National Cancer Institute

Facing Forward

Life After Cancer Treatment

U.S. DEPARTMENT
OF HEALTH AND
HUMAN SERVICES

National Institutes
of Health

A Note About Cancer Survivors

There are more than 10 million people in the U.S. today who are cancer survivors. Three out of every four American families will have at least one family member diagnosed with cancer. To help support survivors' unique needs, the National Cancer Institute (NCI) formed the Office of Cancer Survivorship (OCS) in 1996. The office is dedicated to enhancing the length and quality of life of people with cancer. OCS also promotes research that looks at the long- and short-term effects of cancer and its treatment. For more information about survivorship issues and OCS, visit online at www.survivorship.cancer.gov.

Acknowledgments

We would like to offer a sincere thank you to the extraordinary survivors who contributed to the development and review of this booklet.

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This booklet is also available in Spanish (visit www.cancer.gov or call 1-800-4-CANCER).

Este folleto también se puede obtener en español.

Facing Forward

Life After Cancer Treatment

"While I was having chemo, I quit doing almost everything. So when treatment ended, the challenge for me was, what am I going to do now with my life? What should I go back to doing?" —LEN

Now that treatment is over …

Many cancer survivors have told us that while they felt they had lots of information and support during their illness, once treatment stopped, they entered a whole new world—one filled with new questions. This booklet was written to share common feelings and reactions that many people just like you have had after treatment ended.

It also offers some practical tips to help you through this time. Use this booklet in whatever way works best for you. You can read it from beginning to end. Or you can just refer to the section you need.

Who is a survivor?

This booklet uses the term "cancer survivor" to include anyone who has been diagnosed with cancer, from the time of diagnosis through the rest of his or her life. Family members, friends, and caregivers are also part of the survivorship experience.

You may not like the word, or you may feel that it does not apply to you, but the word "survivor" helps many people think about embracing their lives beyond their illness.

This booklet shares what we have learned from other survivors about life after cancer: practical ways of dealing with common problems and guidelines for managing your physical, social, and emotional health. When possible, we include specific information from research with cancer survivors.

While cancer is a major event for all who are diagnosed, it brings with it the chance for growth. As hard as treatment can be, many cancer survivors have told us that the experience led them to make important changes in their lives. Many say they now take time to appreciate each new day. They also have learned how to take better care of themselves and value how others care for them. Others draw from their experience to become advocates to improve cancer research, treatment, and care.

We hope that this booklet will serve as a resource and inspiration to you as you face forward to your life after cancer.

For ease of reading, rather than listing the many professionals that you may see as part of your medical care, you'll find the term "doctor" used in the booklet to describe all medical interactions.

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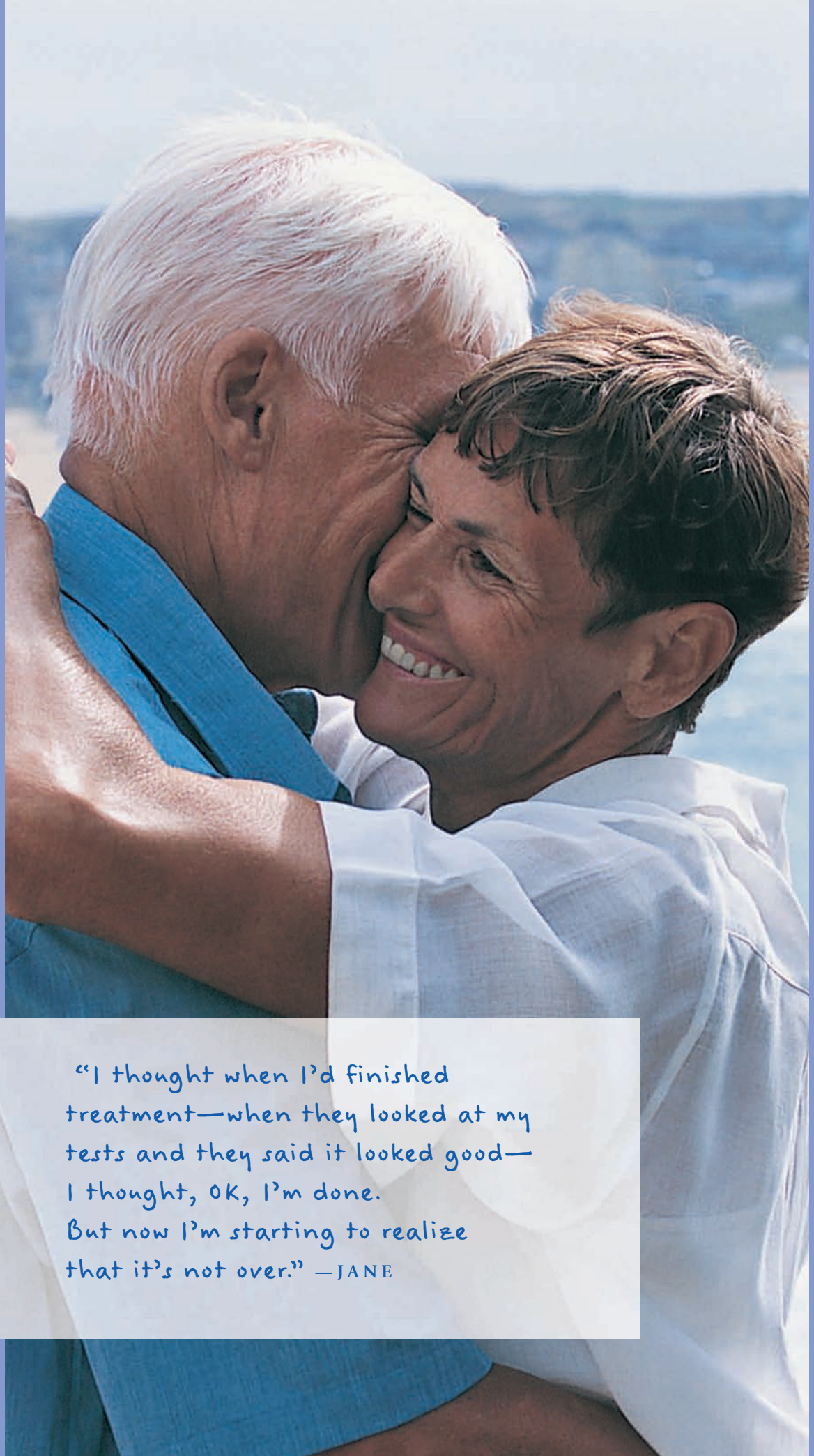

"I thought when I'd finished treatment—when they looked at my tests and they said it looked good—I thought, OK, I'm done. But now I'm starting to realize that it's not over." —JANE

Congratulations on Finishing Your Cancer Treatment

The end of cancer treatment is often a time to rejoice. You are probably relieved to be finished with the demands of treatment and are ready to put the experience behind you. Yet at the same time, you may feel sad and worried. It's common to be concerned about whether the cancer will come back and what you should do after treatment.

When treatment ends, you may expect life to return to the way it was before you were diagnosed with cancer. But it can take time to recover. You may have permanent scars on your body, or you may not be able to do some things you once did easily. Or you may even have emotional scars from going through so much. You may find that others think of you differently now—or you may view yourself in a different way.

One of the hardest things after treatment is not knowing what happens next.

> "Because the doctors and nurses never told me what to expect, I had very unrealistic expectations of wellness, and so did my family and friends. This led to a great deal of worry." —BOB

What Is "Normal" After Cancer Treatment?

Those who have gone through cancer treatment describe the first few months as a time of change. It's not so much "getting back to normal" as it is finding out what's normal for you now. People often say that life has new meaning or that they look at things differently now. You can also expect things to keep changing as you begin your recovery.

Your new "normal" may include making changes in the way you eat, the things you do, and your sources of support, all of which are discussed in this booklet.

Getting Follow-up Medical Care

All cancer survivors should have follow-up care. Knowing what to expect after cancer treatment can help you and your family make plans, lifestyle changes, and important decisions.

Some common questions you may have are:

- Should I tell the doctor about symptoms that worry me?
- Which doctors should I see after treatment?
- How often should I see my doctor?
- What tests do I need?
- What can be done to relieve pain, fatigue, or other problems after treatment?
- How long will it take for me to recover and feel more like myself?
- Is there anything I can or should be doing to keep cancer from coming back?

Coping with these issues can be a challenge. Yet many say that getting involved in decisions about their medical care and lifestyle was a good way for them to regain some of the control they felt they lost during cancer treatment. Research has shown that people who feel more in control feel and function better than those who do not. Being an active partner with your doctor and getting help from other members of your health care team is the first step.

If you don't have health insurance, Medicare, or Medicaid, you may feel that some of the information in this booklet won't be helpful to you. You may have already struggled just to get treated and now see follow-up care as another battle. It can be hard to get care if you don't have good medical coverage, but you must make sure you continue to get the care you need—especially now that treatment is over.

There may be resources in your community to help you get these services. Talk with your doctor, social worker, or the business office at your local hospital or clinic. There are also organizations listed in the Resources section on page 57 that may be able to help you with health care costs.

What Is Follow-up Care?

Follow-up care means seeing a doctor for regular medical checkups. Your follow-up care depends on the type of cancer and type of treatment you had, along with your overall health. It is usually different for each person who has been treated for cancer.

In general, survivors usually return to the doctor every 3 to 4 months during the first 2 to 3 years after treatment, and once or twice a year after that. At these visits, your doctor will look for side effects from treatment and check if your cancer has returned (recurred) or spread (metastasized) to another part of your body.

At these visits, your doctor will:

- Review your medical history
- Give you a physical exam

Your doctor may run follow-up tests such as:

- Blood tests
- MRI or CT scans. These scans take detailed pictures of areas inside the body at different angles.
- Endoscopy (en-DOSS-koh-pee). This test uses a thin, lighted tube to examine the inside of the body.

At your first follow-up visit, talk with your doctor about your follow-up schedule.

See page 11 for a list of organizations and programs that give follow-up care guidelines for survivors or Resources on page 57 for a detailed list of cancer-related organizations.

Follow-up care can also include home care, occupational or vocational therapy, pain management, physical therapy, and support groups. (See pages 12–13 for a description of these services.)

Medical Records and Follow-up Care

Be sure to ask your oncologist for a written summary of your treatment. In the summary, he or she can suggest what aspects of your health need to be followed. Then, share this summary with any new doctors you see, especially your primary care doctor, as you discuss your follow-up care plan.

Many people keep their medical records in a binder or folder and refer to them as they see new doctors. This keeps key facts about your cancer treatment in the same place. Other kinds of health information you should keep include:

- ✔ The date you were diagnosed
- ✔ The type of cancer you were treated for
- ✔ Pathology report(s) that describe the type and stage of cancer
- ✔ Places and dates of specific treatment, such as:
  - Details of all surgeries
  - Sites and total amounts of radiation therapy
  - Names and doses of chemotherapy and all other drugs
  - Key lab reports, x-ray reports, CT scans, and MRI reports
- ✔ List of signs to watch for and possible long-term effects of treatment
- ✔ Contact information for all health professionals involved in your treatment and follow-up care
- ✔ Any problems that occurred during or after treatment
- ✔ Information about supportive care you received (such as special medicines, emotional support, and nutritional supplements)

Be sure to give any new doctors that you see a copy of your treatment summary or medical records.

Which Doctor Should I See Now? How Often?

You will need to decide which doctor will provide your follow-up cancer care and which one(s) you will see for other medical care. For follow-up cancer care, this may be the same doctor who provided your cancer treatment. For regular medical care, you may decide to see your main provider, such as a family doctor. For specific concerns, you may want to see a specialist. This is a topic you can discuss with your doctors. They can help you decide how to make transitions in care.

Depending on where you live, it may make more sense to get follow-up cancer care from your family doctor, rather than your oncologist. It's important to note that some insurance plans pay for follow-up care only with certain doctors and for a set number of visits.

In coming up with your schedule, you may want to check your health insurance plan to see what follow-up care it allows. No matter what your health coverage situation is, try to find doctors you feel comfortable with.

Always tell any new doctors you see about your history of cancer. The type of cancer you had and your treatment can affect decisions about your care in the future. They may not know about your cancer unless you tell them.

A Survivor's Wellness Plan

After cancer treatment, many survivors want to find ways to reduce the chances of their cancer coming back. Some worry that the way they eat, the stress in their lives, or their exposure to chemicals may put them at risk. Cancer survivors find that this is a time when they take a good look at how they take care of themselves. This is an important start to living a healthy life.

When you meet with your doctor about follow-up care, you should ask about developing a wellness plan that includes ways you can take care of your physical, emotional, social, and spiritual needs. If you find that it's hard to talk with your doctor about these issues, it may be helpful to know that the more you do it, the easier it becomes. And your doctor may suggest other members of the health care team for you to talk with, such as a social worker, clergy member, or nurse. For tips on talking with your doctor, see pages 7–9.

Changes You May Want To Think About Making

- ✔ **Quit smoking.** Research shows that smoking can increase the chances of getting cancer at the same site or another site.

- ✔ **Cut down on how much alcohol you drink.** Research shows that drinking alcohol increases your chances of getting certain types of cancers.

- ✔ **Eat well.** Healthy food choices and physical activity may help reduce the risk of cancer or recurrence. Talk with your doctor or a nutritionist to find out about any special dietary needs that you may have. The American Cancer Society and the American Institute for Cancer Research have developed similar diet and fitness guidelines that may help reduce the risk of cancer:

  - Eat a plant-based diet and have at least 5–9 servings of fruit and vegetables daily. Try to include beans in your diet, and eat whole grains (such as cereals, breads, and pasta) several times daily.
  - Choose foods low in fat and low in salt.
  - Get to and stay at a healthy weight.

  For more tips on nutrition and healthy eating, go to www.aicr.org and click on "Cancer Survivors," or go to www.cancer.org and click on "Survivors."

- ✔ **Exercise and stay active.** Several recent reports suggest that staying active after cancer can help lower the risk of recurrence and can lead to longer survival. Moderate exercise (walking, biking, swimming) for about 30 minutes every—or almost every—day can:

  - Reduce anxiety and depression
  - Improve mood and boost self-esteem
  - Reduce fatigue, nausea, pain, and diarrhea

  It is important to start an exercise program slowly and increase activity over time, working with your doctor or a specialist (such as a physical therapist) if needed. If you need to stay in bed during your recovery, even small activities like stretching or moving your arms or legs can help you stay flexible, relieve muscle tension, and help you feel better. Some people may need to take special care in exercising. Talk with your doctor before you begin any exercise program.

Talking With Your Doctor

During cancer treatment, you had a lot of practice in getting the most out of every doctor's visit. These same skills now apply to you as a survivor and are especially helpful if you are changing doctors or going back to a family or primary care doctor you may not have seen for a while.

It is important to be able to talk openly with your doctor. Both of you need information to manage your care. Be sure to tell your doctor if you are having trouble doing everyday activities, and talk about new symptoms to watch for and what to do about them. If you are concerned that the treatment you had puts you at a higher risk for having health problems, be sure to discuss this with your doctor as you develop your follow-up plan.

At each visit, mention any health issues you are having, such as:

- New symptoms
- Pain that troubles you
- Physical problems that get in the way of your daily life or that bother you, such as fatigue, trouble sleeping, sexual problems, or weight gain or loss
- Other health problems you have, such as heart disease, diabetes, or arthritis
- Medicines, vitamins, or herbs you are taking and other treatments you are using
- Emotional problems, such as anxiety or depression, that you may have now or that you've had in the past
- Changes in your family's medical history, such as relatives with cancer
- Things you want to know more about, such as new research or side effects

Just because you have certain symptoms, it doesn't always mean the cancer has come back. Symptoms can be due to other problems that need to be addressed.

Considering Complementary and Alternative Medicine

Complementary and alternative medicine includes many different healing approaches that people use to prevent illness, reduce stress, prevent or reduce side effects and symptoms, or control or cure disease. An approach is generally called "complementary" when it is used *in addition to* treatments prescribed by a doctor. When it is used *instead of* treatments prescribed by a doctor, it is often called "alternative." Research has shown that more than half of all people with a history of cancer use one or more of these approaches.

Some common methods include imagery or relaxation (see page 60), acupressure and massage, homeopathy, vitamins or herbal products, special diets, psychotherapy, prayer, yoga, and acupuncture.

Even though you have finished your cancer treatment, if you are thinking about using any of these methods, discuss it with your doctor or nurse first. Some complementary and alternative therapies may interfere or be harmful when used with medicines normally prescribed by a doctor. For more information, see the Resources section on page 57 to order the NCI brochure *Thinking About Complementary & Alternative Medicine: A Guide for People With Cancer*.

Asking About Your Family's Cancer Risk

You may worry that having cancer might increase your children's risk. It's important to know that most cancer is not passed down through families. Only about 5–10 percent of the most common cancers (such as breast, colon, and prostate) are inherited. In most of the families that have inherited cancers, researchers have found relatives who may have had:

- Cancer before they were 50 years old
- Cancer in two of the same body parts (like both kidneys or both breasts)
- Other risk factors for cancer (such as colon polyps or skin moles)

If you think that your cancer may be inherited, talking with a cancer genetic counselor can help answer your questions and those of your family. He or she can also help you and your doctor decide on the medical care that you and your family might need if a genetic link is found. Genetic testing can determine whether the cancers that occur in your family are due to genes or to other factors.

Getting the Most From Your Follow-up Visits

Here are some ideas that helped others with their follow-up care:

- Ask someone to come with you to your doctor visits. A friend or family member can help you think about and understand what was said. He or she also may think of new questions to ask.
- Make a list of questions ahead of time and bring it with you.
- Take notes or ask if you can tape-record the answers.
- Ask your most important questions first, in case the doctor runs out of time.
- Don't be afraid to ask for more time when you make your next appointment. Or ask the doctor to suggest a time when you could call and get answers to your questions.
- Ask to talk with the doctor or nurse in a private room with the door closed.
- Express yourself clearly.
- Describe your problem or concern briefly.
- Tell the doctor how your problem or concern makes you feel.
- Ask for what you want or need, for example, "I am tired most of the time each day. I've tried napping, but it doesn't help. My fatigue gets in the way of my daily life. What can be done to help me with this problem?"
- Tell your doctor if you need more information.
- Ask for booklets or other materials to read at home.
- Ask the doctor to explain what he or she said in terms you understand.
- Repeat back in your own words what you think the doctor meant.
- Ask your doctor or pharmacist about the best way to take your medicine and about possible side effects.
- Keep your own set of records about any follow-up care you have.

Questions About Your Follow-up Plan

1. How often should I see my doctors?

Doctor's Name	How Often

2. What follow-up tests, if any, should be done (for example, CT scan, MRI, bone scan)? How often?

Test	How Often

3. Are there symptoms that I should watch for?

_____
_____
_____
_____
_____

4. If I develop any of these symptoms, whom should I call?

_____
_____
_____
_____
_____

Guidelines for Follow-up Care

These organizations have follow-up care guidelines for some cancers. You can use them as you talk with your doctor—they aren't meant to contradict or take the place of your doctor's knowledge or judgment.

Cancer: Keys to Survivorship

Hosted by the National Coalition of Cancer Survivorship and the Leukemia & Lymphoma Society, this program teaches survivors, families, and caregivers the necessary skills to help live with, through, and beyond cancer. A series of seminars focuses on leading healthy lives, preparing for doctor visits, managing side effects, and handling insurance and employment issues. Seminars can be viewed online at www.canceradvocacy.org/programs/keys.aspx.

Children's Oncology Group Long-Term Follow-up Guidelines

The Children's Oncology Group offers long-term follow-up guidelines for survivors of childhood, adolescent, and young adult cancers at www.survivorshipguidelines.org.

Life After Cancer Care

M.D. Anderson's Cancer Center Web site lists follow-up guidelines for 15 different disease sites at www.mdanderson.org/departments/lacc, and click on "Follow-up Guidelines by Disease."

People Living With Cancer

The American Society of Clinical Oncology has a series of follow-up care guides focused on breast, colorectal, and lung cancer. They can be viewed at www.plwc.org.

Services To Think About

Talk with your doctor to help you locate services such as these:

- **Couples Counseling**
  You and your partner work with trained specialists who can help you talk about problems, learn about each other's needs, and find ways to cope. Counseling may include issues related to sex and intimacy.
- **Faith or Spiritual Counseling**
  Some members of the clergy are trained to help you cope with cancer concerns, such as feeling alone, fear of death, searching for meaning, and doubts about faith.
- **Family Support Programs**
  Your whole family may be involved in the healing process. In these programs, you and your family members take part in therapy sessions with trained specialists who can help you talk about problems, learn about each other's needs, and find answers.
- **Genetic Counseling**
  Trained specialists can advise you on whether to have genetic testing for cancer and how to deal with the results. It can be helpful for you and for family members who have concerns about their own health.
- **Home Care Services**
  State and local governments offer many services that you may find useful after cancer treatment. For example, a nurse or physical therapist may be able to come to your home. You may also be able to get help with housework or cooking. Check the phone book under the categories Social Services, Health Services, or Aging Services.
- **Individual Counseling**
  Trained mental health specialists can help you deal with your feelings, such as anger, sadness, and concern for your future.
- **Long-Term Follow-up Clinics**
  All doctors can offer follow-up care, but there are also clinics that specialize in long-term follow-up after cancer. These clinics most often see people who are no longer being treated by an oncologist and who are considered disease-free. Ask your doctor if there are any follow-up cancer clinics in your area.
- **Nutritionists/Dietitians**
  They can help you with gaining or losing weight and with healthy eating.
- **Occupational Therapists**
  They can help you regain, develop, and build skills that are important for day-to-day living. They can help you relearn how to do daily activities, such as bathing, dressing, or feeding yourself, after cancer treatment.

- **Oncology Social Workers**
  These professionals are trained to counsel you about ways to cope with treatment issues and family problems related to your cancer. They can tell you about resources and connect you with services in your area.
- **Ostomy Information and Support**
  The United Ostomy Association provides education, information, and support for people with intestinal/urinary diversions. Call 1-800-826-0826, or visit online at http://www.uoa.org.
- **Pain Clinics (also called Pain and Palliative Care Services)**
  These are centers with professionals from many different fields who are specially trained in helping people get relief from pain.
- **Physical Therapists**
  Physical therapists are trained to understand how different parts of your body work together. They can teach you about proper exercises and body motions that can help you gain strength and move better after treatment. They can also advise you about proper postures that help prevent injuries.
- **Quitting Smoking (Smoking Cessation Services)**
  Research shows that the more support you have in quitting smoking, the greater your chance for success. Ask your doctor, nurse, social worker, or hospital about available programs, or call NCI's Smoking Quitline at 1-877-44-U-QUIT (1-877-448-7848).
- **Speech Therapists**
  Speech therapists can evaluate and treat any speech, language, or swallowing problems you may have after treatment.
- **Stress Management Programs**
  These programs teach ways to help you relax and take more control over stress. Hospitals, clinics, or local cancer organizations may offer these programs and classes.
- **Support Groups for Survivors**
  In-person and online groups enable survivors to interact with others in similar situations. (See pages 44–45.)
- **Survivor Wellness Programs**
  These types of programs are growing in number, and they are meant for people who have finished their cancer treatment and are interested in redefining their life beyond cancer.
- **Vocational Rehabilitation Specialists**
  If you have disabilities or other special needs, these specialists can help you find suitable jobs. They offer services such as counseling, education and skills training, and help in obtaining and using assistive technology and tools.

"I thought I could get right back into my normal work routine, but I'm finding that I just don't have the same energy that I used to." —BILL

Ways To Manage Physical Changes

"If I could stop feeling so tired all the time, I think I'd be fine. I've started getting used to everything else." —ROSA

Some have described survivorship as being "disease-free, but not free of your disease." What you experience with your body may be related to the type of cancer you had and the treatment you received. It's important to remember that no two people are alike, so you may experience changes that are very different from someone else's, even if that person had the same type of cancer and treatment.

You may find that you are still coping with the effects of treatment on your body. It can take time to get over these effects. You may wonder how your body should feel during this time and what are signs that cancer is coming back. This section describes some of the problems that can occur when treatment is over. Some of the most common problems that people report are:

- Fatigue
- Memory and concentration changes
- Pain
- Nervous system changes (neuropathy)
- Lymphedema, or swelling
- Mouth or teeth problems
- Changes in weight and eating habits
- Trouble swallowing
- Bladder or bowel control problems
- Menopause symptoms

Fatigue

Some cancer survivors report that they still feel tired or worn out. In fact, fatigue is one of the most common complaints during the first year of recovery.

Rest or sleep does not cure the type of fatigue that you may have. Doctors do not know its exact causes. The causes of fatigue are different for people who are receiving treatment than they are for those who have finished.

- Fatigue during treatment can be caused by cancer therapy. Other problems can also play a part in fatigue, like anemia (having too few red blood cells) or having a weak immune system. Poor nutrition, not drinking enough liquids, and depression can also be causes. Pain can make fatigue worse.
- Researchers are still learning about what may cause fatigue after treatment.

How long will fatigue last? There is no normal pattern. For some, fatigue gets better over time. Some people, especially those who have had bone marrow transplants, may still feel energy loss years later.

Some people feel very frustrated when fatigue lasts longer than they think it should and when it gets in the way of their normal routine. They may also worry that their friends, family, and coworkers will get upset with them if they continue to show signs of fatigue.

Getting Help

Talk with your doctor or nurse about what may be causing your fatigue and what can be done about it. Ask about:

- How any medicines you are taking or other medical problems you have might affect your energy level
- How you can control your pain, if pain is a problem for you
- Exercise programs that might help, such as walking
- Relaxation exercises
- Changing your diet or drinking more fluids
- Medicines or nutritional supplements that can help
- Specialists who might help you, such as physical therapists, occupational therapists, nutritionists, or mental health care providers

Coping With Fatigue

Here are some ideas:

- ✔ **Plan your day.** Be active at the time of day when you feel most alert and energetic.
- ✔ **Save your energy by changing how you do things.** For example, sit on a stool while you cook or wash dishes.
- ✔ **Take short naps or rest breaks between activities.**
- ✔ **Try to go to sleep and wake up at the same time every day.**
- ✔ **Do what you enjoy, but do less of it.** Focus on old or new interests that don't tire you out. For example, try to read something brief or listen to music.
- ✔ **Let others help you.** They might cook a meal, run errands, or do the laundry. If no one offers, ask for what you need. Friends and family might be willing to help but may not know what to do.
- ✔ **Choose how to spend your energy.** Try to let go of things that don't matter as much now.
- ✔ **Think about joining a support group.** Talking about your fatigue with others who have had the same problem may help you find new ways to cope.

Memory and Concentration Changes

"Not being able to concentrate the way I used to has been the hardest for me. I'm hoping it doesn't affect my work." —JOSH

Research shows that one in four people with cancer reports memory and attention problems after chemotherapy. This is sometimes called "chemobrain." Many survivors describe this as "brain fog," which can lead to problems paying attention, finding the right word, or remembering new things.

These effects can begin soon after treatment ends, or they may not appear until much later. They don't always go away. If a person is older, it can be hard to tell whether these changes in memory and concentration are a result of treatment or of the aging process. Either way, some feel they just can't focus as they once did.

Research is starting to explore why some people develop problems with memory and concentration while others don't. It seems that people who have had chemotherapy or have had radiation to the head area are at higher risk for these problems. People who had high doses of chemotherapy may have memory problems, but even those who had standard doses have reported memory changes.

Getting Help

Your doctor can help you with memory and concentration problems. Talk with him or her if:

- **You are still having memory and thinking problems.** You may want to ask about seeing a specialist (called a neuropsychologist) to help you with these problems.
- **You think a medicine you are taking could be causing or adding to your problem.**
- **You think you suffer from depression or anxiety.** These problems can affect attention, concentration, and memory.
- **You are going through menopause.** Some memory and concentration problems can be related to menopause.

Improving Memory and Concentration

Cancer survivors have found many ways to help improve their memory after cancer treatment. See if any of these ideas work for you:

- ✔ **Jot it down.** You can write down each task, how long it will take, and where you need to go in a notebook or pocket calendar. Plan your whole day. Keep it simple, and be realistic about how much you can do in a day.
- ✔ **Set up reminders.** Put small signs around the house to remind you of things to do, such as taking out the trash or locking the door.
- ✔ **Group long numbers into chunks.** For example, the phone number 812-5846 can be repeated as "eight-twelve, fifty-eight, forty-six."
- ✔ **Talk yourself through tasks.** When doing a task with a number of steps, such as cooking or working on a computer, whisper each step to yourself.
- ✔ **Manage stress.** Managing stress better may improve your memory and attention. And learning how to relax can help you remain calm even in stressful moments.
- ✔ **Go over what you plan to say.** Before you go to family events or work functions, go over names, dates, and key points you want to make.
- ✔ **Repeat what you want to remember.** Saying it a couple of times can help your mind hold on to the information.

For more information about chemobrain, see Cancer*Care*'s listing in the Resources section on page 57 or view the fact sheet "Cognitive Problems After Chemotherapy" online at www.cancercare.org/pdf/fact_sheets/fs_chemobrain_cognitive.pdf.

Pain

Some people have a lot of pain after treatment, while others have less. Everyone is different. Types of pain you may feel after cancer treatment include:

- **Pain or numbness in the hands and feet due to injured nerves.** Chemotherapy or surgery can damage nerves, which can cause severe pain. For more information on nervous system changes, see page 23.
- **Painful scars from surgery.**
- **Pain in a missing limb or breast.** While doctors don't know why this pain occurs, it is real. It's not just "in your mind." This is sometimes called phantom pain.

Getting Help

If you find that you still have pain after treatment ends, your doctor can help find the source of your pain and get relief. You do not have to be in pain. And wanting to control pain is not a sign of weakness. It's a way to help you feel better and stay active. Pain may be caused by treatment or other health issues, such as arthritis.

With your help, your doctor can assess how severe your pain is and may recommend one or more of the following approaches:

- **Pain-relief medicines.** In most cases, doctors will try the mildest medicines first. Then they will work up to stronger ones if you need them. The key to getting relief is to take all medicines just as your doctor prescribes. To keep pain under control, do not skip doses or wait until you hurt to take these medicines.

  You may be afraid that if you use these medicines you'll become addicted, but this rarely happens if you take the correct dose and see your doctor regularly.

- **Antidepressant medicines.** Some of these are prescribed to reduce pain or numbness from injured nerves.
- **Physical therapy.** Going to a physical therapist may help relieve your pain. The therapist may use heat, cold, massage, pressure, and/or exercise to help you feel better.
- **Braces.** These limit movement of a painful limb or joint.
- **Acupuncture.** This is a proven method that uses needles at pressure points to reduce pain.

- **Hypnosis, meditation, or yoga.** Any of these may help your pain. A trained specialist can teach you these approaches.
- **Relaxation skills.** Many people with cancer have found that practicing deep relaxation helps relieve their pain or reduce their stress.
- **Nerve blocks or surgery.** If you don't get relief from the other approaches in this section, you may want to ask your doctor about these. Nerve blocks or surgery often help if you have persistent, limiting pain, but they may put you at risk for other problems. They may also require you to stay in the hospital.

Talking With Your Doctor About Pain

There are different ways you can describe your pain to your doctor:

- ✔ **Use numbers.** Talk about how strong the pain feels on a scale of 0 to 10, with 0 being no pain and 10 being the worst pain you could have.
- ✔ **Describe what the pain feels like.** Is it sharp, dull, throbbing, steady?
- ✔ **Point out the exact places it hurts,** either on your body or on a drawing. Note whether the pain stays in one place or whether it moves outward from the spot.
- ✔ **Explain when you feel pain.** Note when it starts, how long it lasts, if it gets better or worse at certain times of the day or night, and if anything you do makes it better or worse.
- ✔ **Describe how your pain affects your daily life.** Does it stop you from working? Doing household chores? Seeing friends and family? Going out and having fun?
- ✔ **Make a list of all the medicines you are taking** (for any reason). If you are taking any for pain relief, how much do they help?
- ✔ **Talk about any side effects** you have from your pain control medicine, such as constipation or other changes in bowel habits, or feeling groggy or "out of it." Many of these problems can be helped.
- ✔ **Keep a record of your pain.** Jotting down notes about your pain can help you track changes over time. It can also show how you respond to any pain control medicine or other treatment you receive.

Make sure your insurance covers the pain relief approaches your doctor recommends.

Pain Diary

Use this pain diary and pain rating scale to record your pain.
(You may want to photocopy this sheet before writing on it.)

0	1	2	3	4	5	6	7	8	9	10
No pain										Worst pain imaginable

Date	Time	Pain rating (0–10)	Pain medication (name, dose, how often taken)	Other pain-relief methods tried	Side effects from pain medication
6/8 (example)	8 a.m.	8	Morphine 30 mg every 4 hrs	massage	constipation

Nervous System Changes (Neuropathy)

Sometimes cancer treatment can cause damage to your nervous system. This is called neuropathy (new-RAH-path-ee), or problems with nerve function. Sometimes these symptoms can be made worse by other conditions, such as diabetes, kidney failure, alcoholism, and malnutrition. Most people first notice symptoms in their hands or feet, usually starting with their fingertips and toes. Sometimes, the tingling and pain move up the fingers to the hands or from the toes to the feet.

Common symptoms include tingling, burning, weakness, or numbness in your hands or feet; sudden, sharp, stabbing, or electric shock pain sensations; loss of sensation of touch; loss of balance or difficulty walking; clumsiness; trouble picking up objects or buttoning clothes; hearing loss; jaw pain; constipation; and being more—or less—sensitive to heat and cold.

Symptoms can start when you begin chemotherapy or after treatment. If they do, tell your health care team right away. Symptoms can improve over time, but it may take up to a year or more.

Getting Help

- Treatments include medications, topical creams, and pain patches.
- Other approaches include acupuncture, physical therapy, and exercise.

Managing Nervous System Changes

- ✔ **Be careful** when handling knives, scissors, and other sharp objects.
- ✔ **Avoid falling.** Walk slowly, hold onto handrails, and put no-slip bath mats in your tub or shower. Remove area rugs or cords you could trip over. Steady yourself when you walk by using a cane or other device.
- ✔ **Wear tennis shoes or other footwear with rubber soles.**
- ✔ **Use a thermometer and gloves instead of your bare hand.** These can help you avoid being burned when checking water temperature. If possible, lower the temperature setting on your hot water heater.
- ✔ **Allow yourself time to rest.**

Lymphedema or Swelling

Lymphedema (LIMF-eh-DEE-ma) is a swelling of a part of the body caused by the buildup of lymph fluids. It often happens in the arm, leg, face, or neck. It can be caused by cancer or its treatment. There are many different types of lymphedema. Some types happen right after surgery, are mild, and don't last long. Other types can occur months or years after cancer treatment and can be quite painful. These types can also develop after an insect bite, minor injury, or burn.

People who are at risk for lymphedema are those who have had:

- **Breast cancer**. If you had radiation therapy, or had your underarm lymph nodes removed, or had radiation in the underarm area after your lymph nodes were removed
- **Melanoma of the arms or legs**. If you had lymph nodes removed and/or had radiation therapy
- **Prostate cancer**. If you had surgery or radiation therapy to the whole pelvis
- **Cancer of the female or male reproductive organs**. If you had surgery to remove lymph nodes or had radiation therapy
- **Other cancers that have spread to the lower abdominal area**. The pressure from the growing tumor can make it hard for your body to drain fluid.

Getting Help

Your doctor or nurse may be able to help you find ways to prevent and relieve lymphedema. Ask about:

- **Skin care.** It's important to keep your skin clean. You should also use lotion to keep it moist.
- **Exercise.** Find out about exercises to help the body drain lymph fluid and what types of exercise you should not do.

- **Ways to treat lymphedema.** Your doctor may suggest:
  - Keeping the arm or leg raised above your chest for periods of time
  - Having special types of massage that can help by moving the lymph fluid from where it has settled
  - Wearing special elastic sleeves and clothing that can help lymph fluid drain
  - Losing weight
  - Finding sources of emotional support to help you cope
  - Avoiding procedures done in the area with lymphedema, such as shots or blood tests

Preventing or Relieving Lymphedema

Other cancer survivors have found these tips helpful:

✔ Watch for signs of swelling or infection (redness, pain, heat, fever). Tell your doctor or nurse if your arm or leg is painful or swollen.

✔ Keep your arm or leg free of cuts, insect bites, and sunburn. Try not to have shots or blood tests done in that area.

✔ Eat a well-balanced, protein-rich, low-salt diet.

✔ Keep regular follow-up appointments with your doctor.

✔ Wear loose-fitting clothing on your arm or leg.

✔ Protect the area. Try not to use that arm or leg to figure out how hot or cold something is, such as bath water or cooked food. You may be less able to feel hot and cold now.

Mouth or Teeth Problems

Many people who have been treated for cancer develop problems with their mouth or teeth. Some problems go away after treatment. Others last a long time, while some may never go away. Some problems may develop months or years after your treatment has ended.

Radiation or surgery to the head and neck can cause problems with your teeth and gums; the soft, moist lining of your mouth; glands that make saliva (spit); and jawbones. If you were treated with certain types of chemotherapy, you may also have these problems. This can cause:

- Dry mouth
- Cavities and other kinds of tooth problems
- Loss of or change in sense of taste
- Painful mouth and gums
- Infections in your mouth
- Jaw stiffness or jawbone changes

Who Has These Problems?

- Almost all people who have had radiation therapy to the head and neck
- Most people who have had bone marrow transplants
- About two out of every five people treated with chemotherapy

Getting Help

If you find that problems persist after cancer treatment ends, talk with your doctor about possible causes and ways to control mouth pain.

Try to see your dentist soon after you are done with treatment. Ask how often you should have checkups and ways to take care of your mouth and teeth.

Preventing or Relieving Mouth or Teeth Problems

✔ Keep your mouth moist.

- Drink a lot of water.
- Suck on ice chips.
- Chew sugarless gum or suck on sugar-free hard candy.
- Use a saliva substitute to help moisten your mouth.

✔ Keep your mouth clean.

- Brush your teeth, gums, and tongue with an extra-soft toothbrush after every meal and at bedtime. If it hurts, soften the bristles in warm water.
- Ask your dentist for tooth sponges, such as Toothettes® or Dentips®, that you can use in place of a toothbrush.
- Use a mild fluoride toothpaste (like children's toothpaste) and a mouthwash without alcohol.
- Floss your teeth gently every day. If your gums bleed or hurt, stay away from the areas that are bleeding or sore, but keep flossing your other teeth.
- Rinse your mouth several times a day with a solution of 1/4 teaspoon baking soda and 1/8 teaspoon salt in 1 cup of warm water. Follow with a plain water rinse.
- If you have dentures, clean, brush, and rinse them after meals. Have your dentist check them to make sure they still fit you well.

✔ If your mouth is sore, remember to stay away from:

- Sharp, crunchy foods, like chips, that can scrape or cut your mouth
- Foods that are hot, spicy, or high in acid, like citrus fruits and juices, which can irritate your mouth
- Sugary foods, like candy or soda, that can cause cavities
- Toothpicks (they can cut your mouth)
- All tobacco products
- Alcoholic drinks

Changes in Weight and Eating Habits

Some survivors who have had certain kinds of chemotherapy or medicines have problems with weight gain. Sometimes the added pounds stay on even when treatment ends. Breast cancer survivors who have had certain types of chemotherapy gain weight in a different way—they may lose muscle and gain fat tissue.

Unfortunately, the usual ways people try to lose weight may not work for them. Try to be patient with yourself. Look for the positive things that you can control, such as eating a healthy diet. Try to focus on the fact that treatment is over, and you are trying to get stronger with time.

Some cancer survivors have the opposite problem: they have no desire to eat, and they lose weight. Some men say that weight loss or loss of muscle tone is a bigger concern for them than weight gain. It makes them feel less strong and like less of a man.

Managing a Healthy Weight

For weight issues, ask your doctor or nurse about:

- Doing strength-building exercises, if you have lost muscle or gained fat tissue
- Talking to a dietitian or nutritionist who can help you plan a healthy diet that won't add extra pounds

Regaining a Lost Appetite

Here are some tips that have helped others improve their appetites:

- ✔ **Start with small meals.** Five small meals a day may be easier to manage than three larger ones.
- ✔ **Focus on your favorite foods.** If the thought of eating still lacks appeal, try the foods you really liked before treatment to jump-start your appetite. Try adding some fresh fruit, juice, or other flavoring to improve the taste.
- ✔ **Stay active.** A short walk before a meal can help you feel hungry.

Trouble Swallowing

Some people who have had radiation therapy or chemotherapy may find it hard to eat because they have trouble swallowing. People who have had radiation therapy to the head, neck, breast, or chest or those who have had surgery involving the larynx may also have this problem.

Getting Help

- Eat soft, bland foods moistened with sauces or gravies. Puddings, ice cream, soups, applesauce, and bananas and other soft fruits are nourishing and usually easy to swallow.
- Use a blender to process solid foods.
- Ask for advice from your health care team, including your doctor, nurse, nutritionist, and/or speech pathologist.
- Tilt your head back or move it forward while you are eating.
- Have a sip of water every few minutes to help you swallow and talk more easily. Carry a water bottle with you so you always have some handy.

Bladder or Bowel Control Problems

Bladder and bowel problems are among the most upsetting issues people face after cancer treatment. People often feel ashamed or fearful to go out in public. "Going back to work was the hardest thing," one prostate cancer survivor noted.

This loss of control can happen after treatment for bladder, prostate, colon, rectal, ovarian, or other cancers. Your surgery may have left you with no bladder or bowel control at all. Or perhaps you still have some control, but you make lots of sudden trips to the bathroom. The opposite problem can happen when a medicine you are taking for pain causes constipation.

Getting Help

It is very important to tell your doctor about any changes in your bladder or bowel habits. Ask your doctor or nurse about:

- Problems with constipation
- Kegel exercises (see page 34 on muscle weakness)
- Medicines that may help
- Help in coping with ostomies. If you have an ostomy, an opening from inside the body to the outside to pass urine or waste material, there are services and support groups to help you cope with changes (see page 13).

Menopause Symptoms

After chemotherapy, some women stop getting their periods every month—or stop getting them altogether. Some cancer treatments (and the medicines tamoxifen and raloxifene) can cause changes in women's bodies and reduce the amount of hormones they make. These changes can cause your periods to stop, as well as cause other symptoms of menopause (also called "the change" or "change of life").

Over time, some women will start getting their periods again (this is more likely for younger women), but others will not. Even though your doctor may have discussed early menopause with you, give yourself permission to mourn the loss of your fertility.

Some common signs of menopause are:

- **Irregular periods.** One of the first signs is a change in your periods. They may become less regular. They could be lighter. Some women have short times of heavy bleeding. Sometimes, they stop all of a sudden.
- **Hot flashes.** Hot flashes are often worse at night and can affect sleep or cause mood changes.
- **Problems with your vagina or bladder.** Tissues in these areas become drier and thinner. You may be more likely to get vaginal infections. As you get older, you may also have problems holding your urine or urinary tract problems.
- **Lack of interest in having sex.** These changes may make it hard for you to become sexually aroused.
- **Fatigue and sleep problems.** You may feel tired or have trouble getting to sleep, getting up early, or getting back to sleep after waking up in the middle of the night.
- **Memory and other problems, such as depression, mood swings, and irritability.** Some of these, especially memory problems, may be related to growing older. There may be a connection between changes in your hormone levels and your emotions.
- **Other changes in your body.** You may notice your waist getting bigger, less muscle and more fat around your body, or thinning and loss of elasticity of your skin.

Ask your doctor if you still need to use birth control, even if you are not getting your period.

Getting Help

See a gynecologist every year. Ask about:

- Medicines, supplements, or other approaches that can help you manage menopause symptoms
- Tests you should have (such as a bone density test to see if you are at risk for osteoporosis)
- Ways you can reduce your chance of getting:
  - **Osteoporosis.** Menopause can put you at risk for losing bone tissue, which can weaken your bones and make them easier to break.
  - **Heart disease.** Menopause can also lead to higher cholesterol, which can increase your risk of diseases that affect your heart and blood vessels.

Relieving Hot Flashes

Here are some tips that have helped others deal with hot flashes:

✔ Quit smoking.

✔ Drink plenty of water.

✔ Through exercise and diet, try to maintain a healthy weight. Exercise most days of the week, doing both weight-bearing and muscle-strengthening activities. Eat wisely. A balanced diet will provide most of the nutrients and calories your body needs to stay healthy.

✔ If you are having hot flashes, try to write down when they happen and what may cause them. This may help you find out what to avoid. You may also want to:

- Sleep in a cool room to avoid being awakened by hot flashes.
- Dress in layers that you can take off if you get warm.
- Use cotton sheets, and wear clothing that lets your skin "breathe."
- Try having a cold drink or turning on a fan at the beginning of a hot flash.
- Try not to eat a lot of spicy foods.
- Limit the alcohol and caffeine you drink.

Body Changes and Intimacy

Some body changes are short-term, and others will last forever. Either way, your looks may be a big concern after treatment. For example, people with ostomies after colon or rectal surgery are sometimes afraid to go out. They may feel ashamed or afraid that others will reject them. They may worry about the idea of having an "accident" in social situations.

Others don't like people being able to see treatment effects such as scars, skin changes, loss of limbs, and changes in weight. Even if your treatment doesn't show, your body changes may trouble you. Feelings of anger and grief are natural. Feeling bad about your body can also lower your sex drive. This loss of or reduction in your sex life may make you feel even worse about yourself.

Changes in the way you look can also be hard for your loved ones, which can be hard on you. Parents and grandparents often worry about how they look to a child or grandchild. They fear that changes in their appearance may scare the child or get in the way of their staying close.

Getting Help

How do you cope with body changes?

- Mourn your losses. They are real, and you have a right to grieve.
- Try to focus on the ways that coping with cancer has made you stronger, wiser, and more realistic.
- If you find that your skin has changed from radiation, ask your doctor about ways you can care for it.
- Look for new ways to enhance your appearance. A new haircut, hair color, makeup, or clothing may give you a lift.
- If you choose to wear a breast form (prosthesis), make sure it fits you well. Your health insurance plan may pay for it.
- Try to recognize that you are more than your cancer. Know that you have worth—no matter how you look or what happens to you in life.

Changes in Sex Life

You may have changes in your sex life after cancer treatment—many people do. Depending on the cancer you had, these problems may be short-term or long-term. For example, about half of women who have had long-term treatment for breast and reproductive organ cancers and more than half of men treated for prostate cancer report long-term sexual problems. Many cancer survivors say they were not prepared for the changes in their sex lives.

Sexual problems after cancer treatment are often caused by changes to your body—from surgery, chemotherapy, or radiation, or by the effects of certain medicines. Sometimes emotional issues can be the cause of sexual problems. Some examples include anxiety, depression, feelings of guilt about how you got cancer, changes in body image after surgery, and stress between you and your partner. Your past sex life is not related to your current sexual problems.

What types of problems occur? People report these main concerns:

- **Worrying about intimacy after treatment.** Some may struggle with their body image after treatment. Even thinking about being seen without clothes may be stressful. People may worry that having sex will hurt or that they won't be able to perform or will feel less attractive. Pain, loss of interest, depression, or cancer medicines can also affect sex drive.

- **Not being able to have sex as you did before.** Some cancer treatments cause changes in sex organs that also change your sex life.
  - Some men can no longer get or keep an erection after treatment for prostate cancer, cancer of the penis, or cancer of the testes. Some treatments can also weaken a man's orgasm or make it dry.
  - Some women find it harder, or even painful, to have sex after cancer treatment. Some cancer treatments can cause these problems; sometimes, there is no clear cause. Some women also have a loss of sensation in their genital area.

- **Having menopause symptoms.** When women stop getting their periods, they can get hot flashes, dryness or tightness in the vagina, and/or other problems that can affect their desire to have sex.

- **Losing the ability to have children.** Some cancer treatments can cause infertility, making it impossible for cancer survivors to have children. Depending on type of treatment, age, and length of time since treatment, you may still be able to have children. For more information about fertility, see the Resources section on page 57.

Getting Help

"I knew about the chance of impotence. What I didn't expect was my total loss of interest in sex, which really caused some problems between my wife and me." —MITCH

Your doctor may be able to help you deal with these problems, but he or she may not bring up the subject. You may have to mention it yourself. If you think you might have trouble getting started, bring this booklet with you.

Often, sexual problems will not get better on their own. To get help with many of these problems, it's important to tell your doctor about any changes in your sex life. Sometimes there can be an underlying medical problem that causes changes, such as:

- **Erection problems.** Medicine, assistive devices, counseling, surgery, or other approaches may help.
- **Vaginal dryness.** Dryness or tightness in the vagina can be caused by menopause. Ask whether using a water-based lubricant during sex, using vaginal dilators before sex, and/or taking hormones or using a hormone cream are options for you.
- **Muscle weakness.** You can help strengthen muscles in your genital area by doing Kegel exercises. Practice by controlling your muscles to stop the flow of urine. You can do these exercises even when you are not urinating. Just tighten and relax the muscles as you sit, stand, or go about your day.

Other issues you may want to discuss include:

- **Concerns about having children.** Discuss family planning concerns with your doctor. If you're a woman, ask if you still need to use birth control, even if you are not getting your period.
- **Talking with a counselor or a psychologist.** You may feel that some of your sexual problems are due to your emotions, like stress or body image. Some people find that sexual problems related to cancer start to strain their relationship with their partner. If this is the case, ask a nurse or social worker if you can talk to a counselor. Talking to someone alone, or with your partner, may help.
- **Seeing a sex therapist.** He or she may be able to help you talk openly about your problems, work through your concerns, and come up with new ways to help you and your partner.

Talking With Your Partner

Even for a couple that has been together a long time, staying connected can be a major challenge at first. It may be comforting to learn that very few committed relationships end because of ostomies, scars, or other body changes. Divorce rates are about the same for people with and without a cancer history.

Tell your partner how you feel about your sex life and what you would like to change. You might want to talk about your concerns, your beliefs about why your sex life is the way it is, your feelings, and what would make you feel better.

Approaching it openly avoids blame, stays positive, and gives your partner a better sense of how you are feeling. Here is an example of how you might start your discussion:

> "I know it's tough to talk about, but I think we should discuss our sex life. We've only made love a few times lately. I miss being close to you. I worry that my scars might be a problem. Can you tell me how you feel?"

Try to be open minded as you listen to your partner's point of view:

- Focus on your partner's comments, not on what you plan to say in response.
- Repeat what he or she says in your own words.
- Ask questions to better understand your partner's concerns.
- Acknowledge that your partner's views matter to you. Say things like "I see why you might think that" or "I never thought of it that way before."

Feeling Intimate After Treatment

- ✔ **Be proud of your body.** It got you through treatment!
- ✔ **Think of things that help you feel more attractive and confident.**
- ✔ **Focus on the positive.** Try to be aware of your thoughts, since they can affect your sex life.
- ✔ **Touch each other.** Kiss, hug, and cuddle, even if you cannot have the kind of sex that you used to have.
- ✔ **Be open to change.** You may find new ways to enjoy intimacy.

Dating

If you're single, body changes and concerns about sex can affect how you feel about dating. As you struggle to accept the changes yourself, you may also worry about how someone else will react to physical things, such as scars or ostomies. Or you may find it awkward to bring up sexual problems or loss of fertility, which can make feeling close even harder.

You may wonder how and when to tell a new person in your life about your cancer and body changes. For some, the fear of being rejected keeps them from seeking the social life they would like to have. Others who choose not to date may face pressure from friends or family to be more sociable. Here are some ideas that can make it easier to get back into social situations:

- Focus on activities that you have time to enjoy, such as taking a class or joining a club.
- Try not to let cancer be an excuse for not dating or trying to meet people.
- Wait until you feel a sense of trust and friendship before telling a new date about your cancer. Practice what you will say to someone if you are worried about how you will handle it. Think about how he or she might react, and be ready with a response.
- Think about dating as a learning process with the goal of having a social life you enjoy. Not every date has to be perfect. If some people reject you (which can happen with or without cancer), you have not failed. Try to remember that not all dates worked out before you had cancer.

Your Feelings

"I don't think you ever forget the fact that it could come back." —EMILY

Just as cancer treatment affects your physical health, it can affect the way you feel, think, and do the things you like to do. It's normal to have many different feelings after treatment ends. Just as you need to take care of your body after treatment, you need to take care of your emotions.

Each person's experience with cancer is different, and the feelings, emotions, and fears that you have are unique. The values you grew up with may affect how you think about and deal with cancer. Some people may feel they have to be strong and protect their friends and families. Others seek support from loved ones or other cancer survivors or turn to their faith to help them cope. Some seek help from counselors and others outside the family, while others don't feel comfortable with this approach.

Whatever you decide, it's important to do what's right for you and try not to compare yourself with others.

Worrying About Your Health

Worrying about the cancer coming back is normal, especially during the first year after treatment. This is one of the most common fears people have after cancer treatment. For some, the fear is so strong that they no longer enjoy life, sleep well, eat well, or even go to follow-up visits. "If I get it again, what am I going to do?" one woman said. "I never thought I'd make it through the first time." Others may react in a more positive way. As one survivor put it, "Cancer is just part of life, and we always have hope."

As time goes by, many survivors report that they think about their cancer less often. However, even years after treatment, some events may cause you to become worried. Follow-up visits, symptoms similar to the ones you had before, the illness of a family member, or the anniversary of the date you were diagnosed can trigger concern.

Coping With Fear of Cancer Returning

- ✔ **Be informed.** Learning about your cancer, understanding what you can do for your health now, and finding out about the services available to you can give you a greater sense of control. Some studies even suggest that people who are well-informed about their illness and treatment are more likely to follow their treatment plans and recover from cancer more quickly than those who are not.
- ✔ **Express your feelings of fear, anger, or sadness.** People have found that when they express strong feelings like anger or sadness, they're more able to let go of them. Some sort out their feelings by talking to friends or family, other cancer survivors, or a counselor. But even if you prefer not to discuss your cancer with others, you can still sort out your feelings by thinking about them or writing them down.
- ✔ **Look for the positive.** Sometimes this means looking for the good even in a bad time or trying to be hopeful instead of thinking the worst. Try to use your energy to focus on wellness and what you can do now to stay as healthy as possible.
- ✔ **Don't blame yourself for your cancer.** Some people believe that they got cancer because of something they did or did not do. Remember, cancer can happen to anyone.
- ✔ **You don't have to be upbeat all the time.** Many people say they want to have the freedom to give in to their feelings sometimes. As one woman said, "When it gets really bad, I just tell my family I'm having a bad cancer day and go upstairs and crawl into bed."
- ✔ **Find ways to help yourself relax.** The exercises on pages 60–61 have been proven to help others and may help you relax when you feel worried.
- ✔ **Be as active as you can.** Getting out of the house and doing something can help you focus on other things besides cancer and the worries it brings.
- ✔ **Look at what you can control.** Some people say that putting their lives in order helps. Being involved in your health care, keeping your appointments, and making changes in your lifestyle are among the things you can control. Even setting a daily schedule can give you a sense of control. And while no one can control every thought, some say that they try not to dwell on the fearful ones.

Feeling Stress

When you were diagnosed, you may have put concerns such as family, work, or finances aside. Now that treatment is over, these issues may begin to resurface.

Many cancer survivors also worry that stress may have played a role in their illness. It's important to remember that the exact cause of many cancers is still unknown. No research shows that stress causes cancer, but we do know that stress can cause other health problems. Finding ways to reduce or control the stress in your life may help you feel better. Devoting time to any activities that make you feel calm or relaxed may help.

Reducing Stress

Many survivors have found activities like the ones below useful in dealing with their worries after treatment ends. Ask your doctor, nurse, social worker, or local cancer organization about taking part in activities like these.

- **Exercise.** Exercise is a known way to reduce stress and feel less tense—whether you've had cancer or not. As one man put it, "I can feel down a little bit, and it is a fine line with depression, but when I walk 30 or 45 minutes in the fresh air, I feel like I can take on the world sometimes." See your doctor before making an exercise plan, and be careful not to overdo it. If you can't walk, ask about other types of movement that may be helpful, such as chair exercises or stretching.
- **Mind-body methods.** Things like meditation or relaxation may help you lower stress by quieting your mind. Try focusing on your breathing or repeating words or phrases to yourself. Other methods include hypnosis, yoga, or imagery.
- **Creative outlets.** Art, music, or dance gives people the chance to express themselves in different ways. Even people who have never danced, painted, or drawn before have found these activities helpful and fun.
- **Sharing personal stories.** Telling and hearing stories about living with cancer can help people air their concerns, solve problems, and find meaning in what they've been through. See pages 44–45 for support group information.

Finding Humor and Laughing

"Is cancer life-threatening? Yes, but why die mad? So I joked about it all the way through, and I think it helped me." —ARI

Laughter can help you relax. When you laugh, your brain releases chemicals that produce pleasure and relax your muscles. Even a smile can fight off stressful thoughts. Of course, you may not always feel like laughing, but other people have found that these ideas can help:

- ✔ Ask people to send you funny cards.
- ✔ Enjoy the funny things children and pets do.
- ✔ Watch funny movies or TV shows.
- ✔ Listen to comedy tapes or CDs.
- ✔ Buy a funny desk calendar.
- ✔ Read joke books or check out jokes on the Internet.
  If you don't own a computer, use one at your local library.

You may even find that you can laugh at yourself. "I went by to help a friend this summer, and it was really hot, so I took my wig off," one woman said. "I got ready to go and I couldn't find it. After searching high and low, I found it hanging from her dog's mouth. But I just stuck it on my head and went home. My husband said, 'What happened?' Needless to say that wig has never been the same."

Coping With Depression and Anxiety

After treatment, you may still feel angry, tense, or sad. For most people, these feelings go away or lessen over time. For some people though, these emotions can become more severe. The painful feelings do not get any better, and they get in the way of daily life. These people may have a medical condition called depression. For some, cancer treatment may have added to this problem by changing the way the brain works.

Getting Help

Talk with your doctor. If your doctor thinks that you suffer from depression, he or she may treat it or refer you to other experts. Many survivors get help from therapists who are experts in both depression and helping people recovering from cancer. Your doctor may also give you medicine to help you feel less tense.

If you find it hard to talk about your feelings, you may want to show your doctor this booklet. It can help you explain what you're going through. Don't feel that you should have to control these feelings on your own. Getting the help you need is important for your life and your health.

Do I Need Help?

If you have any of the following signs for more than 2 weeks, talk to your doctor about treatment. Some symptoms could be due to physical problems, so it's important to be willing to talk about them with your doctor.

✔ Emotional signs:

- Feelings of worry, anxiety, or sadness that don't go away
- Feeling emotionally numb
- Feeling overwhelmed, out of control, or shaky
- Having a sense of guilt or feeling unworthy
- Feeling helpless or hopeless
- Feeling short-tempered or moody
- Having a hard time concentrating, or feeling scatterbrained
- Crying for long periods of time or many times each day
- Focusing on worries or problems

- Having a hard time getting certain thoughts out of your mind
- Finding it hard to enjoy everyday things, such as food or being with friends
- Finding yourself avoiding situations or things that you know are really harmless
- Thinking about hurting or killing yourself

✔ Body changes:

- Unintended weight gain or loss not due to illness or treatment
- Sleep problems, such as not being able to sleep, having nightmares, or sleeping too much
- Racing heart, dry mouth, increased perspiration, upset stomach, diarrhea
- Physically slowing down
- Fatigue that doesn't go away, headaches, or other aches and pains

Feeling Angry

Many people find themselves feeling angry about having cancer or about things that happened to them during their diagnosis or treatment. They may have had a bad experience with a health care provider or with an unsupportive friend or relative.

Feeling angry is normal. And sometimes it can motivate you to take action. But hanging on to it can get in the way of taking care of yourself or moving on. If you can, look at what's causing your anger and what you can do to lessen it.

Feeling Alone

"I went to radiation treatment every day, and the staff became like part of my family. And then when I finished, there was this instant separation, and I really felt a loss." —TOM

After treatment, you may miss the support you got from your health care team. You may feel as if your safety net has been pulled away and that you get less attention and support from health care providers now that treatment is over. Feelings like these are normal any time your regular contact with people who mean a lot to you comes to an end.

It's also normal to feel somewhat cut off from other people—even family and friends—after cancer treatment. Often, friends and family want to help, but they don't know how. Others may be scared of the disease. You may also feel that only others who have had cancer can understand your feelings.

Getting Help

What can you do to make yourself feel better? Try to think about how you could replace the emotional support you used to receive from your health care team, such as:

- **Asking one of your nurses or doctors if you could call sometimes.** This could help you stay connected and help you feel less alone. Even just knowing you can call them may help.
- **Finding support services offered over the phone or Internet.**
- **Finding new sources of support for your recovery.** Friends, family, other cancer survivors, and clergy members are a few ideas.
- **Joining a cancer support group.** People who have had cancer meet in groups to talk about their feelings and concerns. Besides sharing their own stories, they hear what others have gone through and how other people have dealt with the same problems they are facing. A support group may also help members of your family cope with their concerns.

Joining a Support Group

"I could feel myself getting down, and I joined this group and we have a great time. We cry, we laugh, we carry on." —ELIA

Support groups can have many benefits. Even though a lot of people receive support from friends and family, the number one reason they join a support group is to be with others who have had similar cancer experiences. Some research shows that joining a support group improves quality of life and enhances survival.

Support groups can:

- Give you a chance to talk about your feelings and work through them
- Help you deal with practical problems, such as problems at work or school
- Help you cope with side effects of treatment

Types of Support Groups and Where To Find Them

There are many different types of support groups. Some may be for one type of cancer only, while others may be open to those with any cancer. Some may be for women or for men only. Support groups may be led by health professionals or fellow cancer survivors.

Support groups aren't just for people who have had cancer. Support groups can be helpful for children or family members of survivors. These groups focus on family concerns such as role changes, relationship changes, financial worries, and how to support the person who had cancer. Some groups include both cancer survivors and family members.

Not only do support groups meet in person, they also meet online. Internet support groups can be a big help to people with computers who live in rural areas or who have trouble getting to meetings. Some Internet groups are sponsored by cancer organizations, while others are not monitored. With informal chat groups, you can seek support at any time of the day or night. While these online groups can provide valuable emotional support, they may not always offer correct medical information. Be careful about any cancer information you get from the Internet, and check with your doctor before making any changes that are based on what you read.

Is a Support Group Right for Me?

A support group may not be right for everyone. For some people, hearing about others' problems can make them feel worse. Or you may find that your need for a support group changes over time.

If you are thinking about joining a support group, here are some questions you may want to ask the group's contact person:

- How large is the group?
- Who attends (survivors, family members, types of cancer, age range)?
- How long are the meetings?
- How often does the group meet?
- How long has the group been together?
- Who leads the meetings—a professional or a survivor?
- What is the format of the meetings?
- Is the main purpose to share feelings, or do people also offer tips to solve common problems?
- If I go, can I just sit and listen?

Before joining a group, here are questions you may want to ask yourself:

- Am I comfortable talking about personal issues?
- Do I have something to offer to the group?
- What do I hope to gain by joining a group?

Support groups vary greatly, and if you have one bad experience, it doesn't mean support groups are not a good option for you. You may also want to find another cancer survivor with whom you can discuss your cancer experience. Many organizations can pair you with someone who had your type of cancer and is close to your age and background.

The Association of Cancer Online Resources (ACOR) offers access to mailing lists that provide support and information to those affected by cancer and related disorders. The ACOR mailing lists are a group of free, unmoderated discussion lists for patients, family, friends, researchers, and physicians to discuss clinical and other issues and advances pertaining to all forms of cancer. Learn more online at www.acor.org.

Finding Meaning After Cancer Treatment

"After treatment for breast cancer, I knew my life had changed forever. Nothing could ever be the same. I was very sad at my losses, but I felt I had been given the gift of a new life." —LINDA

Survivors often express the need to understand what having had cancer means to their lives now. In fact, many find that cancer causes them to look at life in new ways. They may reflect on spirituality, the purpose of life, and what they value most.

These changes can be very positive. Many report feeling lucky or blessed to have survived treatment and take new joy in each day. For some, the meaning of their illness becomes clear only after they have been living with cancer for a long time; for others, the meaning changes over time. It's also common to view the cancer experience both negatively and positively at the same time.

Often, people make changes in their lives to reflect what matters most to them now. You might spend more time with your loved ones, place less focus on your job, or enjoy the pleasures of nature. You might also find that going through a crisis like cancer gives you renewed strength.

"I feel good that I've found ways to cope," one colon cancer survivor said. "I also feel better able to handle any future problems that might come up. I have strength that I didn't know I had."

Faith, Religion, or Spirituality

Having a serious illness can affect your spiritual outlook, regardless of whether you feel connected to traditional religious beliefs. After treatment, you and your loved ones may struggle to understand why cancer has entered your lives. You may wonder why you had to endure such a trial in your life.

Cancer survivors often report that they look at their faith or spirituality in a new way. For some, their faith may get stronger or seem more vital. Others may question their faith and wonder about the meaning of life or their purpose in it. Many say they have a new focus on the present and try to live each day to the fullest.

Many survivors have found that their faith, religion, or sense of spirituality is a source of strength. They say that through their faith, they have been able to find meaning in their lives and make sense of their cancer experience. Faith or religion can also be a way for survivors to connect with others in their community who may share similar experiences or outlooks or who can provide support. Studies have also shown that for some, religion can be an important part of both coping with and recovering from cancer.

The way cancer affects faith or spirituality is different for everyone. It's common to question your beliefs after cancer. These questions can be difficult, but for some, seeking answers and searching for personal meaning in spirituality helps them cope.

Finding Comfort and Meaning

- ✔ Read uplifting stories about the human spirit.
- ✔ Pray or meditate to help you gain perspective.
- ✔ Take part in community or social gatherings for your own support and to support others.
- ✔ Talk with others who have had similar experiences.
- ✔ Find resources at a place of worship for people dealing with chronic illnesses like cancer.

Finding Support

How can you find faith-based support in your community? Here are some ideas that have helped other cancer survivors:

- **Contact a religious or spiritual leader in your community.** Most have been trained in counseling people with major illnesses.
- **Contact the chaplain at your local hospital or treatment facility.** Most hospitals have a staff chaplain who can provide support to people of different faiths and religions, as well as people who do not consider themselves religious at all. These chaplains have also been trained to provide spiritual support to patients and families in crisis.

- **Talk with your hospital, health care team, or social worker.** They may know about faith-based organizations in your community that provide specialized services for cancer survivors.

How Can You Find New Meaning in Your Life After Cancer?

- **Assess your life.** Some survivors say their cancer gave them a wake-up call and a second chance to make life what they want it to be. Ask yourself: do your roles in your family fulfill you, or are you doing what people expect of you? What are things you've always wanted to try? Are you happy in your job, or are you just used to it?
- **Seek spiritual support.** A trusted clergy member or professional counselor may be able to help you with life questions.
- **Keep a journal.** Write down your thoughts about what gives meaning to your life now.
- **Think about helping others who have had cancer.** For some, reaching out and helping others helps them find meaning. Others want to get cancer out of their minds and prefer to focus their energy in other ways. If you want to help, many local and national cancer groups need volunteers. Or you may prefer to reach out to people you know and spread the word through family and friends. (The NCI booklet *Facing Forward: Ways You Can Make a Difference in Cancer* gives more information. See the Resources section on page 57 for how to order it.)
- **Think about taking part in a research study.** Research studies are trying to identify the effects of cancer and its treatment on survivors. Joining a research study is always voluntary, and it could benefit both you and others. If you want to learn more about studies that involve cancer survivors, talk with your doctor or see the Resources section.

Social and Work Relationships

"I think some families become stronger because of it. We've had our rough spots, but we have never again taken each other for granted." —DARRYL

Having cancer can change relationships with the people in your life. It's normal to notice changes in the way you relate to family, friends, and other people that you are around every day—and the way they relate to you.

Your Family

When treatment ends, families are often not prepared for the fact that recovery takes time. In general, your recovery will take much longer than your treatment did. Survivors often say that they didn't realize how much time they needed to recover. This can lead to disappointment, worry, and frustration for everyone. Families also may not realize that the way their family works may have changed permanently as a result of cancer. They may need help to deal with the changes and keep the "new" family strong.

Some survivors say they would not have been able to cope without their family members and the help they offered. And even though treatment has ended, they still receive a lot of support. For others, problems that were present before the cancer may still exist, or new ones may develop. You may receive less support from others than you had hoped.

Even though treatment has ended, you may face problems with your family. For instance, if you used to take care of the house or yard before your treatment, you may find that these jobs are still too much for you to handle. Yet family members who took over for you may want life to go back to normal and expect you to do what you used to do around the house. You may feel that you aren't getting the support you need.

At other times, you may expect more from your family than you receive. They may disappoint you, which might make you angry or frustrated. For one woman, it was a family member's lack of support during her treatment that upset her. "Never once, not a card, not a phone call, and I have a hard time looking at her today."

You may still need to depend on others during this time, even though you want to get back to the role you had in your family before. At the same time, your family is still adjusting. It may be hard for you and your family to express feelings or know how to talk about your cancer.

To help your family members, you may want to share NCI's booklet for caregivers, *Facing Forward: When Someone You Love Has Completed Cancer Treatment* (see the Resources section on page 57 for how to order this booklet).

Getting Help With Family Issues

Some family members may have trouble adjusting to changes or feel that their needs aren't being met. Your family may want to deal with issues such as these on its own, or you may want to consider getting help. Ask your doctor or social worker to refer you to a counselor or therapist. An expert on family roles and concerns after cancer treatment may be able to help your family solve its problems.

How do you cope with family issues? Here are some ideas that have helped others deal with family concerns:

- Let others know what you are able to do as you heal—and what not to expect. For example, don't feel you must keep the house or yard in perfect order because you always did in the past.
- Give yourself time. You and your family may be able to adjust over time to the changes cancer brings. Just being open with each other can help ensure that each person's needs are met.
- Help the children in your family understand that you were treated for cancer and that it may take a while for you to have the energy you used to have.

Children of cancer survivors have said that these things are important:

- Being honest with them
- Speaking as directly and openly as possible
- Allowing them to become informed about your cancer and involved in your recovery
- Spending extra time with them

With your permission, other family members should also be open with your children about your cancer and its treatment.

Your Workplace

Research shows that cancer survivors who continue to work are as productive on the job as other workers. Most cancer survivors who are physically able to work do go back to their jobs. Returning to work can help them feel they are getting back to the life they had before being diagnosed with cancer.

Some cancer survivors change jobs after cancer treatment. If you decide to look for a new job after cancer treatment, remember that you do not need to try to do more—or settle for less—than you are able to handle. If you have a résumé, list your jobs by the skills you have or what you've done, rather than by jobs and dates worked. This way, you don't highlight the time you didn't work due to your cancer treatment.

Whether returning to their old jobs or beginning new ones, some survivors are treated unfairly when they return to the workplace. Employers and employees may have doubts about cancer survivors' ability to work.

Handling Problems at Work

- **Decide how to handle the problem.**
  - What are your rights as an employee?
  - Are you willing to take action to correct a problem?
  - Do you still want to work there? Or would you rather look for a new job?
- **If necessary, ask your employer to adjust to your needs.**
  - Start by talking informally to your supervisor, personnel office, employee assistance counselor, shop steward, or union representative.
  - Ask for a change that would make it easier for you to keep your job (for example, flextime, working at home, special equipment at work).
  - Document each request and its outcome for your records.
- **Get help working with your employer if you need it.**
  - Ask your doctor or nurse to find times for follow-up visits that don't conflict with your other responsibilities.
  - Get your doctor to write a letter to your employer or personnel officer explaining how, if at all, your cancer may affect your work or your schedule.

You have no legal obligation to talk about your cancer history unless your past health has a direct impact on the job you seek.

"My boss has been good about the time off I've taken—so far. But I still worry that questions about my health will hurt my future here."

—LISA

Friends and Coworkers

"When you say the 'C' word, it just turns some people right off, and they will mumble something and walk off." —JACK

The response of friends, coworkers, or people at school after your cancer treatment may differ. Some may be a huge source of support, while others may be a source of anger or frustration. Some people mean well, but they do not know the right thing to say. Maybe they just don't know how to offer support. Others don't want to deal with your cancer at all.

If friends and coworkers seem unsupportive, it could be because they are anxious for you or for themselves. Your cancer experience may threaten them because it reminds them that cancer can happen to anyone. Try to understand their fears and be patient as you try to regain a good relationship.

Many survivors say that acting cheerful around others for their comfort is a strain. "I don't want to smile any more," one melanoma survivor said. "I don't have the energy to be upbeat all the time." A prostate cancer survivor noted, "You know if you complain sometimes, for some people, it turns them off. So I try not to do that."

As survivors sort out what matters most, they may even decide to let some casual friendships go, to give more time to the meaningful ones. One brain cancer survivor found that after cancer, "You really know how many true friends you've got. And they don't stop calling just because they hear you're in remission. They really love you and think something of you." A kidney cancer survivor found that "letting weak friendships go was hard, but I also got support I didn't expect from people at work and in church."

On the job or where you volunteer, some people may not understand about cancer and your ability to perform while recovering from treatment. They may think you aren't able to work as hard as before or that your having had cancer means you are going to die soon. Sometimes, fear and lack of knowledge result in unfair treatment.

Getting Help

If you find that a friend or coworker's feelings about cancer are hurting you, try to resolve the problem with that person face-to-face. If it is still affecting your work after that, your manager, shop steward, company medical department, employee assistance counselor, or personnel office may be able to help.

When hurtful remarks or actions get you down, talking with a friend, family member, or counselor may help you come up with ideas for handling it. But if coworker attitudes get in the way of doing your job, it is a problem that management should address.

Relating to Others

How do you relate to other people in your life after cancer treatment?

- **Accept help.** When friends or family offer to help, say yes, and have in mind some things that they could do to make your life easier. In this way, you will get the support you need, and your loved ones will feel helpful. "When I first started treatment, I had a lot of help," said one colon cancer survivor. "So I felt bad asking my friends for more help when my treatment ended. But I still really needed it, so I let them know."

- **Address any problems that come up when you go back to work or school.** Your supervisor (or his or her supervisor), teacher, or coworkers may be able to help those around you understand how you want to be treated as a cancer survivor. If problems with others get in the way of your work or studies, you may want to talk with your bosses, your union, the company's Human Resources department, or the school's Student Affairs office.

- **Keep up contacts during your recovery.** Friends and coworkers will worry about you. If they find out about your treatment and progress, they will be less anxious and scared. Talk to them on the phone, send email, or appoint a trusted friend or family member to do this for you. When you are able, have lunch with friends or stop in for an office party. Your return to work or other activities will be easier for you and others if you stay in touch.

- **Plan what you'll say about your cancer.** There is no right way to deal with others about your illness, but you do need to think about what you'll say when you're back on the job. Some cancer survivors don't want to focus on their cancer or be linked in people's minds with the disease. Others are very open about it, speaking frankly with their boss or other workers to air concerns, correct wrong ideas, and decide how to work together. The best approach is the one that feels right to you.

Reflection

courage doesn't always roar.
sometimes courage is the
quiet voice at the end of the day saying,
"i will try again tomorrow."

—MARY ANNE RADMACHER*

The end of treatment can be a time to look forward to the future. New rituals and new beginnings can bring a sense of relief and joy. It may also be a time of physical and emotional change. Now that treatment is over, try to take time to get back in tune with yourself. Allow healing time for you and your family members and caregivers. Think about what you can do to begin living without cancer as a main focus.

Whether good or bad, life-changing situations often give people the chance to grow, learn, and appreciate what's important to them. Many people with cancer describe their experience as a journey. It's not necessarily a journey they would have chosen for themselves. But it sometimes presents the opportunity to look at things in a different way.

* *used with permission*

Financial and Legal Matters

The financial challenges that people with cancer and their families face are very real. During an illness, you and your family may have found it hard to find the time or energy to review your options. Yet it's important to keep your family financially healthy.

For hospital bills, you may want to talk with a hospital financial counselor. You may be able to work out a monthly payment plan or even get a reduced rate. You may also want to stay in touch with your insurance company to make sure costs are covered.

For information about resources that are available, see the Resources section. You can also get the NCI fact sheet "Financial Assistance for Cancer Care" at www.cancer.gov, search terms "financial assistance." Or call toll-free 1-800-4-CANCER (1-800-422-6237) to ask for it.

Legal Documents

If you haven't developed an advance directive, you may want to consider it. Advance directives are legal documents that let a person decide important issues ahead of time, including how much treatment to receive and who should make decisions if he or she can't. Having an advance directive helps ensure that you get the treatment you want. Understanding your wishes will also make it easier for family members if a time comes when treatment decisions need to be made.

Advance directives:

- **A living will** lets people know what kind of medical care patients want if they are unable to speak for themselves.
- **A durable power of attorney for health care** names a person to make medical decisions for a patient if he or she can't make them. This person, chosen by the patient, is called a health care proxy.

Other legal papers that are not part of the advance directives:

- **A will** tells how a person wants to divide money and property among his or her heirs. (Heirs are usually the surviving family members. Other people may also be named as heirs in a will.)
- **A trust** appoints the person a patient chooses to manage money for him or her.
- **Power of attorney** appoints a person to make financial decisions for the patient when he or she can't make them.

A lawyer does not always need to be present when you fill out these papers. However, a notary public may be needed. Each state has its own laws about advance directives. Check with your lawyer or social worker about the laws in your state. See the Resources section on page 57 for more information.

Resources

For a Complete List of Resources

See the fact sheet, "National Organizations That Offer Services to People With Cancer and Their Families," at www.cancer.gov, search terms "national organizations." Or call 1-800-4-CANCER (1-800-422-6237) to ask for it.

Federal Agencies

National Cancer Institute

NCI provides current information on cancer prevention, screening, diagnosis, treatment, genetics, and supportive care. It also lists clinical trials and specific cancer topics in NCI's Physician Data Query (PDQ®) database. The following free material may also be helpful. To order, visit NCI's Web site or call NCI's Cancer Information Service (CIS) toll-free.

- *Facing Forward: Ways You Can Make a Difference in Cancer*
- *Facing Forward: When Someone You Love Has Completed Cancer Treatment—Support for Caregivers*
- *Moving Beyond Breast Cancer* (DVD or videotape)

Cancer Information Service

CIS answers questions about cancer, clinical trials, and cancer-related services and helps users find information on the NCI Web site. It also provides NCI printed materials.

Phone: 1-800-4-CANCER (1-800-422-6237)
TTY: 1-800-332-8615
Web site: www.cancer.gov
Chat online: www.cancer.gov/help

Administration on Aging

The Administration on Aging provides information, assistance, individual counseling, organization of support groups, caregiver training, respite care, and supplemental services.

Phone: 1-202-619-0724
TTY: 1-800-877-8339
Web site: www.aoa.gov

Centers for Medicare & Medicaid Services

The Centers for Medicare & Medicaid Services provides information for consumers about patient rights, prescription drugs, and health insurance issues, including Medicare and Medicaid.

Phone: 1-800-MEDICARE (1-800-633-4227)
Web site: www.medicare.gov (for Medicare information) or www.cms.hhs.gov (for the free booklet *Medicare Basics: A Guide for Caregivers*)

Equal Employment Opportunity Commission

EEOC provides fact sheets about job discrimination, protections under the Americans With Disabilities Act, and employer responsibilities. It also coordinates investigations of employment discrimination.

Phone: 1-800-669-4000
TTY: 1-800-669-6820
Web site: www.eeoc.gov

National Association of Area Agencies on Aging/Eldercare Locator

The Eldercare Locator is a nationwide directory assistance service designed to help older persons and caregivers find local resources for support. Areas of support include transportation, meals, home care, housing alternatives, legal issues, and social activities.

Phone: 1-800-677-1116
Web site: www.eldercare.gov

U.S. Department of Labor/Office of Disability Employment Policy

The U.S. Department of Labor provides fact sheets on a variety of disability issues, including discrimination, workplace accommodation, and legal rights.

Phone: 1-866-ODEP-DOL (1-866-633-7365)
TTY: 1-877-889-5627
Web site: www.dol.gov/odep

Nonprofit Organizations

American Cancer Society/National Cancer Information Center

ACS provides cancer information and support to patients, families, and caregivers. It also supports research, community education, and advocacy and public policy issues.

Phone: 1-800-ACS-2345 (1-800-227-2345)
Web site: www.cancer.org

Cancer*Care*

Cancer*Care* provides free, professional support services to anyone affected by cancer: people with cancer, caregivers, children, loved ones, and the bereaved. Cancer*Care* programs—including counseling, education, financial assistance and practical help—are provided by trained oncology social workers and are free of charge.

Phone: 1-800-813-HOPE (1-800-813-4673)
Web site: www.cancercare.org

Cancer Hope Network

Cancer Hope Network matches patients and families with trained volunteers who have recovered from a similar cancer experience.

Phone: 1-877-HOPENET (1-877-467-3638)
Web site: www.cancerhopenetwork.org

Family Caregiver Alliance

FCA addresses the needs of families and friends who provide long-term care at home.

Phone: 1-800-445-8106
Web site: www.caregiver.org

Gilda's Club, Inc.

Gilda's Club provides social and emotional support for patients, families, and friends.

Phone: 1-888-GILDA-4-U (1-888-445-3248)
Web site: www.gildasclub.org

Lance Armstrong Foundation

The Lance Armstrong Foundation seeks to inspire and empower people living with, through, and beyond cancer to live strong. It provides education, advocacy, and public health and research programs.

Phone: 1-512-236-8820 (general number)
1-866-235-7205 (LIVESTRONG Survivor*Care* program)

Web site: www.livestrong.org

National Coalition for Cancer Survivorship

NCCS provides information and resources on cancer support, advocacy, and quality-of-life issues to cancer survivors and their loved ones.

Phone: 1-877-NCCS-YES (1-877-622-7937)

Web site: www.canceradvocacy.org

National Family Caregivers Association

NFCA provides information, education, support, public awareness, and advocacy for caregivers.

Phone: 1-800-896-3650

Web site: www.nfcacares.org

NeedyMeds

The NeedyMeds Web site lists medicine assistance programs available from drug companies. **NOTE:** Usually, patients cannot apply directly to these programs. Ask a doctor, nurse, or social worker to contact NeedyMeds on your behalf.

Web site: www.needymeds.com

Patient Advocate Foundation

PAF provides education, legal counseling, and referrals to cancer patients and survivors. It specializes in matters related to managed care, insurance, financial issues, job discrimination, and debt crisis.

Phone: 1-800-532-5274

Web site: www.patientadvocate.org

The Well Spouse Association

The association provides support to wives, husbands, and partners of chronically ill and/or disabled persons.

Phone: 1-800-838-0879

Web site: www.wellspouse.org

The Wellness Community

The Wellness Community is a national organization that provides support groups, stress reduction and cancer education workshops, nutrition guidance, exercise sessions, and social events.

Phone: 1-888-793-WELL (1-888-793-9355)

Web site: www.wellness-community.org

Learning To Relax

Many people with cancer have found that practicing deep relaxation has helped relieve their pain or reduce their stress. The exercises on the next few pages may not be right for everyone. Ask your doctor or nurse if these exercises can help you. Before trying the full exercise below, first practice steps 1 through 5, so you can get used to deep breathing and muscle relaxation.

You may find that your mind wanders. When you notice yourself thinking of something else, gently direct your attention back to your deepening relaxation. Be sure to maintain your deep breathing. If any of these steps makes you feel uncomfortable, feel free to leave it out.

Practicing Relaxation To Relieve Pain and Stress

Relaxation can help you feel better—both mentally and physically. For most of us, though, it is not easy to "just relax." Relaxation is a skill, and it needs to be practiced, just like any other skill.

Many people wait until they are in a lot of pain or feel a lot of stress before they try to relax, when it can be hardest to succeed. Then they might try to relax by overeating, smoking, or drinking—activities that are not helpful and might even be harmful.

Take the time to learn helpful relaxation skills and practice them often. You can also take a class or buy a relaxation tape or CD.

Exercise 1

1. Find a quiet place where you can rest undisturbed for 20 minutes. Let others know you need this time for yourself.
2. Make sure the setting is relaxing. For example, dim the lights if you like, and find a comfortable chair or couch.
3. Get into a comfortable position where you can relax your muscles. Close your eyes and clear your mind of distractions.
4. Breathe deeply, at a slow and relaxing pace. People usually breathe shallowly, high in their chests. Concentrate on breathing deeply and slowly, raising your belly, rather than just your chest, with each breath.
5. Next, go through each of your major muscle groups, tensing (squeezing) them for 10 seconds and then relaxing. If tensing any particular muscle group is painful, skip the tensing step and concentrate just on relaxing. Focus completely on releasing all the tension from your muscles and notice the differences you feel when they are relaxed. Focus on the pleasant feeling of relaxation.

   In turn, tense, hold, and relax your:

   - Right and left arms. Make a fist and bring it up to your shoulder, tightening your arm.
   - Lips, eyes, and forehead. Scowl, raise your eyebrows, pucker your lips, and then grin.
   - Jaws and neck. Thrust your lower jaw out, and then relax. Then tilt your chin down toward your chest.

- Shoulders. Shrug your shoulders upward toward your ears.
- Chest. Push out your chest.
- Stomach. Suck in your stomach.
- Lower back. Stretch your lower back so that it forms a gentle arch, with your stomach pushed outward. Make sure to do this gently, as these muscles are often tight.
- Buttocks. Squeeze your buttocks together.
- Thighs. Press your thighs together.
- Calves. Point your toes up, toward your knees.
- Feet. Point your toes down, like a ballet dancer's.

6. Review these parts of your body again and release any tension that remains. Be sure to maintain your deep breathing.
7. Now that you are relaxed, imagine a calming scene. Choose a spot that is particularly pleasant to you. It may be a favorite comfortable room, a sandy beach, a chair in front of a fireplace, or any other relaxing place. Concentrate on the details:
   - What can you see around you?
   - What do you smell?
   - What are the sounds that you hear? For example, if you are on the beach, how does the sand feel on your feet, how do the waves sound, and how does the air smell?
   - Can you taste anything?
   - Continue to breathe deeply as you imagine yourself relaxing in your safe, comfortable place.
8. Some people find it helpful at this point to focus on thoughts that enhance their relaxation. For example: "My arms and legs are very comfortable. I can just sink into this chair and focus only on the relaxation."
9. Spend a few more minutes enjoying the feeling of comfort and relaxation.
10. When you are ready, start gently moving your hands and feet and bringing yourself back to reality. Open your eyes and spend a few minutes becoming more alert. Notice how you feel now that you have completed the relaxation exercise, and try to carry these feelings with you into the rest of your day.

Exercise 2

1. Sit comfortably. Loosen any tight clothes. Close your eyes. Clear your mind and relax your muscles using steps 4 and 5 above.
2. Focus your mind on your right arm. Repeat to yourself, "My right arm feels heavy and warm." Stick with it until your arm does feel heavy and warm.
3. Repeat with the rest of your muscles until you are fully relaxed.

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