

Coping With Advanced Cancer



For more information . . .

This booklet is only one of many free booklets for people with cancer. Here are some others you and your loved ones may find useful:

- *Chemotherapy and You*
- *Eating Hints for Cancer Patients*
- *Taking Part in Cancer Treatment Research Studies*
- *Pain Control*
- *Radiation Therapy and You*
- *Taking Time: Support for People With Cancer*
- *Thinking About Complementary and Alternative Medicine: A Guide for People With Cancer*
- *When Your Parent Has Cancer: A Guide for Teens*
- *When Someone You Love Is Being Treated for Cancer: Support for Caregivers*
- *When Someone You Love Has Advanced Cancer: Support for Caregivers*

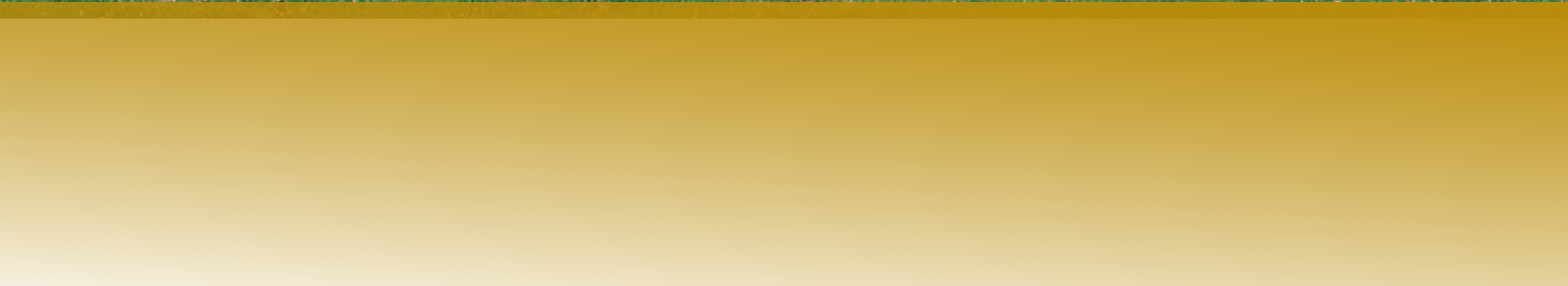
These booklets are available online from the National Cancer Institute (NCI). To learn more about the specific type of cancer you have or to request any of these booklets, visit NCI's website (<http://www.cancer.gov>). You can also call NCI's Cancer Information Service at 1-800-4-CANCER (1-800-422-6237) to speak with an information specialist.

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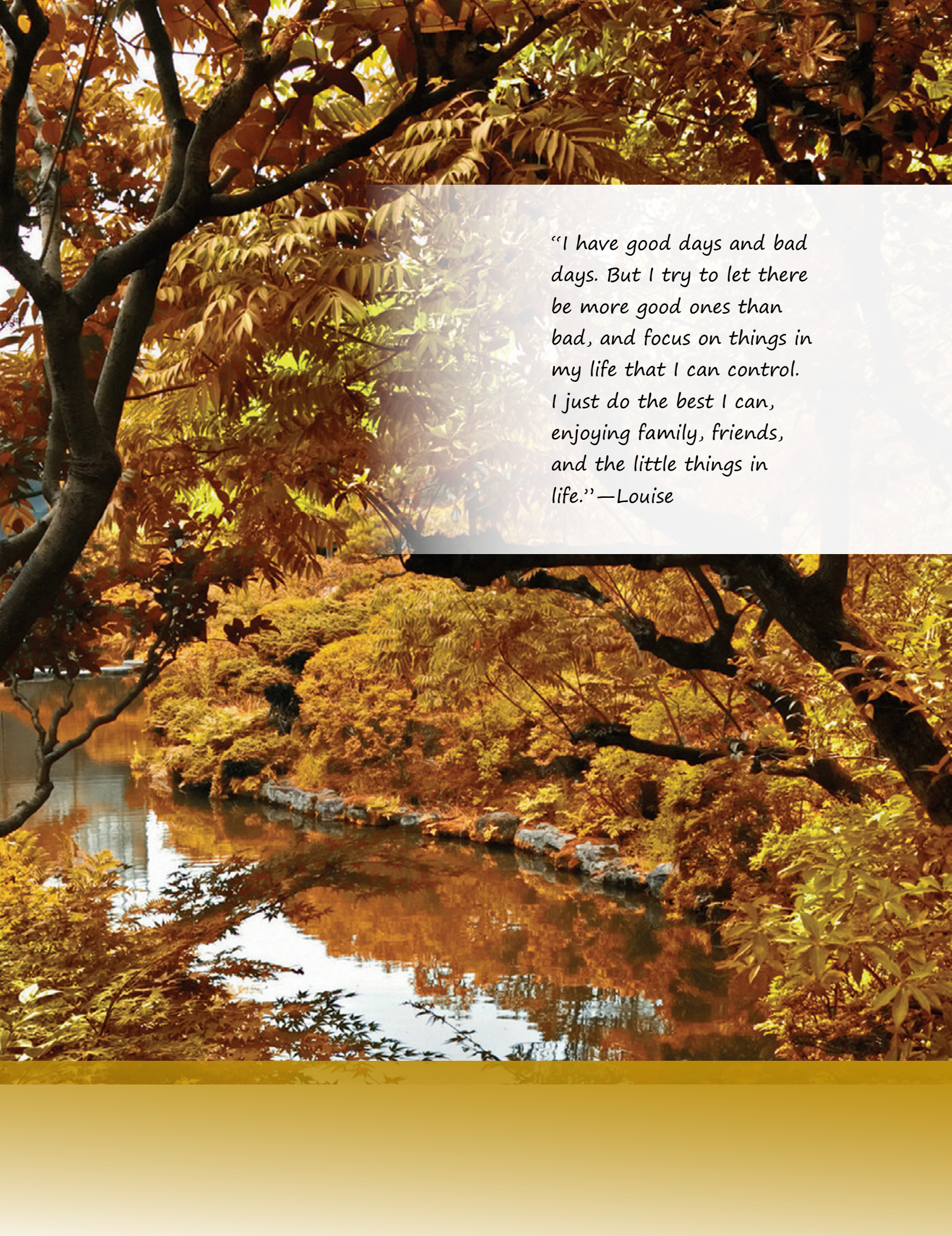
“What lies behind us
and what lies before us
are tiny matters
compared to what lies
within us.”

—*Ralph Waldo Emerson*



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“I have good days and bad days. But I try to let there be more good ones than bad, and focus on things in my life that I can control. I just do the best I can, enjoying family, friends, and the little things in life.”—Louise

About This Booklet

You've struggled with the **diagnosis**, treatment, and maybe the **recurrence** of cancer. Now doctors may have told you that you have **advanced cancer**. They may have said that your cancer is not responding to treatment and that long-term **remission** is no longer likely. Or they may have said they have run out of **standard treatment** options. However you learn the news, it can be devastating to you and your loved ones. Often it's hard to believe or accept at first.

Having advanced cancer can bring anxiety and uncertainty to your life. But some people with advanced cancer live far longer than expected. And remember, you are still in control of your choices and actions. Having an advanced disease can be a time of personal growth. It can even be a time of second chances. Many people say they started to see life in a new way after learning that their cancer had progressed despite treatment. They realized the importance of making the most of each day.

This booklet stresses four main points:

- Learning more about ways you can help yourself may ease some of your concerns.
- Your treatment may change, but as always, you deserve to ask for and receive good medical attention from your health care team and support from your caregivers.
- It's important to talk about your worries, frustrations, and problems, and get support from others. In fact, it may be one of the best things you can do for yourself.
- As your medical care changes, you still have many choices. You can choose the way you wish to live each day.

"There are lots of things I still want to do, but I know that I may not be able to do them the way I planned. But that doesn't stop me from trying to achieve them in a different way." —Millie

Reading This Booklet

No two people are alike. Some chapters of this booklet may apply to you, while others may not. Or some may be more useful later on. As you read this booklet, choose the parts that are right for you. Share it with your family members and loved ones. They may find it helpful to read it with you. Keep in mind that this booklet is for you, an adult with advanced cancer, and the people close to you. For other information for a parent or loved one of a child or young person with cancer, see the NCI booklet, *Young People With Cancer*. Your friends and family members may also want to see the NCI booklet, *When Someone You Love Has Advanced Cancer*.

Above all else, try to remember that you are still in charge of your life. It may be hard to do this with all that you are going through. You may have trouble coping with your feelings from time to time. Or you may be grieving that your life has gone a different way than you had hoped. It's natural to feel negative at times. You'll have ups and downs. We hope this booklet will help you. Our goal is to help you stay in control as much as you can, and make the rest of your life fulfilling and satisfying. You can still have hope and joy in your life, even as you cope with what lies ahead.

Making Choices About Care

People have different goals for care when dealing with advanced cancer. And your goals for care may be changing. Perhaps you had been hoping for a remission. Yet now you need to think more about controlling the spread or growth of the cancer. Your decisions about treatment will be very personal. You will want to seek the help of your loved ones and health care providers. But only you can decide what to do. Your desire to avoid future regrets should be measured against the positives and negatives of treatment.

Questions you may want to ask:

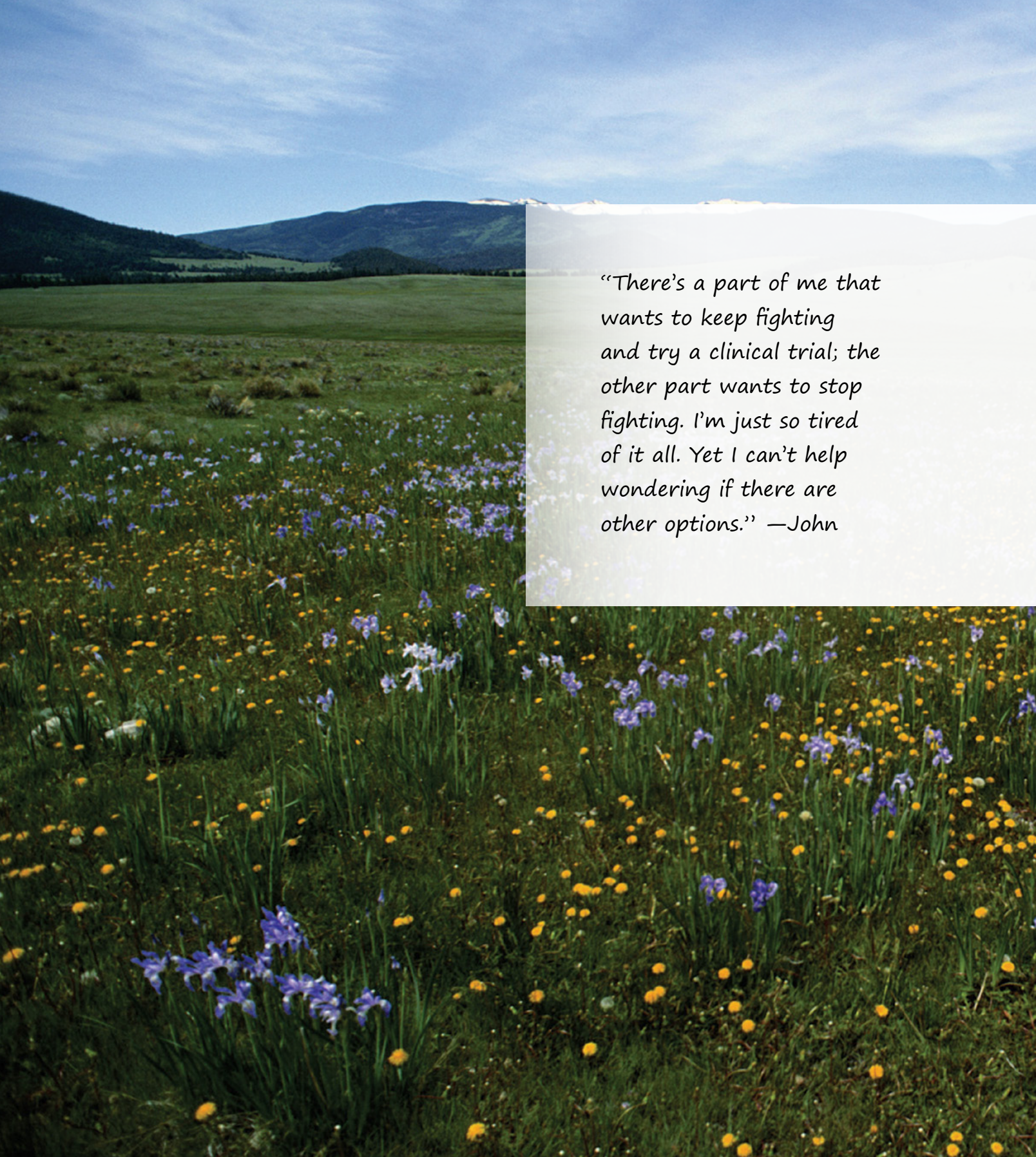
- What's the best we can hope for by trying another treatment? What is the goal?
- Is this treatment plan meant to help side effects, slow the spread of cancer, or both?
- Is there a chance that a new treatment will be found while we try the old one?
- What's the most likely result of trying this treatment?
- What are the possible side effects and other downsides of the treatment? How likely are they?
- Are the possible rewards bigger than the possible drawbacks?

It is important to ask your health care team what to expect in the future. It's also important to be clear with them about how much information you want to receive from them.

Comfort Care

You have a right to comfort care both during and after treatment. This kind of care is often called **palliative care**. It includes treating or preventing cancer symptoms and the side effects caused by treatment. Comfort care can also mean getting help with emotional and spiritual problems during and after cancer treatment. Sometimes patients don't want to tell the doctor about their symptoms. They only want to focus on the cancer. Yet you can improve your quality of life with comfort care.

People once thought of palliative care as a way to comfort those dying of cancer. Doctors now offer this care to all cancer patients, beginning when the cancer is diagnosed. You should receive palliative care through treatment, survival, and advanced disease. Your **oncologist** may be able to help you. But a palliative care specialist may be the best person to treat some problems. Ask your doctor or nurse if there is a specialist you can go to.



“There’s a part of me that wants to keep fighting and try a clinical trial; the other part wants to stop fighting. I’m just so tired of it all. Yet I can’t help wondering if there are other options.” —John

Your Choices

You have a number of options for your care. These depend on the type of cancer you have and the goals you have for your care. Your health care team should tell you about any procedures and treatments available, as well as the benefits and risks of those treatments.

Options include:

- Clinical trials
- Palliative radiation, chemotherapy, or surgery
- Hospice care
- Home care

Many patients choose more than one option. Ask all the questions you need to.

Try to base your decision on your own feelings about life and death, and the pros and cons of cancer treatment. If you choose not to receive any more active cancer treatment, it does not necessarily mean a quick decline and death. It also does not mean you will stop being given palliative care. Your health care team can offer information and advice on options. You also may want to talk about these options with family members and others who are close to you.


Clinical Trials

Treatment clinical trials are research studies that try to find better ways to treat cancer. Every day, cancer researchers learn more about treatment options from clinical trials. The different types of clinical trials are:

- **Phase 1** trials test how to give a drug, how often it should be given, and what dose is safe. Usually, only a small number of patients take part.
- **Phase 2** trials discover how cancer responds to a new drug treatment. More patients take part.
- **Phase 3** trials compare an accepted cancer treatment (standard treatment) with a new treatment that researchers hope is better. More treatment centers and patients take part.

If you decide to try a clinical trial, the trial you choose will depend on the type of cancer you have. It will also depend on the treatments you have already received. Each study has rules about who can take part. These rules may include the patient's age, health, and type of cancer. Clinical trials have both benefits and risks. Your doctor and the study doctors should tell you about these before you make any decisions.

Taking part in a clinical trial could help you and help others who get cancer in the future. But insurance and managed care plans do not always cover costs. What they cover varies by plan and by study. Talk with your health care team to learn more about coverage for clinical trials for your type of cancer.



“I know that just because I have stage-4 cancer doesn't mean I'm going to die tomorrow. My friend has lived a long time with her advanced cancer.” —Li

For more information about clinical trials, see NCI's booklet, *Taking Part in Cancer Treatment Research Studies*. Or talk to the NCI's Cancer Information Service at 1-800-422-6237 (1-800-4-CANCER).

Palliative Radiation, Chemotherapy, or Surgery

Some **palliative chemotherapy** and **palliative radiation** may help relieve pain and other symptoms. In this way, they may improve your quality of life, even if they don't stop your cancer. These treatments may be given to remove or shrink a **tumor**. Or they may be given to slow down a tumor's spread. **Palliative surgery** is sometimes used to relieve pain or other problems.

For more information, see the NCI booklets *Chemotherapy and You* and *Radiation Therapy and You*.



Hospice

Hospice care is an option if you feel you are no longer benefiting from cancer treatments. Choosing hospice care doesn't mean that you've given up. It just means the treatment goals are different at this point. It does not mean giving up hope, but rather changing what you hope for. But be sure to check with the hospice you use to learn what treatments and services are covered. Check with your insurance company also. The goal of hospice is to help patients live each day to the fullest by making them comfortable and lessen their symptoms. Hospice doctors, nurses, spiritual leaders, social workers, and volunteers are specially trained. They are dedicated to supporting their patients' and families' emotional, social, and spiritual needs, as well as dealing with patients' medical symptoms.

People usually qualify for hospice services when their doctor signs a statement that says that patients with their type and stage of disease, on average, aren't likely to survive beyond 6 months. Many people don't realize that they can use hospice services for a number of months, not just a few weeks. In fact, many say they wish they had gotten hospice care much sooner than they did. They were surprised by the expert care and understanding that they got. Often, control of symptoms not only improves quality of life but also helps people live longer. You will be reviewed periodically to see if hospice care is still right for you. Services may include:

- Doctor services
- Nursing care
- Medical supplies and equipment
- Drugs to manage cancer-related symptoms and pain

Hospice and Home Care

What to Expect With Hospice Care

You can get hospice services at home, in special facilities, in hospitals, and in nursing homes. They have specialists to help guide care. They also have nurses on call 24 hours a day in case you need advice. And they have many volunteers who help families care for their loved one. Some hospices will give palliative chemotherapy at home as well. Hospice care doesn't seek to treat cancer, but it does treat reversible problems with brief hospital stays if needed. An example might be pneumonia or a bladder infection.

Medicare, Medicaid, and most private insurers cover hospice services. For those without coverage and in financial need, many hospices provide care for free. To learn more about hospice care, call the National Hospice and Palliative Care Organization at 1-800-658-8898. Or visit their website at <http://www.nhpco.org>. The website can also help you find a hospice in your community.

Benefits of Hospice and Home Care

Hospice and home care professionals can help you and your family work through some tough emotional issues. A social worker can offer emotional support, help in planning hospice or home care, and ease the move between types of care. Many people prefer the comfort of their own home, familiar surroundings, and having friends and family members nearby. Getting health care at home gives family members, friends, and neighbors the chance to spend time with you and help with your care.

- Short-term in-patient care
- Homemaker and home health aide services
- Respite (relief) services for caregivers. This means someone else helps with care for awhile, so the caregiver can take a break
- Counseling
- Social work services
- Spiritual care
- Bereavement (grief) counseling and support
- Volunteer services

Home Care

Home care services are for people who are at home rather than in a hospital. Home care services may include:

- Monitoring care
- Managing symptoms
- Providing medical equipment
- Physical and other therapies

You may have to pay for home care services yourself. Check with your insurance company. Medicare, Medicaid, and private insurance will sometimes cover home care services when ordered by your doctor. But some rules apply. So talk to your social worker and other members of your health care team to find out more.

Talking With Your Health Care Team

As your disease advances, it's still important to give feedback to your doctor. That's the only way he or she can know what is working for you. Many people have a treatment team of health providers who work together to help them. This team may include doctors, nurses, **oncology social workers**, **dietitians**, and other **specialists**. They need to fully know your desires during treatment and at the end of your life. Let them know about any discomfort you have. You have a right to live your remaining days with dignity and peace of mind. So it's important to have a relationship and an understanding with those who will be caring for you.

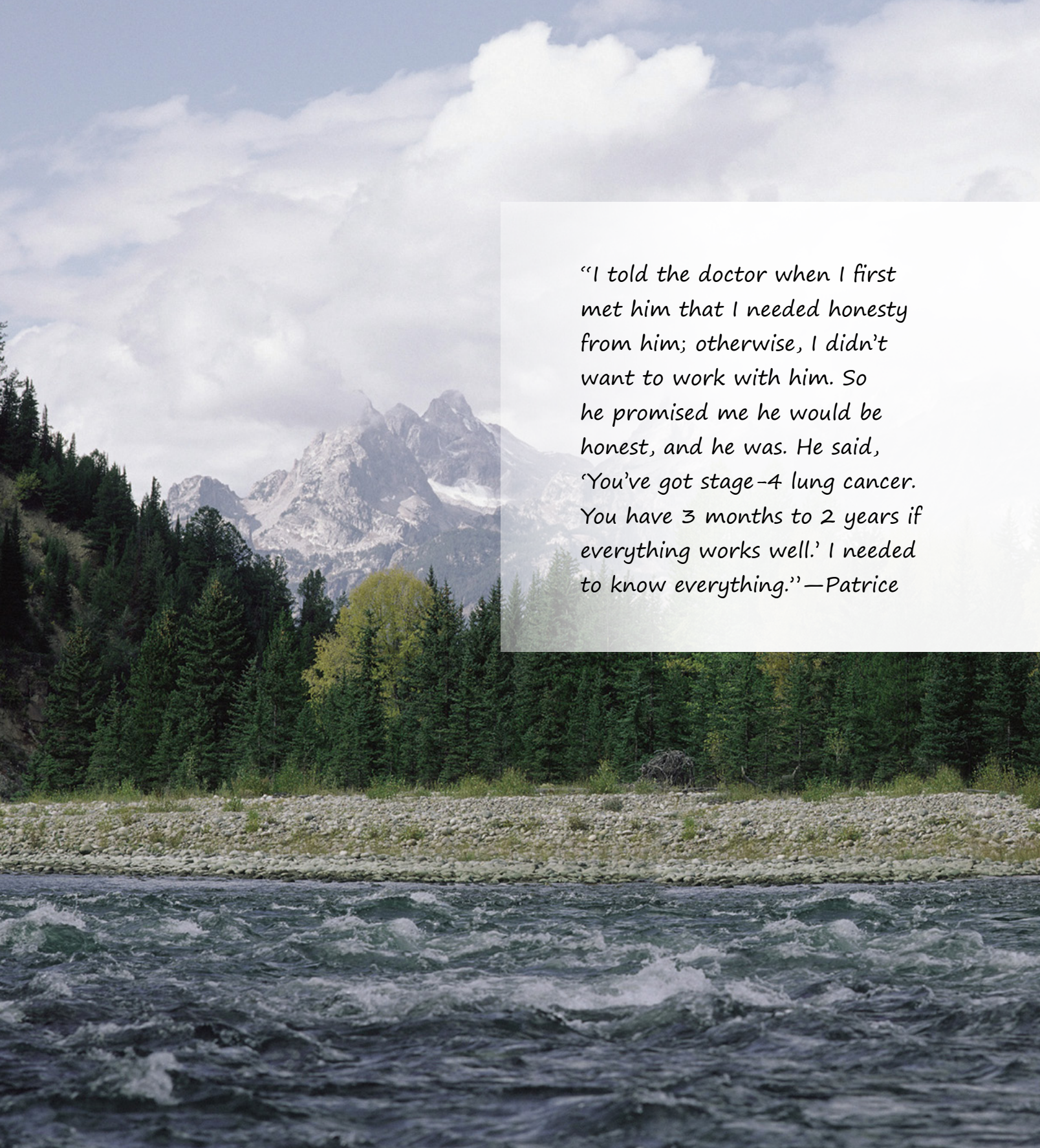
Here are just a few topics you may want to discuss with your doctor or other members of your health care team:

- **Pain or other symptoms.** Be honest and open about how you feel. Tell your doctor if you have pain and where. Also tell him or her what you expect in the way of pain relief. (See Chapter 4 for more about pain and other symptoms.)
- **Communication.** Some people want to know details about their care. Others prefer to know as little as possible. Some patients want their family members to make most of their decisions. What would you prefer? Decide what you want to know, how much you want to know, and when you've heard enough. Choose what is most comfortable for you, then tell your doctor and family members. Ask that they follow through with your wishes.
- **Family wishes.** Some family members may have trouble dealing with cancer. They don't want to know how far the disease has advanced or how much time doctors think you have. Find out from your family members how much they want to know, and tell your health care team their wishes. Do this as soon as possible. It will help avoid conflicts or distress among your loved ones. (See Chapter 7 for more on talking to your loved ones.)



Remember that only you and those closest to you can answer many of these questions. Having answers to your questions can help you know what to expect now and in the future.

“My doctor said, ‘The cancer is spreading to your lungs,’ and from that moment on, I didn’t hear a word he said. He started talking about my options, but all I saw were lips moving. I was in total shock.” —Tyrone



“I told the doctor when I first met him that I needed honesty from him; otherwise, I didn’t want to work with him. So he promised me he would be honest, and he was. He said, ‘You’ve got stage-4 lung cancer. You have 3 months to 2 years if everything works well.’ I needed to know everything.”—Patrice

Tips for Meeting With Your Health Care Team

- Make a list of your questions before each appointment.
- Bring a family member or trusted friend with you to your medical visits. This person can help you remember what the doctor or nurse said, and talk with you about it after the visit.
- Ask all your questions. If you do not understand an answer, keep asking until you do. There is no such thing as a “stupid” question.
- Take notes. You can do this or you can ask a family member or friend to take them for you. Or you can ask if it’s okay to use a tape recorder.
- Get a phone number of someone to call with follow-up questions.
- Keep a file or notebook of all the papers and test results that your doctor has given you. Take this with you to your visits. Also keep records or a diary of all your visits. List the drugs and tests you have taken.
- Keep a record of any upsetting symptoms or side effects you have. Note when and where they occur. Take this with you on your visits.
- Find out what to do in an emergency. This includes whom to call, how to reach them, and where to go.



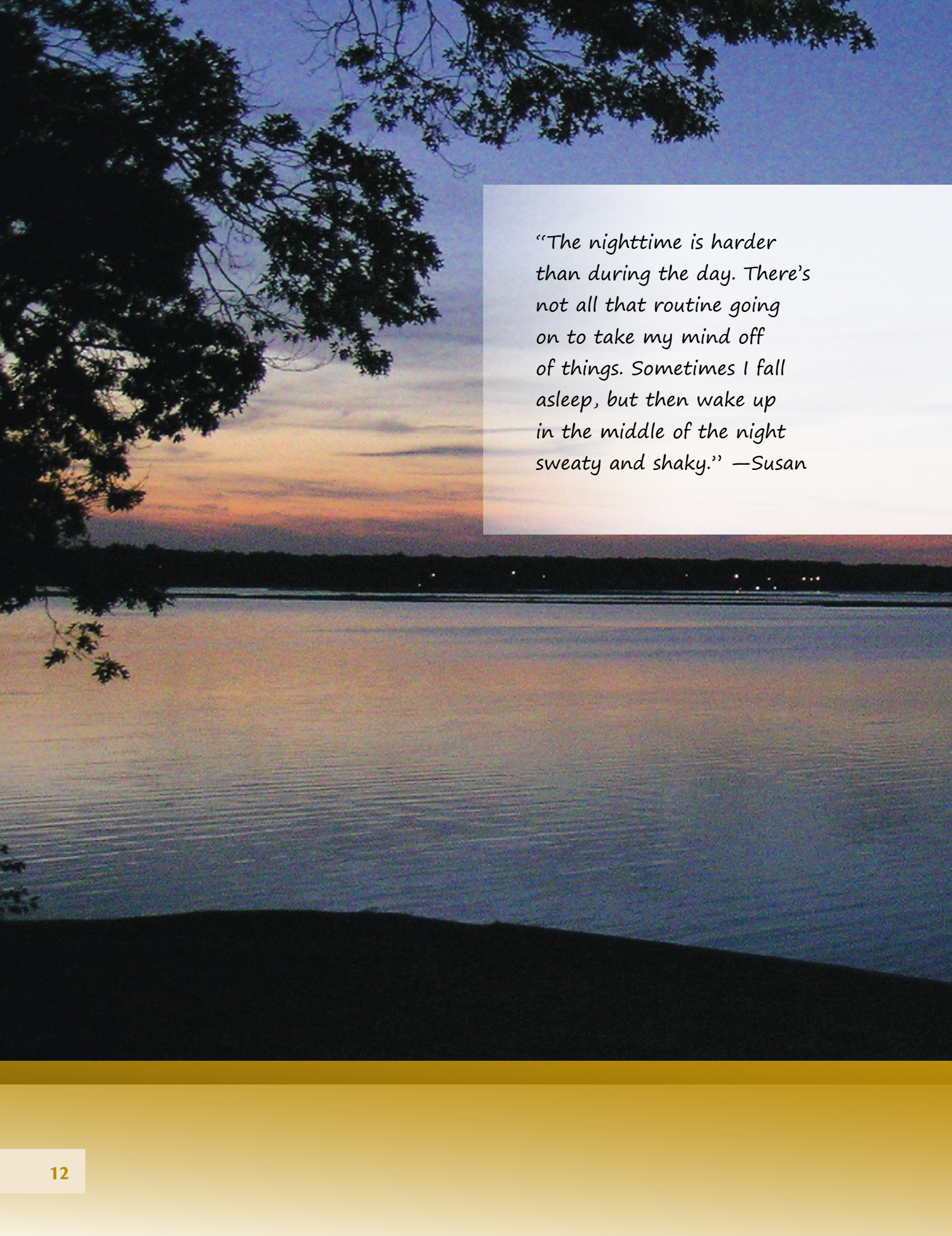
No One Knows the Future

It’s normal for people to want to know how long they will have to live. It’s also natural to want to prepare for what lies ahead. You may want to prepare emotionally as well as to make certain arrangements and plans.

But predicting how long someone will live is not exact. Your doctor may be able to give you an estimate, but keep in mind that it’s a guess. Every patient is different. Your doctor has to take into account your type of cancer, treatment, past illnesses, and other factors.

Some patients live long past the time the doctor first predicted. Others live a shorter time. Also, an infection or other complication could happen and change things. Your doctor may know your situation best, but even he or she cannot know the answer for sure. And doctors don’t always feel comfortable trying to give you an answer.

In truth, none of us knows when we are going to die. Unexpected events happen every day. The best we can do is try to live fully and for today.



“The nighttime is harder than during the day. There’s not all that routine going on to take my mind off of things. Sometimes I fall asleep, but then wake up in the middle of the night sweaty and shaky.” —Susan

Getting Help for Your Symptoms

Cancer and its treatment affect people differently. Some have symptoms, while others have no symptoms for a long time. As we said earlier, you have a right to comfort care throughout your illness.

Sometimes people assume their symptoms will get worse as their cancer progresses. But with good supports in place and good care, your symptoms should always be managed. So don't downplay your symptoms if you're having them. It's important to report how you are feeling. Tell your doctor, members of your health care team, and your loved ones. If you feel very sick or tired, your doctor may be able to adjust your treatment or give you other medicine.

Following are some of the symptoms you may have.

Pain

Having cancer doesn't always mean that you'll have pain. But if you do, you shouldn't accept pain as normal. Most types of pain can be treated. Your doctor can control pain with different medicines and treatments.

You may want to ask your doctor if you can talk to a pain specialist. Many hospitals have doctors on staff who are experts at treating pain. They may also have palliative medicine specialists.

Managing your pain helps you sleep and eat better. It makes it easier to enjoy your family and friends and focus on what gives you joy.

There are a few different ways to take pain medicine, including:

- By mouth
- Through the skin (like with a patch)
- By shots
- Through an I.V. or an S.C. pump

Your medicine, and how you take it, will depend on the type of pain and its cause. For example, for constant pain you may need a steady dose of medicine over a long period of time. You might use a patch placed on the skin or a slow-release pill.

Controlling Pain

What to Tell Your Doctor

When describing pain to your doctor, be as detailed as you can. Your doctor may ask:

- Where exactly is your pain? Does it move from one spot to another?
- How does the pain feel—dull, sharp, burning?
- How often does your pain occur?
- How long does it last?
- Does it start at a certain time—morning, afternoon, night?
- What makes the pain better? What makes it worse?

Using Strong Drugs To Control Pain

People with cancer often need strong medicine to help control their pain. Don't be afraid to ask for pain medicine or for larger doses if you need them. The drugs will help you stay as comfortable as you can be.

When treating pain in people with cancer, addiction is not an issue. Sadly, fears of addiction sometimes prevent people from taking medicine for pain. The same fears also prompt family members to encourage loved ones to “hold off” between doses. But people in pain get the most relief when they take their medicines and treatments on a regular schedule.

Medicines can be used for all types of pain, including:

- Mild to medium pain
- Medium to very bad pain
- **Breakthrough pain**
- Tingling and burning pain
- Pain caused by swelling

You should have regular talks with your healthcare team about the type and extent of your pain. That's because pain can change throughout your illness. Let them know the kind of pain you have, how bad it is, and where it hurts.

You may want to keep a “pain diary.” Write down the time of day that the pain occurred and what you were doing. Rate the pain on a scale of 0 to 10. (Zero means no pain, and 10 is the worst pain you could have.) Use the diary when you talk to your doctor about your pain.

Unlike other medicines, there is no “right” dose for many pain medicines. Yours may be larger or smaller than someone else's. The right dose is the one that relieves your pain and makes you feel better. (For more information on pain, see the NCI booklet, Pain Control.)

Other Ways To Treat Pain

Cancer pain is usually treated with medicine and other therapies. But there are also some non-drug treatments. They are forms of **complementary and alternative medicine (CAM)**. Many people have found the methods listed below helpful. But talk with your health care team before trying any of them. Make sure they are safe and won't interfere with your cancer treatment.

- **Acupuncture** is a form of Chinese medicine that stimulates certain points on the body using small needles. It may help treat nausea and control pain. Before using acupuncture, ask your health care team if it is safe for your type of cancer.

- **Imagery** is imagining scenes, pictures, or experiences to feel calmer or perhaps to help the body heal.
- **Relaxation techniques** include deep breathing and exercises to relax your muscles.
- **Hypnosis** is a state of relaxed and focused attention. One focuses on a certain feeling, idea, or suggestion.
- **Biofeedback** is the use of a special machine to help the patient learn how to control certain body functions. These are things that we are normally not aware of (such as heart rate).
- **Massage therapy** brings relaxation and a sense of well-being by the gentle rubbing of different body parts or muscles. Before you try this, you need to check with your doctor. Massage is not recommended for some kinds of cancer.

These methods may also help manage stress. Again, talk to your health care team before using anything new, no matter how safe it may seem. Ask your health care team for more information about where to get these treatments. To learn more, see the NCI booklets *Thinking About Complementary and Alternative Medicine* and *Pain Control*.

Anxiety

Cancer takes a toll on both your body and your mind. You are coping with many different things now. You may feel overwhelmed. Pain and medicines for pain can also make you feel anxious or depressed. And you may be more likely to feel this way if you have had these feelings before.

Here are some signs of anxiety:

- Feeling very tense and nervous
- Racing heartbeat
- Sweating a lot
- Trouble breathing or catching your breath
- A lump in your throat or a knot in your stomach
- Sudden fear



Feeling anxious can be normal. But if it begins disrupting your daily life, ask for help from the members of your health care team. They can recommend someone for you to talk to. Counseling from a mental health professional has been shown to help many people cope with anxiety. Your doctor can also give you medicines that will help. Some of the complementary and alternative medicine choices listed above for pain may work for your anxiety as well. Art therapy and music therapy have also helped people cope.