensure caretaker(s) are available
- Ensure that you have transportation
- Refer to social services to help with pulling together the resources that you need
- Ensure adequate caretaker support and education
- Respond to caregiver’s needs and stresses
- Discuss personal, spiritual, and cultural issues related to your prognosis (your disease outlook)
- Identify any cultural customs or beliefs that may make it harder for you to get effective care
- Use translators not related to you and your family as needed
- Follow the NCCN Distress Management Guidelines* for spiritual/religious issues
- Assess bereavement risk
- Help family and caregiver when they need a break from caregiving

See the Decision Tree on page 76

Palliative care: Social support

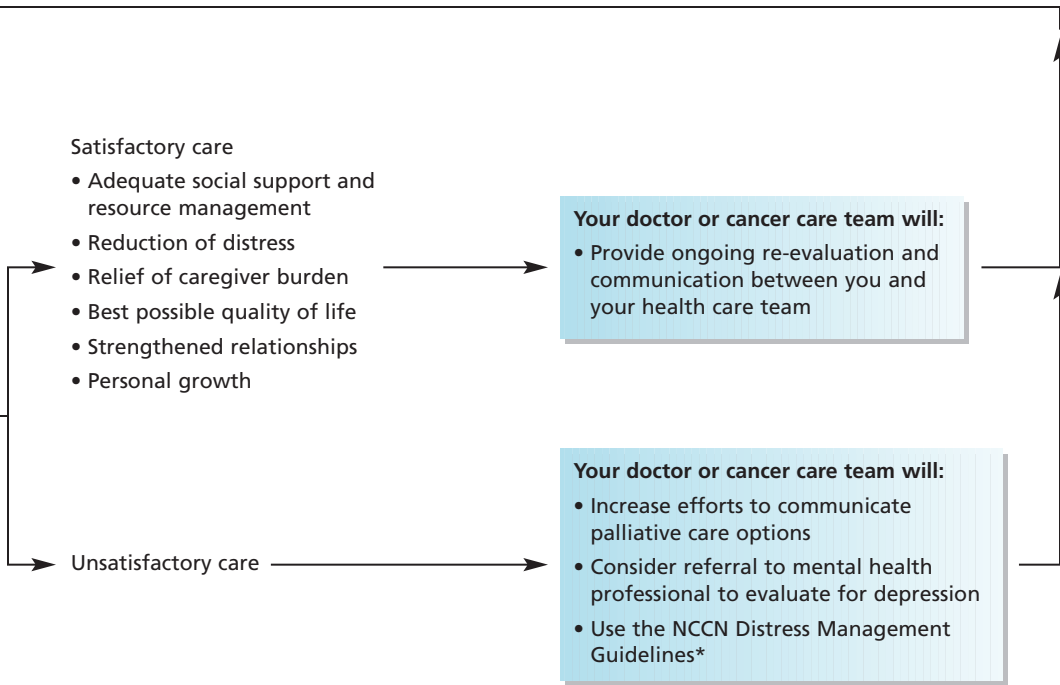
Social support includes support from one’s family and community, religious or spiritual support, and support from one’s culture. Patients define who their support system is. Each person may turn to all or just one of these for their support.

A year to months or months to weeks:

During this time, the doctor or cancer care team will ensure that the patient has a safe home environment and that a caretaker (or caregiver) is available to help the patient. They will also see that transportation is available for hospital or doctor visits. Financial resources

Palliative care: Social support

Reassessment



* The guideline for your doctor is available at www.nccn.org. A free copy of the patient version is available by calling 1-800-ACS-2345.

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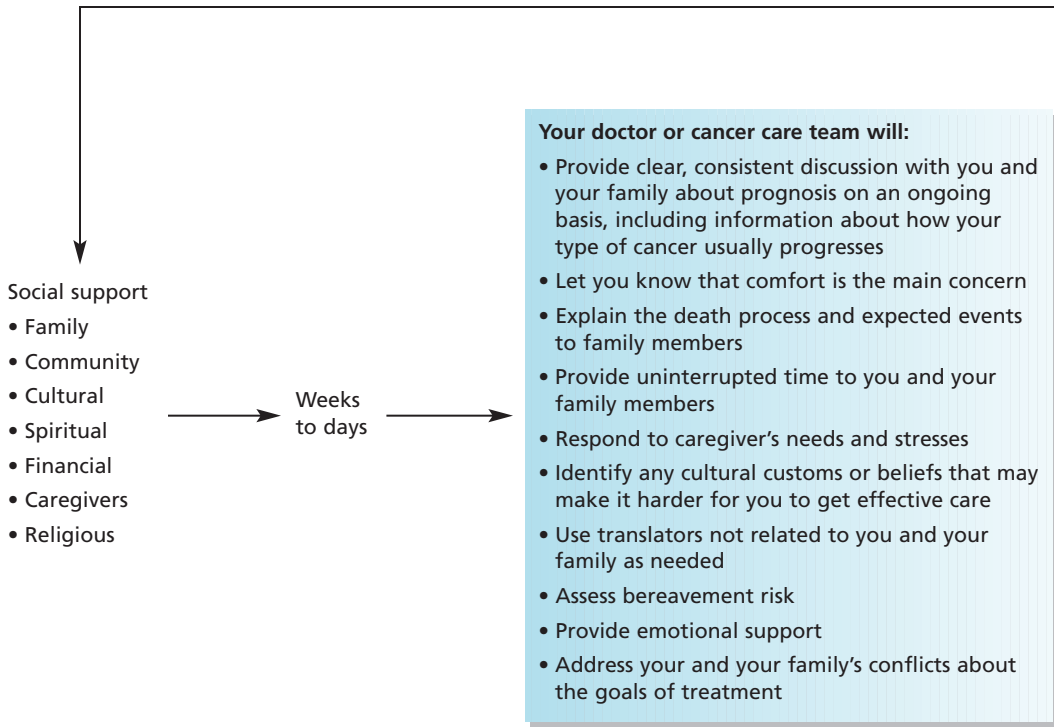
will be identified and social services will be asked to help pull together resources the patient may need. Since the caregiver will have a lot of responsibility, they will see to it that this person has the support and education needed to provide good care. The team will be available to help the caregiver's needs and

stresses, and help the caregiver identify ways to get a break from caregiving (called respite care) if that is needed. The patient's personal, spiritual, and cultural needs and wishes will be reviewed and discussed. The team will look at the caregivers' and family's ability to cope with grief, and identify any factors that

Issue

Estimated life expectancy

Treatment

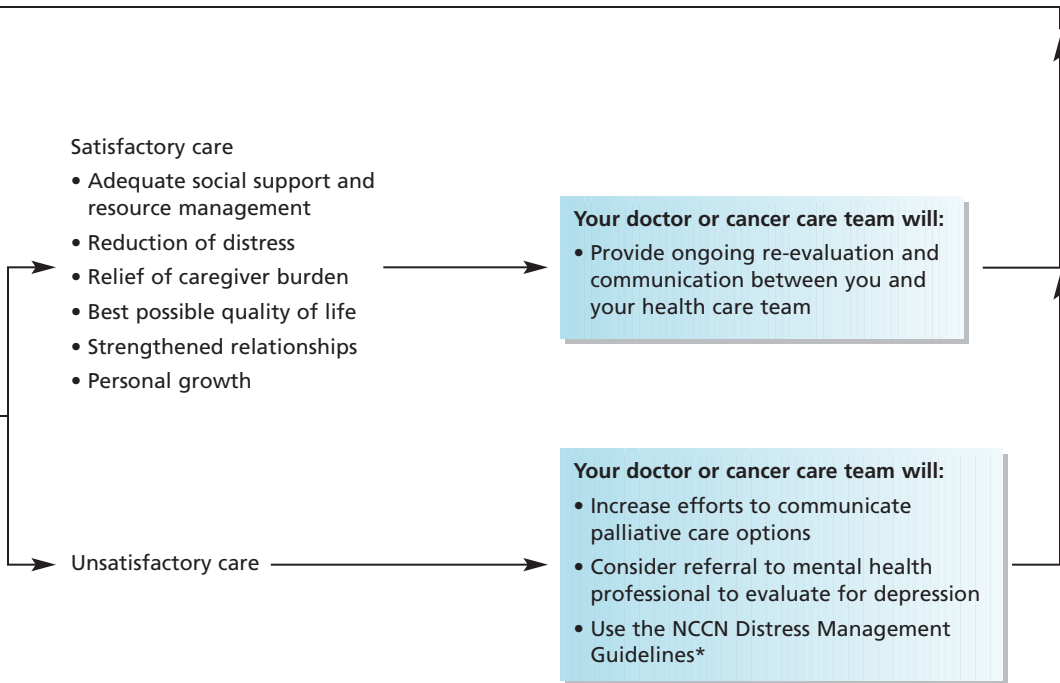


Weeks to days: Here the doctor or cancer care team will have a clear discussion with the patient and family about prognosis (outlook for survival) on an ongoing basis, including information on what to expect with the cancer. They will let the patient know that keeping him or her comfortable is the main concern. They will explain what usually happens during the dying process, including

expected events, to family members. The cancer care team may need to get help to resolve any remaining conflicts between the patient and family about the goals of treatment. Time will be given for the patient and family to be together without interruption. Respect will be given to any cultural customs or beliefs that might require changes in the patient’s care.

Palliative care: Social support (continued)

Reassessment



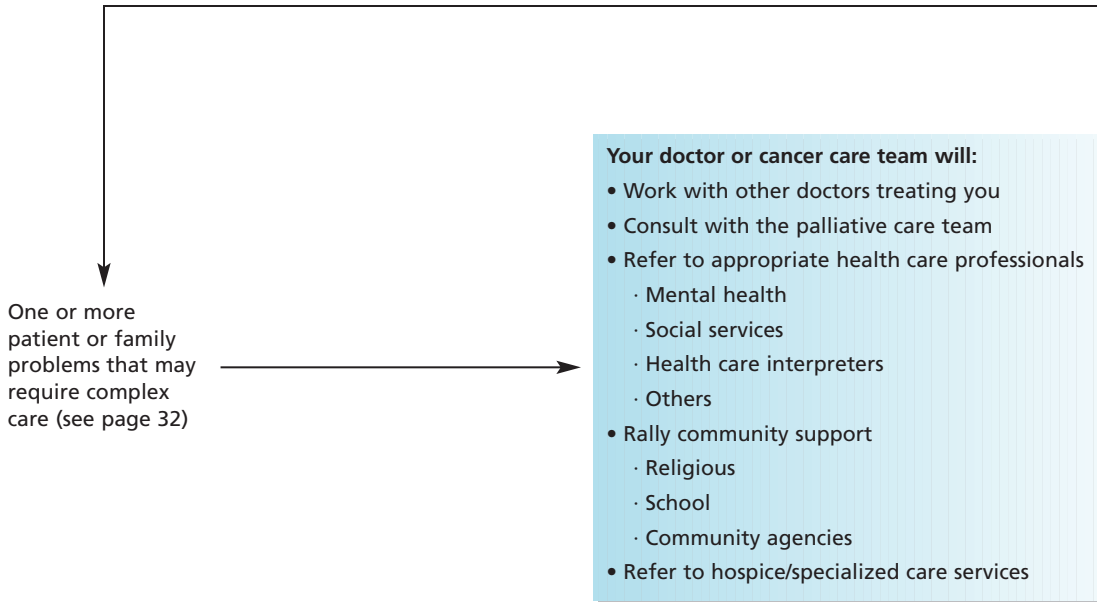
* The guideline for your doctor is available at www.nccn.org. A free copy of the patient version is available by calling 1-800-ACS-2345.

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Once these measures are in place, the doctor or cancer care team will determine whether the patient's personal goals are being met. If the care is satisfactory, the doctor will provide an ongoing evaluation and communication between the patient and cancer care team. If the care is not satisfactory, it

will be changed. The cancer care team will increase efforts to talk with the patient and family about palliative care options. They may consider referring the patient to mental health professionals to determine if the patient is depressed. The NCCN Guidelines on Distress Management may also be helpful.

Treatment

**Palliative care: Complex care**

Some patients might need more complex palliative care earlier in their treatment, as identified by the risk factors listed on page 32.

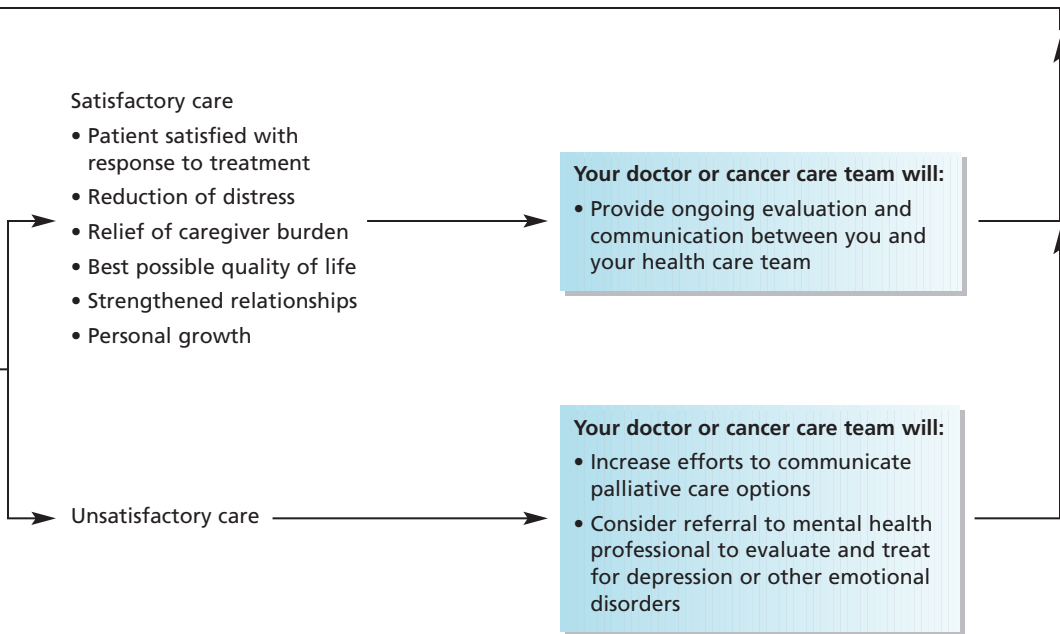
The doctor or cancer care team will work with others and refer to health care professionals as needed for palliative care, mental health services, social services, health care services, and interpreters, if needed. Religious,

school, and community groups will be rallied to support the patient and family with any problems that have been identified. Hospice or specialized palliative care services will be requested.

Once these measures are in place, the doctor or cancer care team will look to see whether the patient's personal goals are being met. If the care is satisfactory, the doctor and

Palliative care: Complex care

Reassessment



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health care team will continue to evaluate it, communicating with the patient and family about what is happening. If the care is not satisfactory, it will be changed. The cancer care team will increase efforts to talk with the

patient and family about palliative care options. They may consider referring the patient to a mental health professional to evaluate for and treat depression, trouble adjusting to the cancer diagnosis, or other emotional disorders.

Treatment

Final days
and hours



Your doctor or cancer care team will:

- Watch you closely
- Provide a private room, if possible
- Stop diagnostic tests
- Turn you for comfort when needed
- Avoid unnecessary needle sticks
- Keep your mouth clean and moist
- Watch for severe constipation and no urine output
- Make sure medicine can be given ways other than by mouth
- Allow you and your family time together
- Ensure that your family understands the dying process and knows what to expect
- Provide support to children and grandchildren
- Encourage visits by children if consistent with family values
- Help family to be present around-the-clock
- Ensure that caregivers and family understand and will honor your advance directives
- Provide respectful space for family members
- Make sure that “good-bye’s” are said
- Consider sedation to relieve uncontrolled symptoms

Palliative care: Specialized care during the final days to hours

During the final days to hours, the doctor and cancer care team will focus on patient and family comfort. They will help the family and caregivers by doing the things listed in the Decision Tree above.

The care team will also help the family and caregivers to be sure that you can get any medicines you need (for pain or symptom

relief) in other ways than by mouth. This becomes more important as the end nears and you are less able to swallow pills or liquids. In the event that symptoms such as pain or vomiting cannot be controlled with medicines, measures such as sedation can be considered. If you are in the hospital, the care team may try to get you into a private room, and help your family find a separate space to express their grief privately.

Palliative care: Specialized care during the final days to hours

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NOTES

Care for family and caregiver

A “good” death

- Free from distress and suffering for patient, family, and caregivers
- Has met patient and family’s wishes
- Was consistent with clinical, cultural, and ethical standards



Your doctor or cancer care team will:

- Provide immediate support
 - Remove IV’s catheters, and implanted devices
 - Provide for the family’s cultural needs regarding care of the body
 - Allow family time with the body
 - Address concerns regarding organ donation or autopsy
 - Assist in notifying other health care providers
- Provide support with grieving
 - Identify the available support to help family and caregivers with grieving
 - Help identify community grief and bereavement resources
 - Look for help for family or caregivers who are having trouble coping with death
- Attend debriefing meeting with family, if family wants one
- Discuss cancer risk with other family members

Palliative care: Care for the family and caregivers after death

Palliative care for the patient’s family and caregivers continues after the patient’s death. Immediate issues include making sure that the body is treated in a sensitive and respectful way that takes any special cultural needs

into consideration. Other needs include making sure that the family has time with the body, making funeral arrangements, completing all paperwork, and notifying all the necessary insurance companies and health care professionals.

Palliative care: Care for the family and caregivers after death

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Grief is a normal part of bereavement but family members should be watched for signs of grieving that may not be normal. This should be identified and treated. The family may request a meeting (debriefing) with the doctor or cancer care team to help them understand everything that happened. They

may need help finding grieving resources in their community. This care is usually best provided by hospice staff or an experienced mental health professional.

Finally, the doctor may want to discuss cancer risk in other family members and outline steps that can be taken to reduce this risk.

Current cancer treatment guidelines for patients

Advanced Cancer and Palliative Care Treatment Guidelines for Patients
(English and Spanish)

Bladder Cancer Treatment Guidelines for Patients (English and Spanish)

Breast Cancer Treatment Guidelines for Patients (English and Spanish)

Cancer Pain Treatment Guidelines for Patients (English and Spanish)

Cancer-Related Fatigue and Anemia Treatment Guidelines for Patients
(English and Spanish)

Colon and Rectal Cancer Treatment Guidelines for Patients (English and Spanish)

Distress Treatment Guidelines for Patients (English and Spanish)

Fever and Neutropenia Treatment Guidelines for Patients with Cancer
(English and Spanish)

Lung Cancer Treatment Guidelines for Patients (English and Spanish)

Melanoma Cancer Treatment Guidelines for Patients (English and Spanish)

Nausea and Vomiting Treatment Guidelines for Patients with Cancer
(English and Spanish)

Non-Hodgkin's Lymphoma Treatment Guidelines for Patients (English and Spanish)

Ovarian Cancer Treatment Guidelines for Patients (English and Spanish)

Prostate Cancer Treatment Guidelines for Patients (English and Spanish)

The *Advanced Cancer and Palliative Care Treatment Guidelines for Patients* were developed by a diverse group of experts and were based on the NCCN clinical practice guidelines. These patient guidelines were translated, reviewed, and published with help from the following individuals.

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